



DIABETES PREVENTION PROGRAM  
OUTCOMES STUDY

CELEBRATING  
**20** YEARS  
*1994-2014*



DIABETES PREVENTION PROGRAM  
OUTCOMES STUDY

CELEBRATING  
**20** YEARS  
*1994-2014*

# MESSAGE FROM THE DIRECTORS



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health  
Bethesda, Maryland 20892

December 23, 2013

Dear DPP/DPPOS Participants,

Over the last 20 years, you have altered history. Your participation in the Diabetes Prevention Program and its Outcomes Study has meant that millions of people may prevent or delay the onset of type 2 diabetes. Funded by the National Institutes of Health, the DPP is a landmark study which has already had a major impact on public health in the United States. We hope this booklet honors you and your commitment to better health through research. With your continued partnership, we expect many more important findings in the future.

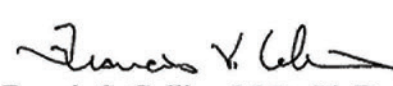
Our collaboration has served as a model for how large-scale clinical studies should be accomplished – as a team of researchers, health care staff and participants like you, all working together, with respect for each other and our common goal of bettering the nation's health. The DPP/DPPOS and your role in these studies have laid the foundation for Congressional establishment of a National Diabetes Prevention Program so that all Americans can reap the proven benefits of the DPP. The DPP/DPPOS will guide this and future efforts to conquer diabetes and its complications.


Through the DPP, we have learned that that an intensive lifestyle intervention resulting in modest weight loss through diet and exercise lowered type 2 diabetes rates by 58 percent, and that the generic diabetes drug metformin reduced diabetes rates by 31 percent, relative to placebo. In the DPPOS, we found that the health benefits of both interventions continued for at least 10 years. We found that both the lifestyle intervention and metformin are cost-effective, meaning their modest net cost was well-justified by the benefits of diabetes prevention, overall improvements in health, and the reduction in other health care costs. These results have transformed the standard of care for prevention and delay of type 2 diabetes worldwide.

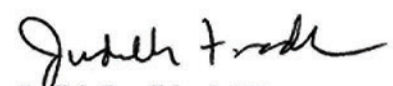
You are a pioneer. Thanks to you, type 2 diabetes is not a foregone conclusion for people at high risk for the disease. In this booklet, you'll see the full breadth of discoveries that you helped create.

From your colleagues at the National Institutes of Health, thank you. Thank you for your dedication to bettering human health, your professionalism in being a true research partner, and your altruism, all of which have led to so many crucial advances in the knowledge of type 2 diabetes. The effects of your extraordinary and steadfast commitment will be felt in the healthier, happier lives of people at risk for type 2 diabetes—both now and in years to come.

With best wishes for good health,

  
Francis S. Collins, M.D., Ph.D.  
Director, NIH

  
Griffin P. Rodgers, M.D., M.A.C.P.  
Director, NIDDK

  
Judith Fradkin, M.D.  
Director, NIDDK Division of  
Diabetes, Endocrinology, and  
Metabolic Diseases

# TABLE OF CONTENTS



## TABLE OF CONTENTS

Message from the Directors	
Letter from David M. Nathan, M.D. ....	1
Introduction .....	3
History of the Diabetes Prevention Program Outcomes Study .....	3
Diabetes Prevention Program Site Descriptions	
Albert Einstein Medical Center .....	12
Indiana University School of Medicine .....	16
Johns Hopkins Diabetes Prevention Program at Green Spring Station .....	22
The Joslin Diabetes Center .....	26
Massachusetts General Hospital .....	30
MedStar Health Research Institute .....	36
The Northwestern University Feinberg School of Medicine .....	42
Pennington Biomedical Research Center .....	46
Shiprock and Zuni Communities .....	50
Southwest American Indian Center—Arizona .....	54
St. Luke's-Roosevelt Hospital Center .....	60
Thomas Jefferson University Hospital .....	64
University of California at Los Angeles (Alhambra) Research Center .....	68
University of California at San Diego .....	72
University of Chicago .....	78
University of Colorado .....	82
University of Hawaii .....	88
University of Miami Miller School of Medicine .....	92
University of New Mexico at Albuquerque .....	96
University of Pittsburgh .....	100
University of Tennessee at Memphis .....	104
University of Texas Health Science Center at San Antonio .....	108
University of Washington .....	112
Washington University School of Medicine .....	118
The Impact of the Diabetes Prevention Program Outcomes Study .....	122
Acknowledgements .....	130



Dear DPPOS Participants,

Back in 1994, when the Diabetes Prevention Program (DPP) clinical trial was being planned, type 2 diabetes was already becoming one of the most common diseases in the world. But it was still difficult to capture people's attention.

Heart disease and cancer, which are as common as diabetes, seemed to demand more attention. The drama of an acute heart attack was captured in television shows and movies and the mere thought of cancer would send chills through the spine.

As a long-term chronic disease, type 2 diabetes is more subtle and insidious. Sometimes it begins with no symptoms at all. Diabetes is often just there in the background, affecting more and more people every year.

Twenty years ago, many people assumed getting diabetes was just part of getting older and felt powerless to do anything about it.

DPP changed that. It helped focus more attention on diabetes and, most importantly, proved that it is not inevitable. As we now know, **type 2 diabetes can be prevented or delayed in many cases.** DPP is the largest and longest trial sponsored by the National Institutes of Health that showed how we might actually reverse this worldwide epidemic.

This book pays tribute to you: the almost 4,000 participants involved in DPP and the many of you who continue so loyally in the follow-up Diabetes Prevention Program Outcomes Study (DPPOS). It presents in pictures and words some of the memories and achievements from the study—the learning, the progress we made together, and especially the impact on lives and communities around the country and around the globe.

While we, the researchers, get our names on journal articles and speak at conferences about the findings of DPP and DPPOS, it is you, the participants, who deserve much of the credit for this groundbreaking study. **We could not have done this study without you.**

I hope you enjoy reading this book as much as we've enjoyed putting it together for you.

With our thanks and admiration,

A handwritten signature in black ink that reads 'David Nathan'.

David M. Nathan, M.D.  
Chairman, DPP/DPPOS



# INTRODUCTION AND HISTORY OF THE DIABETES PREVENTION PROGRAM OUTCOMES STUDY



## INTRODUCTION

Since 1994, the percentage of the population diagnosed with type 2 diabetes has nearly doubled from 4.5 percent to 8.2. Each year, another 2 million people discover they have the disease. But there's a group of people that have bucked that trend, a group that has proved that diabetes is not destiny and that preventive action—such as a healthful diet and regular exercise and, in some cases, medication—can prevent or delay the disease and that lifestyle can trump genetics.

This group is the nearly 4,000 participants in the Diabetes Prevention Program and the follow-up Diabetes Prevention Program Outcomes Study.

These men and women of varying ages, ethnic, educational and geographic backgrounds have spent 17 years as active volunteers in a groundbreaking clinical trial that has transformed the way we approach diabetes in this country and around the world.

This is the story of those participants who—along with the researchers and staff—made possible the Diabetes Prevention Program and Diabetes Prevention Program Outcomes Study.

**This book is dedicated to them.**

## HISTORY

**Diabetes**, a condition in which glucose (sugar) builds up in the blood, affects nearly 26 million United States residents. As big as that number is, there's an even bigger one. An estimated 79 million people have **prediabetes**, which means their blood sugar is higher than normal, but not quite high enough to be diabetes. People who have prediabetes are at greater risk for developing type 2 diabetes and heart disease. In fact, each year about 10 percent of people with prediabetes “convert” to full-blown diabetes. The problem is, most people with prediabetes don't even know they have the condition.

Higher than normal blood sugar causes damage to the body long before most people show symptoms that might prompt a visit to the doctor. The average time between onset of diabetes and diagnosis of the disease can be as long as five or even 10 years. By then, much of the damage is already done. Early detection and treatment may help people avoid some of the complications of diabetes.

### AHEAD OF THE CURVE

Twenty years ago, most doctors didn't talk about “prediabetes.” Doctors sometimes mentioned

high blood sugar or impaired glucose tolerance or insulin resistance and knew that these conditions increased the risk of developing type 2 diabetes, but it wasn't until 1997—until after the launch of the Diabetes Prevention Program clinical trial—that the term was formally used as a diagnosis.

The year 2014 marks 20 years since the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), part of the National Institutes of Health, launched a major study into how to prevent type 2 diabetes in those most at risk for the disease—in other words, how to treat prediabetes. But the beginnings of this trial go back even further.

Since the 1960s, NIDDK and the Pima Indian community worked together to look into why this tribe has such high rates of type 2 diabetes—and to figure out how to bring those rates down. At about the same time, researchers in Sweden, Finland and England were also investigating a rise in type 2 diabetes. Among the risk factors identified: family history, obesity, and impaired glucose tolerance (IGT), a reduced ability to break down sugars, which leads to a buildup of glucose in the blood.

As researchers on both sides of the Atlantic looked more carefully at who got the disease and what happened as the disease progressed, they started developing theories about how they could prevent diabetes by encouraging people at risk to lose weight or by treating IGT with medication.

Another milestone in the development of DPP was the successful conclusion in the early 1990s of the Diabetes Control and Complications Trial, also funded by NIDDK. This landmark multi-center clinical trial showed that intensive treatment and tight blood sugar control dramatically reduced complications from type 1 diabetes. Type 1 diabetes, in which the immune system attacks the pancreas and makes it unable to produce insulin, is a serious condition that affects about 3 million Americans. For these people with type 1 diabetes, DCCT was a life-changing study. “The Diabetes Control and Complications Trial was a grand slam, a home run,” says Dr. Nathan, who was also chair of the DCCT.

Now it was time to explore ways to reduce complications or even prevent type 2 diabetes, which affected about 20 times as many people in the country. The National Institutes of Health brought together leaders in the field to discuss what should come next.

“What we chose to do followed many, many years of epidemiological and clinical studies” that indicated the link between diabetes and impaired glucose tolerance, family history, sedentary lifestyle, and obesity, says Sanford (“Sandy”) Garfield, PhD, who was NIDDK Project Scientist for DPP/DPPOS from 1987 to 2013. Dr. Garfield explains, all the elements were there, “just waiting for someone to take them and put them together and say, ‘we can do something’ about this.”



***“The group was really the best of the best,” says Dr. Sandy Garfield speaking of the researchers and the institutions that made the final cut.***

In 1993, Dr. Garfield and his team at NIDDK accepted applications for what was then called the “Non-insulin Dependent Diabetes Primary Prevention Trial.” In a multi-center trial, each institution prepares its own proposal to meet the goals of the study—in this case, to figure

out if type 2 diabetes can be prevented by a lifestyle or medication intervention in those most at risk. Then, once the finalists are chosen, the researchers from the chosen institutions get together and hammer out a common solution. More than 100 different institutions across the country responded with applications. At the same time as institutions applied to carry out the study, another set of research centers applied for the job of coordinating the study, facilitating communication, collecting and analyzing data, and ensuring that the many different sites spread across the country follow the same protocol and study standards.

In the end 22 applications were chosen to set up a total of 27 study sites. The Biostatistics Center at George Washington University in Washington, DC was named the Coordinating Center. “The group was really the best of the best,” says Dr. Garfield, speaking of the researchers and the institutions that made the final cut. All of the institutions funded were leaders in the field of diabetes research and innovation.

The next step for this who’s who of diabetes researchers was to decide on a common approach and protocol to ensure reliable results. There were many details to work out. What medications would be most likely to work? What should a lifestyle intervention look like? Should there be some sort of meal replacement or should participants be taught how to do this on their own? What’s the best way to recruit those at highest risk for diabetes?

A range of committees took on those questions and more over the course of two years of meetings.

“It’s a highly complicated, demanding and exhausting process,” says Dr. Nathan. “But I think everyone would agree without exception that the DPP that came out of that work was better than anything any one of us had individually submitted. It lends a tremendous amount of strength as well as intellectual ownership of the study. And that’s really important, because we’re in this for a long period of time.”

The final study design included three different arms:

- A lifestyle intervention consisting of 16 sessions aimed at reducing weight by 7 percent and increasing exercise to 150 minutes a week;
- Treatment using metformin, a diabetes drug with a long safety history in Europe but not yet approved for use in the United States; and
- Administration of a placebo, or pill containing no actual medicine.

The medication and placebo arms of the study were double-blinded, meaning the participants and the staff working directly with them did not know whether they were taking one of the two active medications or placebo. (There was no way to mask the lifestyle intervention.)

### THE LIFESTYLE CORE

The University of Pittsburgh led the effort to develop the lessons and approach to the lifestyle intervention. Rena Wing, PhD, a behavioral scientist who had already developed a successful obesity management program and a professor and researcher at the university, led the Lifestyle Core team from 1994 to 2002. Elizabeth Venditti, PhD, continued work on the program after Dr. Wing moved on to other projects.

Dr. Venditti is quick to point out, “It’s not just Pittsburgh deciding what the lifestyle emphasis should be. It’s Pittsburgh in a leadership position along with many advisors from across the study.” Program coordinators and other staff from the different sites serve on a Lifestyle Advisory Group to ensure that the curriculum is relevant and adaptable to all the sites in the study.

### THE FOURTH ARM: TREATMENT WITH TROGLITAZONE

The study originally included a fourth arm: treatment using troglitazone, an experimental drug that showed promise but was not yet approved for use in the United States. Although it had only been tested in small clinical trials, the researchers believed that it held great potential for preventing and treating diabetes.

“The drug was so logical in its mechanism of action,” says Ronald Goldberg, MD, Principal Investigator for the University of Miami site. “This was a medicine that improved insulin resistance,” which is at the root of type 2 diabetes. The researchers decided to try it.

---

*“[The participants] are still as enthusiastic as ever about the study,” says Mary Lou Carrion-Peterson, RN, Program Coordinator for San Diego. “They still stay in touch and they want to learn as much as they can.”*

---

“Troglitazone turned out to be quite powerful at reducing diabetes development,” Dr. Nathan says. Participants taking the drug reported feeling better and had a lower incidence of diabetes than even the lifestyle group. But there were also problems. One in 20,000 to 30,000 people taking the drug experienced serious liver damage. Because the side effect was rare it hadn’t turned up in earlier clinical trials. But once troglitazone was approved by the FDA in 1997 and more people started using it, the reports of liver problems began to come in.

“As soon as we started seeing these danger signals, we stopped using this drug,” Dr. Nathan says. “We were, after all, doing prevention, and for prevention you need drugs that are incredibly safe.”

The DPP participants taking troglitazone took the drug for an average of 9 months, but the study continued to follow them for a full 10 years after the study began. They were offered the lifestyle intervention during the bridge period between DPP and DPPOS, just like all the other participants. When DPPOS was launched in 2002, troglitazone participants signed up at the same rate as participants in the other three groups.

Although the study stopped formally following these participants in 2006, they continue to attend special events. In fact, at the San Diego site, a retired biology teacher who was one of the original troglitazone participants led a special tour of the zoo for DPPOS participants.

“They are still as enthusiastic as ever about the study,” says Mary Lou Carrion-Peterson, RN, Program Coordinator for San Diego. “They still stay in touch and they want to learn as much as they can.”



## THE TRUE FACE OF TYPE 2 DIABETES

From the very beginning, there was an effort to ensure that the participants in this study represented the true face of type 2 diabetes in the country. In addition to the quality of the applications and the capabilities of the institutions, the sites were selected on their ability to connect with and recruit from the communities most affected by the disease, including people over age 60, people who were overweight, women who had diabetes when pregnant, and people from minority communities.

“We were requested to try to duplicate as best we could the over-representation of diabetes among minorities,” Dr. Nathan remembers. “As common as diabetes is in white Americans, it affects Hispanic Americans, Asian Americans, African Americans and American Indians even more.”

The NIDDK staff at the Southwest American Indian Center worked with American Indian tribes in Shiprock, Zuni, Salt River and Gila River. Urban centers in Seattle, New York, Chicago and Miami made extra efforts to recruit Asian Americans, African Americans and Hispanic Americans.

“We approached recruitment in a very scientific way,” Dr. Garfield explains. The researchers worked with consultants both on a national level and on a grassroots level to identify the most effective outreach methods for each site. The brochures and other printed materials developed for the study allowed some level of customization for the local area, and the text was translated into several different languages and dialects, such as Spanish, Mandarin, and Japanese.

Local DPP staff members—including principal investigators, program coordinators and recruitment specialists—made presentations at churches, community groups, businesses and neighborhood events. In many cases, they visited local healthcare providers or partnered with healthcare organizations to encourage clinicians to refer patients at risk for diabetes to the study. Most of the sites also used targeted direct mail to let people in the area know about the study.

In the final count, 20 percent of the participants were over age 60 when the study began. Even more remarkable: 48 percent of DPP and DPPOS participants represent minorities—something that few multi-center trials can claim.

## LANDMARK RESULTS

It wasn’t long after the study launched that Sharon Edelstein, ScM, Research Scientist at the Biostatistics Center at George Washington University, the DPP Coordinating Center, started to realize that the results of the study had the potential to turn standard assumptions about diabetes prevention on their heads.

By 2001—five years into the study that was supposed to last six or seven years—the results reached “statistical significance,” meaning the researchers had enough data to attribute the results to the interventions and not just to chance. The lifestyle and metformin groups were converting to diabetes more slowly than those taking placebo. The lifestyle group had lost weight and had lower blood pressure, lower cholesterol, overall.

---

***“The participants and staff deserve all the credit,” Dr. Nathan says. “Those of us who planned it did a good job with that, but the majority of commendations and recognition should go to all the partners that were involved in this.”***

---

That’s when the Data and Safety Monitoring Board—the group of independent experts that oversees clinical trials—stopped the study early.

Sometimes monitoring boards stop studies early when something has gone wrong. This time they stopped the study because something was going very right. The number of participants and length of the study were chosen so that a one-third reduction in diabetes incidence would indicate a successful intervention. The actual results showed

a 31 percent decrease in diabetes in the metformin group and a 58 percent decrease in the lifestyle group—almost twice the expected results.

This was news the country needed. In the time since the study started, the rate of diabetes in the United States had grown beyond even the projections in the early 1990s. The study outcome was so important that Tommy Thompson, then U.S. Secretary for Health and Human Services, made the announcement at a national press conference in Washington, DC.

But before Secretary Thompson spoke to reporters, each site called its participants and staff members together so they could hear the news first. After all, they were the ones who made the results possible.

## DIGGING DEEPER: DPPOS

But, that’s not the end of the story.

NIDDK wanted to know if the participants would continue to see benefits. Would the participants who lost weight keep the weight off? How would that affect their health? What about the metformin group? Do the benefits justify the cost of the intervention?

The study organizers also wanted to make sure that all participants had a chance to get the benefits of the lifestyle intervention during a “Bridge” period which ran from early 2002 to the start of DPPOS in September 2002. While the organizers put together proposals to continue the study, they offered all participants lifestyle classes to learn about making diet changes and adding activity to prevent or delay diabetes. And they told participants to bring family members, too. Even

if participants couldn't make it to the classes, the sites sent them written materials that explained how they could make changes on their own. Hundreds of participants and their family members took advantage of this offer and changed eating habits and activity patterns.

After the Bridge period, participants were given the choice whether to continue with the Diabetes Prevention Program Outcomes Study (DPPOS). That's when something amazing happened: Nearly 90 percent of those who took part in DPP signed up for DPPOS. And, most of them have continued with the study.

During this phase of the trial, everyone was offered quarterly Healthy Lifestyle Program (HELP) sessions to review diet and exercise recommendations. In addition, participants were divided into three groups:

- Those who were originally assigned to the lifestyle group in DPP attended BOOST campaigns twice a year. These campaigns consisted of three or four sessions and focused on different aspects of the lifestyle intervention, such as eating healthy grains, increasing exercise or cutting out hidden sugar in food.
- The group that took metformin in DPP continued with their dosage.
- Those who had been in the placebo group discontinued taking study pills but continued regular study visits.

The good news continued. Results partway through DPPOS showed continued protective effects from both the lifestyle intervention and metformin. While participants in all groups developed diabetes at about the same rate during the first six years of DPPOS, overall throughout DPP and DPPOS, the rate of diabetes was 34 percent lower in the lifestyle group than the group previously assigned to placebo. Metformin participants developed diabetes at a rate 18 percent lower than those who had taken placebo during DPP.

During DPPOS, the researchers also turned their attention to screening for complications associated with diabetes, including retinopathy (damage to the blood vessels of the eye that leads to impaired vision), neuropathy (loss of feeling in the extremities), heart disease and kidney disease. Participants had eye photos, foot exams (to check for neuropathy), coronary CT scans of the heart, and kidney function assessments. The idea was to detect and treat these complications early, when treatment can be most successful.

The researchers are also looking at how differences in diabetes rates affect rates of these complications. This should also give a better sense of how lifestyle intervention or metformin to prevent diabetes affects the different systems of the body and may eventually lead to a fuller understanding of how to prevent and treat the disease.

Through it all, the participants have cooperated—eagerly, cheerfully and with impressive dedication.

“Nobody has better [retention] levels, and very few studies have levels anywhere as good as ours,” Dr. Nathan says. He and the other study organizers attribute that retention rate to two things: The stellar staff at all of the sites and the loyalty of the participants.

“There is a remarkable esprit de corps, sense of family, that sustains us,” Dr. Nathan says.

---

***“Nobody has better [retention] levels, and very few studies have levels anywhere as good as ours,”  
Dr. Nathan says.***

---

## IMPORTANT DATES FOR THE DIABETES PREVENTION PROGRAM OUTCOMES STUDY

- 
- 1992** Diabetes control or complications trial ends  
Working group meetings with experts in the field and within NIDDK to discuss whether a trial was warranted and what funds were available for a trial
  - Launch of the National Diabetes Education Program, based on success of DCCT
  - 1993** Request for Applications goes out for a “Non-insulin Dependent Diabetes Primary Prevention Trial”
  - 1994** 22 Applications funded representing 27 DPP sites
  - 1995** Protocol version 1.0 adopted
  - 1996** Recruitment and randomization begins
  - 1998** Troglitazone arm discontinued
  - 2001** NIDDK Early DPP Termination Decision
  - 2002** NEJM article comes out  
DPP Bridge when lifestyle intervention is offered to all participants  
Diabetes Prevention Program Outcomes Study begins (BOOST/HELP Sessions begin)
  - 2004** Protocol version 2.0 adopted
  - 2006** Protocol version 2.1 adopted
  - 2009** Scheduled end of six-year – Phase I  
Protocol version 3.0 adopted

# ALBERT EINSTEIN MEDICAL CENTER



## ALBERT EINSTEIN MEDICAL CENTER BRONX, NEW YORK

It's difficult to get a public health message across in a city of 8 million. That's what staff at the Albert Einstein Medical Center site found out back in 1996 as they were trying to get the word out and recruit participants for the Diabetes Prevention Program.

"There's lots of information going out in the area," says Janet Brown-Friday, RN, Program Coordinator for the Einstein DPP site.\* "Trying to get heard above everything else was a challenge. We had to figure out the right formula for New York."

Like many other sites, they started by sending out mass mailings into the community. With large Hispanic/Latino and African American populations in the Bronx, Einstein hoped to recruit many from those communities hard hit by diabetes and its complications.

---

***"Trying to get heard above everything else was a challenge. We had to figure out the right formula for New York," says Janet Brown-Friday, RN.***

---

But mass mailings didn't turn out to be the best way to reach these people. It took more than getting a letter in the mail from a research group

to prompt potential participants to send in the reply card and show up for a screening. It took more personal contact. The best recruitment method was the relationship the site forged with the medical director of a clinic affiliated with New York's Health Insurance Plan (HIP), now part of EmblemHealth.

Einstein staff explained the program to the clinicians, including the study criteria and goals. This helped in two ways. "The [clinicians] helped us identify people who met the study criteria," Ms. Brown-Friday says. They also helped reinforce the mailing message when patients asked them about it. About 35 to 40 percent of Einstein's enrolled study participants come from that particular HIP clinic.

DPP staff also dragged an old carousel slide projector and a screen around the Bronx to community groups, church groups, the VFW Hall (Veterans of Foreign Wars), basically anyone who might be interested in hearing about the study.

In the end, the site recruited a wonderful group of participants that are "very mixed ethnically, economically and educationally—just as you would expect in New York," Ms. Brown-Friday says. "We even have a politician who is a participant."

---

\* In July 2013, Ms. Brown-Friday handed DPPOS over to a new program coordinator, Gilda Trandafirescu. But Ms. Brown-Friday is not going far away. She is moving on to another diabetes study also under Dr. Jill Crandall and expects to stay in touch with the DPPOS participants she's come to love.



Another participant was one of the original Tuskegee Airmen, the first African American pilots in the U.S. military. His fellow participants are a bit in awe of him, Ms. Brown-Friday says.

But when it comes to the study, everyone is equal. “Everybody has the same need or concern about their health,” she explains. “So we’re working from that level.”

Many of the participants have at least one family member who had diabetes and cite that as their reason for participating in the study. Others say they were concerned about their own health and felt that the study would help them get to the bottom of what was affecting their health. Once in the study, most have stuck with it, even if their lives have taken them in different directions. “We have a couple participants who no longer live on the continental U.S. who still come in for their visits,” Ms. Brown-Friday says, mentioning participants who live in Puerto Rico and Barbados.

Friendships have formed within the group and participants support each other. Sometimes participants will meet each other in the park on their regular walks. Two participants regularly come to classes together.

---

***Once in the study, most have stuck with it, even if their lives have taken them in different directions.***

---

“At this point, for some, it’s become a way of life,” says Ms. Brown-Friday. One participant who has really embraced this change was diagnosed with Parkinson’s several years ago but has only recently developed symptoms. “She believes her dedication to exercise has really helped her,” Ms. Brown-Friday says.

Even those who weren’t part of the original lifestyle arm of the study have now embraced the tenets of the study. “Everybody has been given the opportunity to learn what the lifestyle group learned,” says Ms. Brown-Friday. “Everyone has been told that we’d like them to maintain an activity level of 150 minutes per week. Everyone knows that we want them to lose weight in order to keep their diabetes under control or to prevent complications.”

Sustaining these changes over 17 years—let alone a lifetime—is a challenge. Life events, other illnesses and injuries, and even just getting older affects how participants are able to keep up with study recommendations. For example, older participants may worry more about walking outdoors or about being able to maintain the same intensity of walking.

“Just because they’re older, don’t count them out,” Ms. Brown-Friday warns. “They have a lot of energy still. They appreciate when we are upfront with them and we don’t treat them like old people.”

Based in part on her experience with the DPP, Ms. Brown-Friday, along with some other DPP study group members, became part of the working group for the Small Steps, Big Rewards campaign developed by the National Diabetes Education Program to raise awareness of type 2 diabetes among those most at risk. The campaign’s messages are based on the successful results of the DPP study. Most recently, the group has started working with physicians who can use the campaign materials in their practices.

She’s determined that this public health message will get through in New York and around the country.

---

***“Just because they’re older, don’t count them out,” Ms. Brown-Friday warns. “They have a lot of energy still. They appreciate when we are upfront with them and we don’t treat them like old people.”***

---



# INDIANA UNIVERSITY SCHOOL OF MEDICINE



## INDIANA UNIVERSITY SCHOOL OF MEDICINE INDIANAPOLIS, INDIANA

Marcia Jackson remembers the day local newscaster Debbie Knox went live with the telephone number to call to get involved with the Diabetes Prevention Program. Ms. Jackson, currently Co-Program Manager, started out with the Indiana site as recruitment manager. “Debbie told everyone watching to get a pencil. ‘You’re going to want to write this number down. This is an important research study,’” Ms. Jackson says.

The site’s phone lines lit up. Staff couldn’t take the messages off the voicemail as fast as they were coming in.

Gina McAtee, Co-Program Coordinator, says people responded because many had the risk factors identified in the study: family history of type 2 diabetes and overweight. “It was a different kind of research study,” she says, contrasting it with studies that look for participants who have already been diagnosed with a specific condition. “It wasn’t as targeted as so many studies are.”

Although not all the people who called met the study qualifications, many did. Between that mention on television and other recruitment efforts—going to churches, health fairs, and community events—the site quickly recruited nearly 200 participants.



Indiana University site participant takes advantage of available educational resources.

### DEDICATED PARTICIPANTS

Many of those who joined the study said they wanted to prevent diabetes. Some had a family history of type 2 diabetes, and they didn’t want to go through what they had seen their loved ones experience. Seventeen years later, 141 are still going strong. “They come in reliably every six months and let us take their blood and subject them to endless questionnaires,” says David Marrero, PhD, Principal Investigator for the Indiana site. “I am sincerely moved by their dedication.”



Indiana University site participants enjoy a minor league baseball game.

Ms. Jackson adds that their dedication has not diminished, even as the participants get older. “A lot of our people were [in their] 50s and 60s—and even some of them older than that—when they first joined the study,” she explains. “We have a lot of people in their 70s and 80s now.” Even at these ages, participants keep coming back.

It has to do with the care they receive, and the activities they do together.

Like other sites in the DPP/DPPOS, the Indiana site has organized events and lifestyle sessions aimed at keeping participants on track with the study. One time, a chef from one of the hospitals came and cooked healthful foods for the

participants to sample. At one point, they even gave away George Foreman grills to promote another way of preparing foods without added fat.

---

***“We have a lot of people in their 70s and 80s now,” says Ms. Debbie Jackson. Even at these ages, participants keep coming back.***

---

“We got a super deal on George Forman grills, and gave those out, and boy, they were busting down the doors for those,” says Ms. Jackson. Local minor league baseball games are also a draw.

Staff try to schedule the lifestyle sessions for both days and evenings to fit different participants’ schedules. For a while they held four lifestyle sessions at different cafeteria-style restaurants—on the east side, west side, north side, and south side. Ms. Jackson says they did it to see if it would make it easier for the patients. “They liked that a lot,” she says.

The site’s location is another draw—it’s located upstairs from Indiana University’s National Institute for Fitness and Sport (NIFS). Local firefighters

and visiting professional basketball players come to the NIFS to work out. During the DPP stage of the study, lifestyle participants had free memberships and could use weight machines or take classes in aerobics, kickboxing, yoga, and more.

---

***Through the years, staff and participants have become like a family, and events feel like reunions.***

---

Indianapolis itself offers a wide range of other options for exercise. Participants also enjoy walking, biking, or running the Monon trail, which winds through the city and heads north.

Through the years, staff and participants have become like a family, and events feel like reunions. In fact, when former program coordinator Susie Kelly, who retired in 2012, showed up at a recent HELP session, participants crowded around her to say ‘hi’ and get a chance to catch up—just like she were a long-lost relative.

## MAKING CHANGES

Ms. Jackson tells the story of one participant, a man in his late 60s when the study started. At the start of DPP, he was a couch potato. His wife says that he would just watch TV and not get off the couch. But, as part of the lifestyle program, he began exercising. Soon he started to enjoy it and would find ways to be active several times a week. All these years later, he’s still active and he is diabetes-free. “His physician told him, ‘That study saved your life,’” says Ms. Jackson.

Kathy Morgan is another participant who believes the study saved her life. Having watched her father lose both his legs and his sight to diabetes, she knew what the disease can do to a person. Her father ended up on dialysis and passed away from complications. So when she saw a notification about wanting participants for the DPP, she called right away.

Ms. Morgan was put into the lifestyle group. At the time she began the study, she was a little overweight and not very active. That soon changed. She went to the NIFS and worked out. But she realized that the free membership participants received wouldn’t last forever. So she purchased a number of VHS tapes with different exercise programs on them. When her VCR broke, she panicked, but her husband came to the rescue and transferred all her tapes to DVDs.

---

***“I’m already 62, and I’m probably healthier than most my age,” participant Kathy Morgan says.***

---

Today, Ms. Morgan still exercises six days a week. Her library has expanded, but she still uses old standbys from the 90s like “The Firm” and Jane Fonda’s workout routines. “It’s no slouch program I’ve worked up for myself,” she says.

Ms. Morgan gets out of bed at 3 a.m. so that she can work out before heading out at 7 a.m. to her job as assistant director of a pre-school. “I’m already 62, and I’m probably healthier than most my age,” she says. “I’ve got the aches and pains and arthritis, but if I can continue to exercise, I’m going to do it!”



Indiana University site participants in 1998.

### SPREADING THE WORD

Participants are proud to spread the word about their involvement with DPP and DPPOS. Staff often get requests for extra copies of the handouts that participants share with family or friends who are at risk for diabetes or already have the disease.

One participant, who lives in Oklahoma and comes up for the study found out that a friend of hers was taking metformin. She was proud to tell her friend that she was part of the study that proved that metformin could help forestall diabetes. “I think they’re

proud about being the first ones that got the medication for prediabetes,” says Ms. AcAtee.

The participants have every right to be proud, says Dr. Marrero. “I think that they should take immense pride in knowing that their hard work, that their sacrifice—and trust me, it was all of that and more—resulted in a level of science that has got tremendous legs and a potentially huge impact. They’ve saved lives. They really have,” he says. “They have done something that is almost extraordinary in the kinds of science that all of us do there. It’s just stunning to me that we’ve had this much impact.”

---

*“I think that they should take immense pride in knowing that their hard work, that their sacrifice—and trust me, it was all of that and more—resulted in a level of science that has got tremendous legs and a potentially huge impact. They’ve saved lives. They really have,” says Dr. Marrero.*

---

### KUDOS TO THE STAFF

In addition to his appreciation to the participants, Dr. Marrero is quick to point out the dedication of the DPP and DPPOS staff members too. Dr. Marrero says: “We couldn’t have done it without the work of an incredibly dedicated staff. [This is] an exacting level of science, it’s not like these are easy studies to implement. All those things came together with [DPP]. It’s just been a remarkable experience.”



# JOHNS HOPKINS DIABETES PREVENTION PROGRAM AT GREEN SPRING STATION



## JOHNS HOPKINS DIABETES PREVENTION PROGRAM AT GREEN SPRING STATION LUTHERVILLE, MARYLAND

Green Spring Station located in Lutherville, Maryland, boasts a high-end shopping center with boutiques, salons, a fitness center, banks and restaurants. It's also home to many outpatient centers of Johns Hopkins Hospital, including the Johns Hopkins Diabetes Center at Green Spring Station—and the Maryland based DPPOS site.

Tracy Whittington and Evonne Utsey are the primary staff members of the site and have been with the study since 1997. Ms. Whittington began as a part-time participant screener, and then became a case manager. When her supervisor Vanessa Bradley resigned, she stepped into the role of research coordinator. Ms. Utsey is a research assistant, and together, they meet the needs of the study participants.

Ms. Whittington says they are a great team: “We do everything. We conduct the lifestyle classes. We see the participants in the clinic. Ms. Utsey does the phlebotomy solely, and, of course, I do the administrative [work],” she explains. “But we’re a team in everything else.”

During the recruitment phase of the study, the DPP staff traveled to different parts of Maryland. At the time, the study site was located in Woodlawn in the suburbs of Baltimore County, about 10 miles away from where it is now. They recruited at the Social Security Administration Building, also



Johns Hopkins at Green Springs Station staff members.

located in Woodlawn and traveled to health fairs and other workplaces, including the Baltimore Sun.

They attended the Native American Festival hoping to recruit participants, as diabetes is prevalent in the American Indian population. The staff also put brochures in clinics, hospitals, community centers, senior centers, and anywhere else they could. “It was a lot of fun. We met a lot of great people,” recalls Ms. Whittington. “But recruiting is hard. I can’t remember how many people we screened just to get to our final recruitment number.”

The participants at the Johns Hopkins site are about equally split between men and women. Although the largest group of participants is





Johns Hopkins at Green Springs Station staff members.

Caucasian, the site also has a good number of African-American, Hispanic, American Indian, and people of mixed race. Overall, the group is a mix of working class, professionals, and retirees.

### MEET ME AT THE MALL

One way the staff reaches out to participants to give them information and keep them active is by conducting lifestyle classes in shopping malls and parks near the participants' homes.

Many malls open before the retail stores in order to give community members a safe place to

walk. The Maryland DPPOS site takes advantage of this trend. A number of participants live in Howard County, so the site holds lifestyle classes at Columbia Mall and Centennial Park, which has a nice path around the lake. Another group lives in Woodlawn, so Ms. Whittington and Ms. Utsey meet them at Security Square Mall, close to the original DPP site.

Participants gather at the food court between 8:00 and 9:30 a.m. Staff arrive with their dry erase board, refreshments and class materials and start class. Halfway through, they take a break and walk a lap around the mall. Then, they return to the food court to finish the class.

Ms. Whittington began holding classes in the malls because it was a way to get more people to participate, but she finds she enjoys these outings as well. "We enjoy the change in scenery, to get out of the office and get some fresh air," she says. "It's nice."

Participants agree that the traveling class makes attendance easier. "It's extremely convenient when they come out here," says Diana Fleck, a retired bookkeeper.

Since joining the study, Ms. Fleck has lost more than 40 pounds and kept it off by exercising and watching what she eats. To keep herself on track, she weighs herself regularly. "When I notice the scale going up, then I get back to the diet."

For her exercise, she walks, takes Pilates classes and lift weights—logging a total of 60 minutes a day, six days a week. "Lifting weights is my favorite," she

says. She meets with a trainer once a week, and he keeps workouts fresh and fun.

All that working out paid off when she recently took her 14-year-old granddaughter on a trip of a lifetime. "We had two days in Paris, then we traveled the Rhone River," Ms. Fleck says. She wore her exercise monitor during the trip and logged more than 53 miles of walking and 72 flights of stairs in just five days. "It was my first time to France and hers, too. We got to experience it together." Despite gourmet food and fine wine at lunch and dinner, she gained just over a pound on the trip. "All the exercise I did offset that eating."

### CLOSE, COZY RELATIONSHIP

Because the participants have known the staff since the study started, they've developed a close, 'cozy' relationship. "We're like their daughters," Ms. Whittington says. "When they come in, it's like, 'Hey Tracy, Hey Evonne.' Hugs and kisses. I'm telling you, it's something special." They even ask about their children by name.

Ms. Fleck agrees that she's forged a special relationship with the DPP staff. When she goes in for her annual visit, "It's like old-home week. Everybody knows everything about everyone." She says she's not only gotten to know the staff, but has also formed friendships with other participants.

"It's not just about having a clinic visit and then they're out the door," says Ms. Whittington. "It's a relationship. It is truly a relationship."

### BLESSING IN THE MIDST OF LOSS

In recent years, the Johns Hopkins site has suffered the loss of three excellent physicians who were leaders in diabetes prevention and treatment not only locally, but nationally. In 2011, the site lost its principal investigator, Christopher D. Saudek, MD, who was a pioneer in the use of the insulin pump and a former President of the American Diabetes Association. Dr. Richard Rubin, PhD, the site's behavioral psychologist, and Fred Brancati, MD, a co-PI, have also passed away.

While it's not been easy to have lost colleagues and members of their work-family, the staff works to make sure that the study goes on. Ms. Whittington and Ms. Utsey made a promise to Dr. Saudek to continue to run the DPPOS to the best of their abilities, and they strive for that every day. Despite so much change, the mission is still clear.

The new PI is Sherita Hill-Golden MD, who is trained in both endocrinology and epidemiology. Ms. Whittington says, "We had a great boss in Dr. Saudek; however, Dr. Golden is wonderful. We continue to be blessed with a great group of participants and a great DPPOS team."

**Los actos contradictorios o unitivos se acumulan en ti.  
Si repites tus actos de unidad interna nada podrá detenerte. (Spanish)  
Contradictory or unifying actions accumulate within you.  
If you repeat your acts of internal unity, nothing can detain you.**

# THE JOSLIN DIABETES CENTER



## THE JOSLIN DIABETES CENTER BOSTON, MASSACHUSETTS

The Joslin Diabetes Center traces its history to 1898 when Elliott P. Joslin, MD opened his private practice for patients with diabetes. One of his first patients was his own mother. His approach included: early diagnosis and a combination of diet and exercise. At a time when most diabetes patients died within a year or two of diagnosis, Joslin's mother lived another decade. Joslin's theory of maintaining tight control of blood glucose through diet, exercise and monitoring soon became the standard treatment for type 1 diabetes.

So, nearly a century later, when the Request for Proposals went out from the National Institutes of Health to test a lifestyle intervention for the prevention of type 2 diabetes, Joslin was a logical choice to host one of the study sites. The clinic's emphasis on patient education and involvement and team management fit right in with the study's design and goals.

"What we're doing is focus on education, education, education, as well as nutrition, healthy exercise, weight management and lifestyle modification," says Edward Horton, MD, Principal Investigator for the Joslin site.

Joslin Diabetes Center is located in the Longwood area of Boston on the Harvard Medical Center main campus. Next door is Beth Israel Deaconess Hospital, and the Dana Farber Cancer Center and Boston Children's Hospital are across the street. Just beyond is Brigham and Women's Hospital.

---

*"There's something said for being small," says Cathy Poirier, BSN, Program Coordinator for the site, "There's a personal feel and cohesiveness."*

---

Massachusetts General Hospital, another DPP site, is about three miles away on the north side of Boston. The two sites worked closely during recruitment for the study and continue to cooperate on some of the specialty testing, like DEXA scans and retinopathy.

"Boston is one of three cities that have two centers in the study," says Dr. Horton. "Mass General tends to get people from that side of town and the North Shore, and we tend to get people from this side of town and the western suburbs. We even refer patients to each other."

In this community of high-tech medical centers, Joslin maintains a personal touch and a tight focus on diabetes prevention and treatment. "There's something said for being small," says Cathy Poirier, BSN, Program Coordinator for the site, "There's a personal feel and cohesiveness."

### CLOSE CONNECTIONS

The Joslin site currently has just over 100 participants. They come from a variety of backgrounds and occupations, but what they have in common is a personal connection to diabetes

and a personal commitment to do what they can to change the course of the current epidemic. Most have seen a close family member suffer from the devastating complications of diabetes. “They figure if they are part of something that could prevent [these complications], they would make the future that much better,” says Ms. Poirer.

Ms. Poirer has worked on the study since it launched at Joslin. “This study is kind of like my baby,” she admits. Having started in healthcare as a hospital floor nurse, she did a stint in healthcare computing. But she found she missed one-on-one interactions with patients. “That’s kind of what brought me back. It’s work, I guess, but it doesn’t really feel like it.”

She got what she was looking for with the DPP and DPPOS participants. “They’re like family,” she says. “I know I have a connection with these people, and they have a connection with me.”

Dr. Horton agrees: “The participants know each other. They know the staff, the staff knows them. We all kind of interact like a family.” Participants feel comfortable asking Dr. Horton questions about their health, even in front of other participants.

---

***“The [DPP and DPPOS participants are] like family,”  
Ms. Cathy Poirer says. “I know I have a connection with  
these people, and they have a connection with me.”***

---

Ms. Poirer says the participants consistently make and keep their study visits, even when that involves travel from Maine, Connecticut or New Hampshire, or if game day at nearby Fenway Park complicates their trip. “It’s tough enough to get into Boston, never mind fighting baseball traffic,” she says.

The Joslin participants have also been enormously successful and persistent at pursuing the goals of the study. “A lot of the participants lost more than their goal weight at the beginning,” she says. “After 16

years, they’re still plugging away and keeping the weight off and abiding by all the lifestyle information we gave them.”

What impresses Dr. Horton is the participants’ curiosity and sophisticated understanding of the study and its significance. “They’re interested in what’s going on with the research,” he says. At the annual “Your Contributions Carry On” event each year, he presents the latest on the study and its impact. “I tell them how the DPP, which is truly a landmark study, is influencing legislation, standards of care, all kinds of stuff,” he says. “And then they ask me a gazillion questions.

We talk about study design, primary outcome variables and secondary outcome variables and why the two are just as important. We really have sophisticated discussions.”

These discussions serve as a reminder for the participants and the staff of the importance of what they’re doing. “When you’re caught up in the day-to-day tasks of the study, you forget how much of an impact you’re having on people or public health,” Ms. Poirer says. “We need to be reminded once in a while that we are affecting people’s lives and making things more positive for people at the clinic, in the population, and the outside world.”

*“The care I received in the DPP and DPPOS program—the lab results of my tests, advice on food choices and exercise, attending the ‘Bridge’ class and HELP classes—have enabled me to deal with my diagnosis without any medical intervention. For 16 years, I have been able to stabilize my type 2 diabetes by food and exercise. I am grateful for the research aspect of the study, the warmth of the nurses and doctors involved in my visits, and the ability to continue to participate in the study.”*

*Carol Goldman, Joslin site DPP/DPPOS participant,  
who converted to type 2 diabetes soon after the study started*



# MASSACHUSETTS GENERAL HOSPITAL



## MASSACHUSETTS GENERAL HOSPITAL BOSTON, MASSACHUSETTS

The DPP/DPPOS participants at the Massachusetts General Hospital (MGH) site are a naturally inquisitive bunch. They keep up with the latest health news, especially when it concerns diabetes and diabetes prevention. At their visits, Charles McKittrick, RN, BSN, CDE, likes to share results from new studies related to diabetes with the DPP/DPPOS participants: “I’ll mention findings from a recently published study, or a new treatment option that’s becoming available. Often our participants have already heard about it.”

The Boston-based participants are not only inquisitive, but also strikingly proactive and team oriented. “They know how to look at the study from a scientific point of view,” says Elyse Raymond, Clinical Research Coordinator at the site. “They understand the importance of retention and of following through when they get reminders in the mail. There’s a sense of teamwork and cooperating with the scientific effort.”

Massachusetts General Hospital has one of the largest hospital-based clinical research programs in the country. Its Diabetes Research Center, led by David Nathan, MD, is home to some of the most important studies in diabetes, including the Diabetes Control and Complications Trial (DCCT) and the Epidemiology of Diabetes Interventions and Complications (EDIC) study, as well as DPP and DPPOS.

While Dr. Nathan leads several national, multi-centered studies, he is also the principal

investigator of the MGH site and stays very involved with the local participants. “As much as I enjoy DPP and DPPOS on a national level, my greatest pleasure comes from interacting with our local participants,” he says. “Their enthusiasm is infectious.”

Mary Larkin, MS, RN, CDE, Assistant Director of the Research Center and Program Coordinator for the DPPOS MGH site, agrees. “Our research participants are our greatest asset,” she says. “Each and every one of the research volunteers is making an important contribution to science and improving the lives of others by their long term participation in DPPOS. We marvel at their dedication and commitment.”

---

*“As much as I enjoy DPP and DPPOS on a national level, my greatest pleasure comes from interacting with our local participants,” Dr. Nathan says. “Their enthusiasm is infectious.”*

---

### LIGHT BULB MOMENT

Sandra Butler Tubbs first found out about the study when she heard Boston talk show host David Brudnoy interviewing Dr. Nathan in 1996. Both Ms. Tubbs’ mother and grandmother had diabetes, and over the years she had seen many members of her church community develop the disease



as well. She assumed that for her, diabetes—or “the sugar” as she heard it called—was inevitable. But Ms. Tubbs heard a different message on the radio that day. “It was the light bulb moment where I realized that I didn’t have to get it.”

---

***“A lot of people have grown up with a lot of fried food and a lot of sugar and they’ve just accepted that diabetes is the way of life. I want to be able to go to them and say, ‘This is my story: I have that background, and I’ve been able to not get diabetes,’” says participant Sandra Tubbs.***

---

At first, she admits, her reasons for joining the study were not completely altruistic—she just wanted to learn how to not get diabetes. But then, as she learned more about the study, she realized its potential to help improve the health of society.

“At my last semi-annual visit I looked at my number since 1997, and I’ve kept my A1c under six,” she says. Originally in the placebo group, she’s now taking the program’s lifestyle advice and staying active and watching what she eats. “I believe the program has given me the tools and information to make change in my life,” she says.

She also shares her story with others, especially at the senior center in her town and with her family members. “A lot of people have grown up with a lot of fried food and a lot of sugar and they’ve just accepted that diabetes is the way of life. I want to be able to go to them and say, ‘This is my story: I have that background, and I’ve been able to not get diabetes.’”

### ACCOUNTABILITY FACTOR

Like Ms. Tubbs, most participants are happy to make their visits to the MGH site. In addition to making a donation to the scientific community, many of the MGH participants also use their study visits to keep themselves on track. Although the original lifestyle group came in more frequently at the beginning of the study, Mr. McKitrick sees a great sense of community and dedication to the study from participants from each

### MUSEUM QUALITY

In November 2013 Boston’s Museum of Science unveiled an exciting new exhibit called “**The Hall of Human Life.**” The exhibit highlights breakthroughs in biology and biotechnology and explores the interaction between our genes and the environment, including what we eat and how active we are. To illustrate the rise in type 2 diabetes over the last generation and the role of diet and exercise in preventing the disease, the exhibit features the results of the DPP and tells the stories of three DPPOS participants from the Massachusetts General Hospital site.

of the treatment arms. “Most of our participants feel like they’re getting a lot back from the study too,” he says.

---

***The study results demonstrated that people who pay attention to their “numbers,” for example by weighing themselves regularly, do better overall.***

---

Accountability is an important factor, says Linda Delahanty, MS, RD, CDE, Lifestyle Interventionist for DPPOS. “I think a lot of people use the study as a way to check in with themselves,” she says. The study results demonstrated that people who pay attention to their “numbers,” for example by weighing themselves regularly, do better overall.

Tim Daly agrees that accountability plays a role in the participants’ success. Mr. Daly called to inquire about the study about a month after his identical twin brother was diagnosed with diabetes. Randomized to the lifestyle group,

Mr. Daly met with Ms. Delahanty frequently during those first years of DPP. “When I was [coming in for the study] every month, the accountability was there because I didn’t want to disappoint anybody,” he remembers. Now, with two visits a year, it can be more of a challenge to stay on track. Still, when he slips he can see it in the numbers. “It’s not just blood sugar. My cholesterol, my blood pressure, the numbers would go up with my weight—and go down when I lost the weight. The proof was there.”

Over the years, the DPP and DPPOS have provided answers and hope to the scientific community about the prevention, delay, and control of diabetes. “We could never say thank you enough,” Ms. Raymond points out. “The DPP/DPPOS participants are contributing not only to the scientific field, but also to the health and well being of their friends and family members. They are the heart of the study, and there is a well deserved sense of success among the MGH participants.”

---

*We could never say thank you enough,” Ms. Raymond points out. “The DPP/DPPOS participants are contributing not only to the scientific field, but also to the health and well being of their friends and family members. They are the heart of the study, and there is a well deserved sense of success among the Massachusetts General Hospital participants.”*

---

When the DPP study was ended early and the landmark results were ready to be announced, Dr. Nathan shuttled between the national press conference in Washington and a special meeting with MGH participants in Boston. “We told the participants before the results were announced in the newspapers and on television so that they would hear it from us first,” Dr. Nathan remembers. “We told them, ‘You’re going to see this in the newspaper in the next two days, and this is you! This is your work, your contributions, and the payoff for all of your hard work.’”

---

*“We told the participants before the results were announced in the newspapers and on television so that they would hear it from us first,” Dr. Nathan remembers. “We told them, ‘You’re going to see this in the newspaper in the next two days, and this is you! This is your work, your contributions, and the payoff for all of your hard work.’”*

---

## LIFESTYLE TRUMPS GENETICS

Tim Daly and his identical twin brother, Paul, are living proof of the power lifestyle changes can make. As identical twins, the men share the same genes. Paul was diagnosed with diabetes more than 15 years ago, but Tim only recently tested within the study’s definition of diabetes. The two have appeared on both TV and radio to tell their story.

The award-winning HBO documentary **“Weight of the Nation”** aired first in 2012 and is still available on the website, <http://theweightofthenation.hbo.com/>. The Daly brothers were highlighted in the documentary, along with other members of the MGH DPP/DPPOS team. In the documentary, they bowl together and discuss the relationship between diabetes, genetics, and lifestyle choices. Neither is an expert bowler, but both of them were eloquent spokespersons for the importance of changing lifestyle.

Tim Daly has seen firsthand the impact of the documentary has made. Soon after it aired, he ran into a colleague and noticed she had slimmed down and looked more energetic and healthier. “Well,” his colleague told him, “I saw that movie you and your brother were in and it made me realize how important this is.”

# MEDSTAR HEALTH RESEARCH INSTITUTE



## MEDSTAR HEALTH RESEARCH INSTITUTE WASHINGTON, DISTRICT OF COLUMBIA

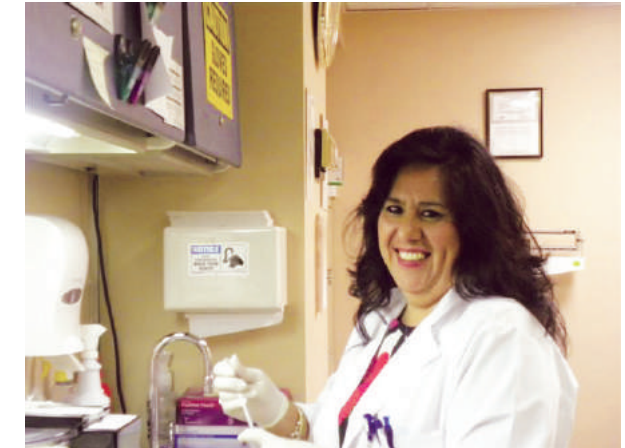
The MedStar Health Research Institute site for the DPP/DPPOS study is housed in a converted movie theater, in Southeast just blocks from the Capitol in Washington, DC. “Our clinic is in the old projection booth,” says Sue Shapiro, RN, BSN, CCRC, Program Coordinator at the site. Sue has worked with the MedStar site since 1998 and has been program coordinator since 2000.

As an intensive care nurse for 15 years, Ms. Shapiro took care of patients ravaged by years with diabetes. Now she works with patients to discover ways of preventing the disease and reducing its complications. She enjoys working on this side of the disease process.

“There is such a sense of family with this group,” she says, referring to the participants as well as her co-workers, Lilia Leon, Outcomes Coordinator, and Renee Wiggins, RD, LD, CPFT, CIC, who teaches the lifestyle classes. “We’re all glad to be here. The participants feel that, and they want to be here too.”

The very first DPP participant recruited in the nation enrolled at the MedStar site. A World War II Veteran, he participates in the Senior Olympics. He credits the program for his continued good health. He celebrated his 89<sup>th</sup> birthday in 2013.

During the recruitment process, MedStar partnered with nearby Howard University to reach out to the city’s African American community. They developed a TV infomercial, distributed flyers and attended health fairs around the city.



Laboratory Scientist at MedStar Health Research Institute.

More than 60 percent of the site’s participants are African American. The participants include Federal workers, lobbyists and others involved in government agencies.

---

***“There is such a sense of family with this group,” says Ms. Sue Shapiro. “We’re all glad to be here. The participants feel that, and they want to be here too.”***

---

### BIG PICTURE CONNECTIONS

The participants are particularly attuned to the connections between the study and government research funding, public health efforts and media coverage of diabetes. “They’ve got their pulse on





MedStar participants get moving in a local walk.

DC and what's happening here," Ms. Shapiro says. They call to ask, "Did you see this about the DPP in the Washington Post?" or "This is based on the DPP results, right?"

---

*"[The participants] can say 'Hey, I'm a part of this. I'm a part of the bigger picture. I'm making a difference,'" Ms. Shapiro says. "They take a lot of pride in knowing that the study has had such an impact not only for themselves, but for the community as a whole and for future generations."*

---

Because MedStar is so close to the National Institutes of Health and the headquarters of the Department of Health and Human Services (HHS), Ms. Shapiro often gets a phone call when institutes or agencies want someone who can speak firsthand about living well with diabetes. And all the MedStar participants were invited to the press conference when then-director of HHS Tommy Thompson announced the groundbreaking results of DPP.

All of this serves to reinforce the participants' pride. "They can say 'Hey, I'm a part of this. I'm a part of the bigger picture. I'm making a difference,'" Ms. Shapiro says. "They take a lot of pride in knowing that the study has had such an impact not only for themselves, but for the community as a whole and for future generations."

The DPP staff also try to make full use of the city when planning programs and events for the participants. Over the years they have gone on walks around the Capitol buildings, toured the National Zoo, picnicked at the National Arboretum, watched a baseball game at Nationals Stadium, and sampled fresh fruits and vegetables at Eastern Market, a historic farmers' market around the corner from the study site. Whether it's in the conference room at the stadium, the dining room of a restaurant, or back at the study site, they get in a lesson about eating right and staying active to prevent the complications of diabetes.

## PARTICIPANT PROFILE: GENOLA WILLIAMS

---

*"I remember that the atmosphere was so warm, I knew that this was something I wanted to get involved with. I wanted to help try to get a handle on this awful disease," Ms. Williams says.*

---

Genola Williams feels lucky to be alive. Her mother and two siblings have already died from diabetes complications. Although she now has type 2 diabetes herself, she credits her continued health to what she's learned through DPP and DPPOS.

Originally in the metformin group, Ms. Williams says she had to discontinue the medicine because of side effects. But she's benefited from the constant monitoring and information about diet and exercise she's gained from the study. "I feel good," she says. "I really have made changes. In fact, I've lost weight. I definitely know my foods better."

Ms. Williams signed up for the study after hearing about it on television. She called the number for the MedStar Health Research Institute site, and came in to get screened to see if she qualified.

"I remember that the atmosphere was so warm, I knew that this was something I wanted to get involved with. I wanted to help try to get a handle on this awful disease," Ms. Williams says.

"I had family members who were diabetics and saw the changes that it inflicted on them. It just almost brings me to tears, you know, because I feel if my family had this opportunity, then they would've had more productive lives."

Ms. Williams certainly touched many lives with hers. As a foster parent for the last 21 years, she estimates that she's helped raise more than 100 children. Sometimes the youngsters she fostered in the past return as adults when they need extra support. "You just never know when that knock might come again," she says. "But it works. I enjoy doing what I do."

Ms. Williams has the full support of her family for her participation in the study. Her husband drives her to her appointments, and her sister, who also has diabetes, appreciates the information about diet and exercise through Genola. "I notice it's made a difference in her life, too" she says.



---

*“We have learned so much from these participants,” Ms. Shapiro says. “They’re really inspirational. They have health issues, family struggles, and yet they come in here with the brightest smiles, so thankful to be part of this.”*

---

At these events and at the study visits, the staff do everything they can to make sure the participants have the information they need to stay healthy. “They come here and they feel special. We talk to them about things they don’t have time to talk about with their physicians,” Sue says.

And of course, they share their own lives, both happy and sad events. They pull out their pictures, and say “Let me show you my grandkids,” and the staff love to take the time to listen.

But the learning goes both ways. “I know this sounds corny, but we have learned so much from these participants,” Ms. Shapiro says. “They’re really inspirational. They have health issues, family struggles, and yet they come in here with the brightest smiles, so thankful to be part of this.”

## DIRECT TRANSLATION

DPP and DPPOS staff at the MedStar site have also worked on some significant “translation activities” that have used the DPP findings to develop programs for the public.

**Gretchen Youssef**, the first DPP program coordinator for MedStar, now works for the MedStar Diabetes Institute, using her DPP experience to spearhead community based programs aimed at diabetes prevention. Gretchen’s department offers lifestyle classes at two DC recreation centers, at the DC Department of Health, a local barbershop and for MedStar employees. Five healthcare professionals received training to facilitate the program which reached more than 700 individuals.

**Vanita Aroda, MD**, current principal investigator for the MedStar site, has used findings from the DPP to help primary care providers identify people at high risk for diabetes. She received a Mentor Research Career Development Award for her work from the Georgetown-Howard Universities Center for Clinical & Translational Science Research Education.

**Robert Ratner, MD**, the original PI for the DC site, is engaged in diabetes prevention activities as the chief medical scientific officer for the American Diabetes Association.

# THE NORTHWESTERN UNIVERSITY FEINBERG SCHOOL OF MEDICINE



## THE NORTHWESTERN UNIVERSITY FEINBERG SCHOOL OF MEDICINE CHICAGO, ILLINOIS

Most people know Chicago's Magnificent Mile for its endless shopping (think Neiman Marcus and the former Marshall Fields), landmark buildings (John Hancock Tower and the Wrigley Building), and world-class museums (The Field Museum of Natural History and The Art Institute of Chicago).

Fewer know that it is also home to a study site for the Diabetes Prevention Program Outcomes Study. "Our actual address is Michigan Avenue, which is very posh," says Mariana Johnson, MS, RN, Program Coordinator for the site hosted by Northwestern University's Feinberg School of Medicine.

The site location was attractive to participants in the study, particularly in the early years of DPP. They would come to the site for the study visits, then spend the rest of the day exploring and enjoying the area. Ms. Johnson, who has been involved since the program began in 1996, says that the site pays for all-day parking so that people can do just that.

Even with the lure of high-end shopping and sightseeing, recruiting for the site took a lot of effort. "We would send out 10,000, 15,000, or 20,000 fliers. If you got anywhere from a half-of-a-percent to a percent-and-a-half response, that was considered good," says Ms. Johnson. But the staff was undeterred.



Northwestern participants walk together during an organized outing.

To get as many participants as possible, staff went to health fairs, they ran advertisements in newspapers, and doctors involved went on radio talk shows. They contacted local companies to participate in their employee events. They also invited whole families to come in and get tested. "We did whatever we could," Ms. Johnson says.

---

***"[The participants] are doing it because it's a good thing to do. They feel like they're contributing something," says Ms. Johnson.***

---

They also held a couple of recruiting events with the University of Chicago, another DPP site. Participants could choose which Chicago site to



This Northwestern participant starts each day with a 30-minute paddle on a small lake near her home.

go to. In fact, there are two brothers in the study: one goes to the Northwestern site, the other goes to the University of Chicago. “Each one chose the site that was more convenient for them,” Ms. Johnson says.

Those who joined the study did so to help themselves, but also for altruistic reasons. “They’re doing it because it’s a good thing to do. They feel like they’re contributing something,” says Ms. Johnson.

Most participants come from the Chicago suburbs, but many live farther away, including a total of 13 who live out of

state. One person flies down regularly from Minneapolis, Minnesota, and another came from Milwaukee, Wisconsin. These participants signed up for the program even before the study offered travel reimbursement—a sign of their dedication and commitment to the study.

This dedication goes both ways. Two staff members have worked on the study since it launched. All have been involved for more than 10 years. The staff have made DPP a part of their lives and integrated the recommendations into their own lifestyles by swimming, running or walking regularly. When the site holds Saturday clinics or weekend events, they often bring family members along to help and to visit with participants.

## EXERCISE PRESCRIPTION

Ms. Johnson says that during a typical study visit, participants don’t have to sit in the waiting room for long. If necessary, she will bring people into the conference room or her office just so they don’t have to wait. “When they come in the door, I want to get started with what they need to do, so that they can be out in the time that they want,” she explains. “Sometimes they want to sit and talk, and that’s fine. If they’re in a hurry for whatever reason, and they’ve got other things to do, but they’re still coming in for their visits, I don’t want to do anything that’s going to slow them down or cause them to think, ‘Oh this is too much trouble.’”

Ms. Johnson encourages participants to think of exercise like medicine. For example, when a participant recently admitted that she wasn’t getting in her 150 minutes of activity per week, Ms. Johnson explained she needed to think of the exercise as a prescription. “You’re not doing something that’s been prescribed for you to do,” she told the participant. The woman had never thought of it that way. “Many people don’t,” says Ms. Johnson. “Exercise is just in a different category in our brains [from medicine].” But it shouldn’t be.

Other participants take the advice to heart. One participant kayaks daily on a small lake near her Indiana home. After 30 minutes of paddling, she walks about a half a mile or so to pick up her newspaper, then walks back. She does this every morning, seven days a week.

---

***“We have good relationships with [the participants], and we enjoy having them come in,” says Ms. Johnson. “It’s just a good feeling when you see these people again.”***

---

The center’s greatest accomplishment is the bond that exists between the staff and the participants. The people who are still coming are like family. “We have good relationships with them, and we enjoy having them come in,” says Ms. Johnson. “It’s just a good feeling when you see these people again.”

# PENNINGTON BIOMEDICAL RESEARCH CENTER



## PENNINGTON BIOMEDICAL RESEARCH CENTER BATON ROUGE, LOUISIANA

Celebrating its 25<sup>th</sup> anniversary in 2014, Pennington Biomedical Research Center is a globally recognized leader in research into the connection between nutrition and health. But, in 1992, Pennington was just establishing itself in the local community and the wider research world. That was the year when Director George Bray, MD, first heard about an upcoming National Institutes of Health study into the effects of a lifestyle intervention on the development of diabetes. Dr. Bray, already recognized as a leading obesity researcher, saw participation in the Diabetes Prevention Program as a logical extension of the Center's original mission.

C.B. "Doc" Pennington donated millions to Louisiana State University (LSU) to build a world-class research center devoted to nutrition and health. "Nutrition is the thing," he told *The New York Times* in 1983, the year he made the gift to LSU. "What we eat makes up our bodies, but also helps determine our mental condition." In 1989, Pennington Biomedical Research Center opened its doors on a beautiful 225-acre campus on the outskirts of Baton Rouge, LA.

"Mr. Pennington wanted a world class nutrition research center," Dr. Bray explains. "We began with calories and their impact on obesity. You pick up obesity, and diabetes isn't far behind so we had already been doing trials related to agents which

would reduce body weight. [DPP] just broadened that base to look at the impact on people who had pre-diabetes."

---

*"It has been a wonderful community of people who have enriched my soul and body. The learning experience has been invaluable and every person in Pennington since I began in 1996 has been truly a delight to deal with," says a DPPOS participant, Pennington Biomedical Research Center.*

---

### RECRUITMENT EFFORTS

As a young organization with no medical school nearby or hospital affiliation, Pennington had to forge its own road in working with the local community and recruiting eligible participants. "Most of the other [DPP] sites are in hospitals or medical schools. We are in neither," Dr. Bray explains. "It took a while for us to be recognized around the community. We didn't have much name recognition."

Despite that, recruitment went quickly. In addition to direct mail efforts, LSU allowed Pennington to attach a flyer to employee paychecks. Staff also



visited area endocrinologists and primary care physicians to inform them about the study and encourage them to refer patients when appropriate.

The Diabetes Prevention Program hit home for many who heard about it. When Irving Coupel saw the flyer in his paycheck, he knew right away he wanted to be part of the study. His mother had suffered from type 2 diabetes and two of his first cousins had recently died from the disease in middle age. Overweight, inactive and in his 40s, Mr. Coupel knew he had to do something to lower his risk and lengthen his life. He picked up the phone, called Pennington, and found he qualified for the study.

The Pennington participants range in age from 55 to 98. More than a third are African American, and nearly all have a family history of diabetes that initially spurred their interest in the study. But while they may have originally gotten involved in the study for their own personal reasons, concern for others plays an increasing role in their continued involvement. "They really get excited about helping out," says Jennifer Arceneaux, RN, one of two program coordinators for the Pennington site. "They are excited about being contributors to the program and diabetes research."

---

*"My body is still 45, although my age is 67 tomorrow," says a DPPOS participant, Pennington Biomedical Research Center.*

---

### PRIDE OF ACCOMPLISHMENT

With the Center's special interest in nutrition research, the Pennington staff take great pride in how much their participants have accomplished. The BOOST and HELP classes are all taught by registered dietitians with vast experience in the topics presented.

"We've been doing this a long time," says Erma Levy, CDE, who teaches the lifestyle classes. "I've taught a lot of classes dealing with diabetes education, weight loss, and weight loss management. I think that experience helps a lot with the BOOST and HELP classes." In addition to the Diabetes Prevention Program, Ms. Levy has worked on other landmark diabetes studies, including Look AHEAD, which is looking at diet and exercise in participants already diagnosed with diabetes, and Heads Up, which is exploring the effects of weight loss surgery and lifestyle counseling on diabetes.

The DPPOS staff at Pennington realize how much effort it takes to keep going with a study over the years. "Most of our participants have been in the study since 1996," says Amber Dragg, RD, who shares the program coordinator position with Ms. Arceneaux. "Some of them have maintained their weights or are below their goal weight. Some of them are teetering around their goal weight. But still, their overall goal each and every time they come is to try to learn something new, try to do things differently than they've done the previous year."

This doesn't necessarily get easier. "It gets a little harder because life changes, things come up," says Monica Lockett, Research Nurse.

"The older they get, there are physical barriers, like arthritis and aches and pains," adds Ms. Levy. "They can't exercise like they used to."

But that doesn't stop them from trying.

"Our 98-year old participant, he's been in really excellent health," Ms. Arceneaux says. "He was in the Senior Olympics in weightlifting, and he still does yoga. He's been active since he started."

Another 82-year-old participant takes water aerobics classes three days a week.

---

*"It is wonderful to be able to look forward to the next day and still wanting to be of service to others. Grateful to all at Pennington! Maybe I will be able to be an informative 'alumnus!' Thanks for the opportunity," says a DPPOS participant, Pennington Biomedical Research Center.*

---

### TOUR DE CURE



Mr. Coupel participates in the Tour de Cure.

Mr. Coupel has also worked hard first to lose weight, then to maintain his weight and his health. Randomized to the medication group, he wasn't going to wait around to find out whether he was taking placebo or metformin. He immediately changed his diet and started exercising. Soon he dropped from 240 pounds to 184. He took advantage of Pennington's facility to exercise and brought his wife along to the classes so she could learn along with him.

In 2001, when he turned 50, Mr. Coupel bought his first bicycle and started a regular routine of riding. He started with short rides around his neighborhood, then worked up to longer rides of about 25 miles roundtrip. Each year, he participates in the local Tour de Cure, sponsored by the Baton Rouge area American Diabetes Association. Irving raises about \$1,500 for the organization each year.

Three bicycles and 12,000 miles later, he is still riding. "To this day, I still don't have diabetes," Mr. Coupel says. "I credit that to the phone call I made in 1997 to Pennington about the Diabetes Prevention Program."

"Doc" Pennington would be proud.

# SHIPROCK AND ZUNI COMMUNITIES



## SHIPROCK AND ZUNI COMMUNITIES NEW MEXICO

The DPP/DPPOS sites in Shiprock and Zuni don't fit the typical profile of a site for a large, multi-center clinical trial. There's no large teaching hospital in the vicinity. The closest university hospital is 220 miles away. The principal investigator (the doctor who oversees the site) is 350 miles away. But with a rate of diabetes twice that of non-Hispanic whites, American Indian participation was essential to the Diabetes Prevention Program.

With more than 10,000 residents, Zuni is one of the oldest, continuously occupied Indian villages and the largest of the 19 New Mexico pueblos. Many Zuni live in traditional adobe houses and take great pride in maintaining ancient customs and religious ceremonies.

About three hours from Zuni, Shiprock (population 8,300) is located along the northeast border of the Navajo Nation, in the Four Corners area where New Mexico, Arizona, Colorado and Utah meet. It is home to the Northern Navajo Medical Center, an Indian Health Service facility that serves more than 45,500 American Indians, mostly members of the Navajo tribe, who live in the surrounding area.

It took a concerted effort to bring the Diabetes Prevention Program to this area: NIDDK's Phoenix satellite branch, the Indian Health Service, the Navajo Nation, the Zuni Pueblo, and the Shiprock community all came together to make sure that the Navajo and Zuni people had the opportunity



A group of Shiprock/Zuni participants take a walk through a local park.

to participate in the research project. William Knowler, MD, DrPH, who oversees these sites as well as the Southwest American Indian Center, spends a full day traveling each way from Phoenix whenever he visits.

The Shiprock and Zuni communities have shown the program great support from the very beginning. "Diabetes is such a huge problem in our community that people are just thankful that the study's here," explains Carol Percy, RN, MS, Program Coordinator for the Shiprock site. "A lot of [participants] have watched loved ones die from complications. They were interested in this study so that we could figure out how to help their children. They joined because they wanted to try to figure out what to do about diabetes."





Linda Benally, a dedicated participant, has dropped 35 pounds and is dedicated to keeping her family active and healthy.

To recruit participants, the DPP staff set up information tables at local grocery stores, the post office, and at community events. In the Zuni pueblo, staff went door to door to talk to residents about the program. In both communities, this personal touch helped recruitment run smoothly.

---

***“A lot of [participants] have watched loved ones die from complications. They were interested in this study so that we could figure out how to help their children. They joined because they wanted to try to figure out what to do about diabetes,” explains Carol Percy.***

---

Linda Benally, a member of the Navajo tribe, found out about the study when she approached the DPP table at the post office in Shiprock. She recognized one of the staff members as Roz Barber, a classmate from high school. Ms. Barber offered to test Linda’s blood to see if she was at risk for diabetes. “My husband and my mom are diabetic, so I just thought, ‘I need to know myself where I stand.’” Ms. Benally eventually found out that she had “borderline” diabetes and qualified for the study. She eagerly signed up.

## DETERMINATION AND DEDICATION

Ms. Percy remembers one winter morning of screening sessions in Shiprock, she woke to 6 inches of snow on the ground and more on the way. She lives 45 minutes from the clinic, so she considered staying home for the day. But then she thought of the people who had fasted overnight to come in for glucose tolerance tests. What if they arrived and no one was there to greet them? She headed into the clinic. Three out of four of the people showed up, despite the snow.

That determination and dedication has served the participants—and the study—well. Keeping up with study visits and following the tenets of DPP can be especially difficult in this remote area. It’s not unusual for Shiprock participants to travel 45 miles one way for their DPP appointments. When the study asks Zuni participants to undergo special tests, they have to travel

even further—145 miles from Zuni to Shiprock or even to Phoenix, about 5 hours away from Zuni.

At the beginning of the study, the one local Zuni grocery store had more processed foods than fresh fruits and vegetables. Most people drove the 30 miles to a larger store with a better selection of healthy choices. A Shiprock participant fit his 150 minutes of exercise into his busy schedule by running on his dirt road in the pitch dark of night, his wife driving behind him to light the way. Despite these challenges, more than 90 percent of participants in the original study still participate today.

---

### ***T'áá hwó' aji t'éego (Navajo)*** ***Your Health is Up to You***

---

A good example is Zuni participant Glenda Vicenti, who balanced participation in the study with her full-time job in the school district, attending college classes at night, raising her four-year-old son and serving as an active member in the Zuni community. Randomized to the lifestyle group, Ms. Vicenti had to jump right in with making changes to reach her diet and exercise goals.

“It was kind of hard in the beginning because sometimes if I had a class late at night I would just grab whatever was available. But as I attended more sessions, I started to look at how I could make changes that would be healthier,” she explains. “Those [lifestyle] classes came in handy. I started to take more caution in what I ate and what I did—even down to parking farther away in the parking lot and taking the stairs. It was just those small changes that I started saying, ‘Hey, I can do these things.’”

Getting her exercise is easier now that she has earned her degree and her son is the one attending college. She works during the day, but in the evenings she’s a regular at the newly renovated Zuni Wellness Center where her husband is a fitness instructor. When her son is home, he joins the family exercise routine. “I’ve been telling him how we have our history of diabetes, so he’s taking part in doing exercise, and doing things on his own as well,” she says.

The Shiprock participants have also shown great devotion to the study—and have been making important lifestyle changes that have improved their health and their lives. For the first round of DPP, Ms. Benally was in the placebo group, but she jumped at the chance to take the lifestyle classes during the bridge period. She started out by watching what she ate and walking daily. Soon she was walking or jogging a 7-mile route in the hills behind the family farm outside of Shiprock. “Usually it was me by myself,” remembers Linda, who has a husband and four grown children. “There were no trees, just wildflowers and sage plants. As I walked, I was mainly praying for my kids, for my family.”

Soon after starting her diet and exercise routine, Ms. Benally dropped 35 pounds. Although her exercise routine has changed with life circumstances, she has been able to maintain and even add to her weight loss. This gives her the energy she needs to garden, help on the farm, care for her husband and play with her two grandchildren. “I like to play ball with [my grandson] and keep him active,” she says.

For all this, Ms. Benally is grateful to the study: “I’d like to thank the program, because if I didn’t participate, where would I be now? I was almost 200 pounds. Would I be 300 now?”

# SOUTHWEST AMERICAN INDIAN CENTER—ARIZONA



## SOUTHWEST AMERICAN INDIAN CENTER—ARIZONA PHOENIX, ARIZONA

Kent Andrews admits it was curiosity more than concern that prompted him to get tested for the Diabetes Prevention Program (DPP). He had just started work for the Salt River Pima-Maricopa Indian Community when representatives from the National Institutes of Health came to the reservation to talk about a new study looking at ways to prevent diabetes in those at risk. Mr. Andrews thought he should at least get tested to see if he qualified.

He thought there was a good chance that he was at risk. In fact, with his family history, he thought that diabetes was inevitable. “I lost my father to complications of diabetes, and my mother and brother were diagnosed too,” says Mr. Andrews, who has lived in the Salt River Community all his life. “I knew that diabetes was something I needed to look out for, but I wasn’t yet educated on how to keep that from happening.”

Mr. Andrews’ family history is not unusual in American Indian communities. In some tribes, as many as half the adult members have diabetes or are at risk. But the good news is that DPP has proved that there *is* something that can be done about it.

The study results announced in 2002 confirmed what many had suspected: activity and weight are the keys to keeping diabetes at bay. “That was the start of people waking up to what we need to do about diabetes in our community,” Mr. Andrew says. “That seemed like the starting point of everyone getting on the same page.”

---

*“[Discovering that activity and weight can keep diabetes away] was the start of people waking up to what we need to do about diabetes in our community,” Mr. Andrew says. “That seemed like the starting point of everyone getting on the same page.”*

---

### ACTIVE INVOLVEMENT FROM TRIBAL LEADERS

Originally, the DPP site at the Southwest American Indian Center in Phoenix focused on recruiting participants in two nearby Indian communities: the Salt River Pima-Maricopa Indian Community, about 15 miles east of Phoenix, and the Gila River Indian Community, about 45 miles to the south. Eventually, recruitment was opened to all American Indians in the Phoenix area. The site’s 55 participants represent at least 12 different tribes. In addition, the site also serves several participants who have relocated to the area and transferred from other DPP sites.

The tribal councils and other leaders of both Salt River and Gila River were actively involved in both the planning and the implementation of the study back in late 1990s. The site team included native professionals, community members, and staff who had experience working



with local tribes. They met monthly during planning and quarterly during the implementation with tribal leaders to come up with recruitment and program ideas that fit with the culture and concerns of the communities.

“All of these communities were very aware of the problem of diabetes,” says William Knowler, MD, DrPH, Principal Investigator for the Phoenix site. “They were clearly interested in hearing about diabetes prevention activities.”

A tribal council leader wrote letters to community members to introduce the study and its aims. Several Community Council members came to the screening events and even got checked themselves. Some who knew they weren’t eligible for the study still went through the screening as a show of support and to find out the details of the project.

One-to-one recruitment worked best. DPP staff went to door-to-door to people’s homes and talked to members at pow-wows, basketball tournaments, and other community events. At the suggestion of one tribal leader, they contacted family matriarchs and offered to meet with extended family members to share some information about diabetes. Staff then tested blood sugars for those interested in knowing their status.

Like Mr. Andrews, many of the people who joined the study are involved in their communities both as professionals and as volunteers. They serve on committees, organize events, and stay active in sports, especially basketball. “They’re very active community members,” says Mary Hoskin, Program Coordinator for the Phoenix site. “They all contribute a lot to their families and communities. Even if they’re retired, they’re still busy.”

---

***“It is also interesting to hear how participants have been able to work toward the DPP goals in their own creative, unique ways. Our participants have taught us a lot over the years,” says Julie Nelson, RDN, a nutritionist with the program.***

---

Their busy lives sometimes make it difficult to follow the lifestyle recommendations and fit in their appointments, but all of the participants make an impressive effort and even share what they learn with their family members.

“We always enjoy hearing how people implement lifestyle changes into their lives and how that change affects their family as well—their children and their grandchildren,” says Julie Nelson, RDN, a nutritionist with the program. “It is also interesting to hear how participants have been able to work toward the DPP goals in their own creative, unique ways. Our participants have taught us a lot over the years.”

---

***“[The staff are] good people,” Mr. Andrews, a participant, says. “Sometimes I forget I’m part of a study. It’s more like we’re friends, just sharing what we know.”***

---

For example, one participant “basically went from the couch to running a marathon,” says Sandra Sangster, RD, another nutritionist with the site. “She started by walking, then built up, and next thing you know she’s running farther than any of us ever dreamed of.” Another participant came up with a way to stick to the DPP diet recommendations at community pot luck events: socialize first, then eat. That way, by the time the participant gets to the buffet, only the healthier selections are left.

The participants also enjoy building relationships with the staff. “They’re good people,” Mr. Andrews says. “Sometimes I forget I’m part of a study. It’s more like we’re friends, just sharing what we know.”

## IHS COLLABORATION

NIDDK and the Indian Health Service (IHS) work closely with the Southwest American Indian sites

in Phoenix as well as Zuni and Shiprock. “This collaboration helps in many ways,” Ms. Hoskin says. The Director of Diabetes Treatment and Prevention at IHS serves as co-investigator, which helps ensure that the lessons learned from DPP are quickly communicated to other tribal communities to improve care for people at risk of diabetes. Staff from the Phoenix, Zuni and Shiprock sites also provide training and technical assistance to tribes and tribal groups that are implementing programs based on DPP. “We help staff with thinking through some of the unique circumstances of implementation for their specific communities,” Ms. Hoskin says. “We do whatever we can to help them get the resources or skills they need to implement DPP.”

The participants also play a role in spreading DPP to other communities. When the results were first released, DPP staff asked participants what they thought should be communicated to other tribes. Instead of a standard how-to presentation, the participants recommended an inspirational message communicated through interviews with American Indian DPP participants. “It’s called ‘A Message of Hope,’ because that was the message participants wanted to send,” Ms. Hoskin says. Participants also occasionally help make presentations at training sessions.

Seeing DPP spread to other tribes is especially rewarding for staff and participants. “That’s why we do the research—so tribes can use what we learn about diabetes prevention or treatment,” says Ms. Hoskin. “To watch tribal programs evolve over time, and be part of it in a small way, has really been exciting for us and makes what we do much more gratifying.”

## CONTINUING NATIVE TRADITIONS



DPPOS participants and staff gather cholla buds during the harvest.

From the very beginning, DPP staff at all the sites—from Boston to Honolulu—tried to make sure that the program took into consideration the cultural traditions of the participants. The DPP food book included selections from all of the cultures represented among the participants, and DPP activities often reflect local customs. This was especially true at the American Indian sites in Shiprock, Zuni, Gila River, Salt River and urban Phoenix.

“We have really tried to make DPP culturally relevant,” Mary Hoskin, Program Coordinator at the Southwest American Indian Center—Arizona says.

Native traditions often fit right in with the goals of DPP. For example, cholla buds, harvested from the cholla cactus in spring time, are high in soluble fiber and calcium and low in fat. “People go out just before Easter and gather them, dry them and eat them,” says Shandin Begay, MPH, Retention Coordinator at the Phoenix site. A couple of years ago, the staff organized an activity to gather cholla buds. “We had some people who were excited to go because they had never gathered them before and they always wanted to. And we have some people who had been doing it for years and really enjoy it.”

At the Shiprock site, one of the traditional foods includes kneel down bread, a special type of cornbread that is traditionally cooked in a pit outside. Linda Benally, a Navajo DPP participant who makes kneel down bread at home, explains it this way: “It’s ground fresh Indian corn. You shave it off the cob and grind it.” After mixing the ground corn with water, the mixture is spread inside green corn husks and placed in a fire pit. It’s called “kneel down bread” because you actually have to kneel down on the ground to place it on the fire.

Ms. Carol Percy, RN, Program Coordinator at Shiprock, had not made kneel down bread before, but that didn’t stop her from asking the local team if they could pull this off as a participant activity. “We taught her to build the oven, shoveling mud to seal the space between the rocks,” Miranda Smart, the Shiprock data collector, remembers. She adds that kneel down bread fits right into the diet recommendations of the lifestyle program: “Since kneel down bread is ground corn baked in a husk, it is a great source of fiber and is low fat, too. Of course, we added green chili to some batches because we love green chili in the Southwest.”

## TEACHING OTHERS

Zuni DPP participant Glenda Vicente and her husband are active members of the Zuni community, continuing traditions that have been followed for generations.

As part of her job in the local schools, Ms. Vicente teaches Zuni language to first graders. The curriculum includes a unit on food. “We talk about nutrition, exercise and all that,” she says. She also likes to tell them about the traditional ways and how their ancestors lived.

*“[Our ancestors] were very active. They still ate the same traditional foods that we eat, but they were more active, gathering their food and doing a lot of farming. The farming they had to do, that was their exercise. They had to weed, they had to harvest the corn. Nowadays, we go to the market and we get the things that we need. We don’t really take time to plant anything. Everything is just provided for us.”*

Each year, Ms. Vicente and her husband participate in the preparations for the Zuni celebration of Shalako, which takes place in December. “It’s a whole year process where we get together at a certain place and prepare food. There are meals served throughout the day.”

Ms. Vicente says it’s easy to eat too much at these events. When she brought up the challenge at a DPP lifestyle session, the group brainstormed ways she could handle the challenge of sticking with her healthy diet while participating wholeheartedly in the important community event. The solution: “Engage in conversation. As long as you’re engaged in conversation, it takes time away from eating.”



# ST. LUKE'S-ROOSEVELT HOSPITAL CENTER



## ST. LUKE'S-ROOSEVELT HOSPITAL CENTER NEW YORK, NEW YORK

There's a bronze plaque in the lobby of the building that houses the St. Luke's-Roosevelt site of the Diabetes Prevention Program Outcomes Study (DPPOS) in midtown Manhattan. On it is engraved the names of all the donors who gave \$100 or more to the development of this hospital building.

It's a tribute to ordinary people who make extraordinary things happen, people who were probably in many ways similar to those who signed up to participate in DPP and DPPOS.

Program Coordinator Jane Lee, MS, RD, remembers the excitement at the beginning of the study: "I was meeting people at the planning meetings who were really famous, people who had written or were cited in the text books I read in college. It was like the crème de la crème of the diabetes medical world."

But as heady as it was to rub elbows with some of the leaders in the field of diabetes prevention and treatment, she knows it's the participants who are the real heroes of this project. Despite changes in their lives and in their city, they've been coming to their appointments for 17 years now.

"The people who have participated have had a sense of accomplishment that they contributed on some level to this historic study," Ms. Lee says. "They have really appreciated the opportunity to make a difference. There are not a lot of things



St. Luke-Roosevelt DPPOS staff members.

you can do in life beyond your job and your family. To have been part of this is kind of cool for a lot of people."

### CITY CHALLENGES

The city that never sleeps presents different challenges from other big cities. First, there was the challenge of finding participants. You'd think it would be easy to find 150 participants in a city of 8 million, but that wasn't the case. First, there was the mailing house that neglected to send out the letters monthly, as was planned. Instead, they saved them up and sent out three times as many at one time. By the time the site staff figured out what was happening (judging from no calls for three months, then a slew of calls at the same time), the site had settled into a peaks and valley





St. Luke-Roosevelt participants walk around Central Park.

pattern that persists to this day. “We have a high season and a low season” for participant visits, says Ms. Lee. In August and September, there can be as many as three participants a day, all arriving before 10:30 a.m. to get their blood tests done.

Even with the study site located close to a subway stop in midtown Manhattan, getting there isn’t easy for many of the participants, especially as they get older. Midtown might have been convenient to their work or home when the study

started, but many people have retired or moved to the outer boroughs—or even further. This has happened at many of the sites, but perhaps more so in New York, where the winters are cold and the cost of living is high.

Some of the original St. Luke’s-Roosevelt participants have transferred to other centers. Others travel back to keep up with their appointments. One woman comes from Germany and another travels two days via Amtrak from North Dakota to New York City.

---

*“The people who have participated have had a sense of accomplishment that they contributed on some level to this historic study,” Ms. Lee says. “They have really appreciated the opportunity to make a difference. There are not a lot of things you can do in life beyond your job and your family. To have been part of this is kind of cool for a lot of people.”*

---

## RHYTHM OF LIFE

For others, regular visits to the St. Luke’s-Roosevelt site have just become part of the rhythm of their lives in the city. Among the participants are a judge and a Broadway producer, as well as teachers, bankers, and store clerks.

Eleanor Lowe, a retired social worker, is one example. She lives on the Upper West side of New York and often walks the 40 blocks from her apartment to the study site in midtown. She embraced the goals of the

lifestyle intervention, changing her diet, upping her exercise and losing more than 50 pounds. “She loves the program and comes to our health classes,” says Ms. Lee. “And she still hasn’t gotten diabetes.”

In fact, she proudly reports that her last couple of blood tests haven’t even shown prediabetes. “It’s a slow process when all your life you’ve been told a certain way to eat, a certain way to live and then you have to make changes,” Ms. Lowe says. “But then I saw the results of these changes. I was prediabetic when I started the program, but I’m not now. My last few tests have been normal. I have grandkids, and this means I can live to see them grow up.”

Along with the motivation of the participants, Ms. Lee also credits the Pittsburgh group that designed the lifestyle component of the program. “They do a fantastic job of coming up with

different ways to present the information,” in a way that encourages people to keep coming back.

Ms. Lowe not only keeps coming back, but she brings her friends and she spreads the word about diet and exercise where ever she goes. Her daughter has recently improved her diet and exercise, and her granddaughter often joins her for a workout with her interactive Wii system. “If I can duplicate what I know to 10 people and then to 10 other people, it just spreads and then the whole country is aware,” she says. “I think this is the way the country needs to stop the epidemic [of diabetes]: You make them aware. You can’t control what people eat, but if they’re aware, they can control that.”

That’s the power of an ordinary person to do extraordinary things, Ms. Lowe says: “We have influence. We can build a building, we can change lives.”

---

**Durante mucho tiempo, el DPPOS me ayudó a mantenerme enfocada sobre mi peso y salud. Las visitas continúan siendo un beneficio durante las décadas. (Spanish)**  
*Throughout the years, the DPPOS has helped me stay focused on issues concerning my weight and health. The visits have continued to be a benefit for almost two decades.*

---

# THOMAS JEFFERSON UNIVERSITY HOSPITAL



## THOMAS JEFFERSON UNIVERSITY HOSPITAL PHILADELPHIA, PENNSYLVANIA

Located in downtown Philadelphia's Washington Square West neighborhood, the Jefferson Diabetes Research Center is the DPPOS site for the tri-state area of Pennsylvania, Delaware, and New Jersey.

When Wendi Wildman, RN, signed on as DPPOS program coordinator here in 2003, she had no idea that she'd have an opportunity to get in touch with her inner party planner. In addition to her many clinical and managerial duties, she's taken great care and pride in selecting great venues and entertainment for the annual "Your Contributions Carry On" event.

"I didn't realize I'd be a social director [when I took the job]. I wear a lot of hats in addition to being a nurse," says Ms. Wildman. But she's not complaining. "It's a lot of fun. It's our way to show appreciation to our participants."

The lineup has included Philly-area jazz vocalist Phyllis Chapell, who performed with a Latin theme and had participants up and dancing the cha-cha. Local musician, Bradley N. Litwin, a ragtime jazz guitarist and singer has entertained them a couple other times. Rick Nollet and his blues band have also performed and "rocked the house" with an active dance floor.

They've had lunches at local restaurants, had a healthy barbecue, took a tour of the city in an amphibious vehicle, and even had a sock hop.

The most recent event was a lunch held at The Walnut Street Supper Club, where professional performers serve up wonderful food along with popular songs and Broadway hits.

---

*"They're a committed bunch," says Ms. Wildman. "We're like a family—we care deeply for each other."*

---

### FEELS LIKE FAMILY

While most of the 110 participants live within an easy drive or commute to the downtown Philadelphia location, a handful fly in from other states, including Florida, the Carolinas and Georgia. Although most of the participants have now retired from their careers, some past professions include FBI agent, nurse, teacher, lawyer, minister, singer, police officer, and a judge.

"They're a committed bunch," says Ms. Wildman. "We're like a family—we care deeply for each other."

Current Jefferson staff includes dietician and Certified Diabetes Educator Jackie Dwyer; phlebotomist Andrea Williams; and Principal Investigator Kevin Furlong, MD. Even though the

other staff have not been with the project as long as Ms. Wildman, there's a strong feeling of connection between them and the participants. "We're a great team," Ms. Wildman says.

Dr. Furlong joined the study just three years ago, but he feels that connection as well. "It feels more like family than any other trial I've ever been involved with," he says. "You don't always get that chance to develop deep relationships with the individuals [in a study]. We all get the same feeling of excitement to work with these participants and to be involved in this research."

The Jefferson staff put extra thought into making study visits pleasant and lifestyle classes motivating and informative. "When they come in, they are our focus, and they feel it," Ms. Wildman says. "We know all about them... We want to know what's going on, and it's reciprocal." They ask about each other's families and share news about their grandkids.

In between visits, staff stay in touch with participants, particularly if they've been having health problems or difficulties sticking with the study regimen. "I think one of the challenges is when they start to lose weight, and then they go off track," Ms. Wildman says. "Or when they get sick and have to take a medication that affects their sugar levels. We just reach right out and let them know they can call us, email us. We are happy to help them and we let them know that we are always available."

---

***"It feels more like family than any other trial I've ever been involved with," Dr. Furlong says. "You don't always get that chance to develop deep relationships with the individuals [in a study]. We all get the same feeling of excitement to work with these participants and to be involved in this research."***

---

Staff also keep the lifestyle sessions interesting with taste tests and games like "Deal or Dud." "We try to present them with things they typically wouldn't go and purchase," Ms. Wildman explains. Then they ask the participants to rate them. They've done this with whole grain snacks, Greek yogurts and even different kinds of milk—almond, soy, rice, coconut, hazelnut, oak and hemp. "We actually had a 'milk bar' where we would pour the samples," Ms. Wildman remembers. "Everybody is used to regular

milk, but we wanted to expose them to something different." The participants rated almond, coconut and soy milks the highest.

## PUTTING DPP INTO PRACTICE

In addition to his duties as principal investigator for DPPOS, Dr. Furlong has a thriving endocrinology practice—and he brings this approach to the DPPOS participants. "I'm more of a clinician than a researcher," he says. "I like being hands-on. I like meeting participants when they come in. They have inquisitive minds and want to learn. They want to take better care of themselves."

Dr. Furlong also uses the findings of DPP and DPPOS with his patients who have prediabetes, diabetes, and obesity. "The information we're gleaning from this trial is directly applicable to my daily practice of medicine, which I find

fascinating," he says. One of the most important lessons from DPP, Dr. Furlong says, is that "natural interventions like diet and exercise—reducing calories, moving the body—are very robust and effective interventions in preventing disease."

The second lesson, he says, is the value of persistence and perseverance, which he's witnessed among both the DPPOS staff and the participants. It's not easy to keep going with diet and exercise changes to continue losing weight and being active. But, Dr. Furlong says, the DPPOS participants keep plugging at it, with the staff acting as motivators and supporters. They're an inspiration to both Dr. Furlong and his patients.

"You keep presenting the message and eventually you're going to get a number of them to buy into that," he says. "It's nice to have DPP to say to the patient, 'Look, this really works.'"

---

***"You keep presenting the message and eventually you're going to get a number of them to buy into that," Dr. Furlong says. "It's nice to have DPP to say to the patient, 'Look, this really works.'"***

---



# UNIVERSITY OF CALIFORNIA AT LOS ANGELES (ALHAMBRA) RESEARCH CENTER



## UNIVERSITY OF CALIFORNIA AT LOS ANGELES (ALHAMBRA) RESEARCH CENTER ALHAMBRA, CALIFORNIA

Alhambra, located about 25 miles east of downtown Los Angeles, is the gateway to the San Gabriel Valley. It's a thriving multicultural city with large, active Asian and Hispanic communities. It's also the site of the University of California at Los Angeles Research Center, which specializes in outreach to minority communities. The Diabetes Prevention Program Outcomes Study (DPPOS) is one of several studies currently underway at the Research Center.

"This center was designed almost 10 years ago to function as a satellite base for UCLA to engage in the communities it wanted to study and actually be located within those communities," says Anthony Sosa, DPPOS Co-Program Coordinator. Other studies hosted at the site include the MESA Study (Multiethnic Study of Artherosclerosis).

The city has undergone some changes since DPP first launched 17 years ago. While the area is now more than 50 percent Asian, in the 1990s the city had a larger Hispanic/Latino community when DPP was recruiting here. The DPPOS participants reflect that.

"Our primary ethnic group in our study cohort is Hispanic," Mr. Sosa says, adding that a majority speak Spanish as their primary language. "We also

have a significant cohort of people with Indian background," he adds, noting that this DPPOS site has the highest number of southeast Asian Indian participants in the study.

"Indians may have certain genetic factors that could predispose that group to developing diabetes," Mr. Sosa explains, even without obesity. "Having [southeast Asian] Indian participants in the study provides important information about how diabetes develops and progresses over time and if the intervention delays diabetes" in that group. The good news from DPP is that both the lifestyle and metformin interventions were effective across all ethnic groups.

---

***"Having [southeast Asian] Indian participants in the study provides important information about how diabetes develops and progresses over time and if the intervention delays diabetes," says Mr. Sosa.***

---

Many of the Alhambra participants live close to the study site, but others travel from across the country to remain part of this group. "We have some participants who have moved to other states and, even though there might be another [study



An Alhambra DPPOS participant celebrated her 50<sup>th</sup> wedding anniversary and invited the site staff to attend the celebration.

site] there, they still prefer to come back to the clinic where they were originally recruited.”

Mr. Sosa attributes this loyalty to the relationships formed between the participants and the staff. “The participants have really come to think of us not just as a research center but as part of their extended family,” Mr. Sosa says.

Recently, a participant celebrated her golden wedding anniversary with an elaborate church ceremony and reception complete with mariachi band. She personally presented the DPPOS staff with an invitation to share in this important life event. “It looked like a wedding invitation. She wanted us to witness this and be a part of it,” Mr. Sosa says.

At the reception, there was a large photograph of the couple taken at the wedding 50 years ago. “She looked as good on her anniversary as she had 50 years earlier when she first married,” Mr. Sosa says. “She’s been doing a good job about maintaining her weight.”

### SHARING CULTURAL TRADITIONS

The DPPOS staff makes sure that the participants know they are respected and encourage them to share their cultural activities. The staff themselves come from many different backgrounds, including Hispanic, Chinese, and Indian. Carmen Muro, DPPOS Research Associate, speaks Spanish as well as English, and she presents the DPPOS lifestyle classes in both languages. Staff also customize the class nutrition materials to include traditional recipes featuring cultural foods that are favored by the participants.

In fact, that’s when Mr. Sosa gets to put on his chef hat and modify traditional recipes so that they’ll fit in with the lifestyle recommendations. “We’ll go ahead and modify that recipe and show that there is a way they can still enjoy their favorite foods from home or from their culture in a healthy manner,” he says. There is a small kitchen at the site where he can prepare simple meals. One of the participants’ favorite recipes is one for Mexican pozole, a rich soup made with pork. Mr. Sosa whipped up a healthy version for the DPPOS participants substituting lean chicken and cutting down the salt.

“We’re constantly showing them ways that they can make meals in even less time so it’s more convenient and more conducive for them to follow these healthy recipes,” Mr. Sosa says.

These classes often inspire participants to modify their own recipes. Mr. Sosa fondly remembers a healthy chicken mole recipe that one participant brought him. “It was actually very good—and a nice kind of feedback” that showed that participants took the program seriously.

Another participant brings in an Indian snack as a way of sharing his culture with the staff.

At a recent retention event, the participants gathered at a nearby Asian restaurant to sample some healthy cooking techniques such as stir-fry. But, Mr. Sosa admits, not everything on the menu was low-calorie. “We present the options and then let them explore and practice some of the skills [they’ve] learned from DPP,” Mr. Sosa says. “Invariably, people come up to us and say, ‘See, I’m eating a salad, I’m having vegetables.’”

Culture can also play a role in the exercise participants choose. The Zumba craze has been a boon especially for Hispanic participants at the Alhambra site. As more senior centers and fitness facilities offer classes and as more DVD’s become available for home use, participants have lots of choices. Because dancing is an important part of their culture, Ms. Muro says, they’re more likely to stick with the activity. One participant who has been doing Zumba and losing weight says she’s losing weight without even really working at it. “She’s building muscle and she looks very healthy,” Ms. Muro says.



Alhambra participants attend a HELP session.

Another participant has built a gym in his home so that he can keep up his exercise routine despite his busy work schedule. Soon one of his sons started using the equipment and becoming more interested in the diet and exercise advice from DPP. Now father and son work out together and the son has lost more than 100 pounds.

Despite the different cultures represented at the site, staff say there’s a cohesiveness among the participants. “When we are together, they all interact,” says Ms. Muro. “There’s no communication problem because they see themselves as a whole family.”

And that makes all the difference to the participants, the staff and the study.

***“We know that in order to make this project work,” Mr. Sosa says, “we have to work with each other like a family. A family works well when everyone is on the same team and has a common goal.”***

# UNIVERSITY OF CALIFORNIA AT SAN DIEGO



## UNIVERSITY OF CALIFORNIA AT SAN DIEGO SAN DIEGO, CALIFORNIA

The DPPOS participants at the University of California San Diego (UCSD) site know how to get something done. In 2008, when all the sites had to apply to receive refunding, several participants volunteered to write letters in support of the study and of the San Diego site in particular. “Our participants were so enthusiastic about the study,” says Mary Lou Carrion-Petersen, RN, Program Coordinator for the site. “They felt it was critical to continue the study because of their family history and the need to answer and address the question” of how to prevent diabetes.

With an active military base, several universities, Scripps Institute of Oceanography, and a slew of innovative businesses nearby, the San Diego site attracted an active, intelligent, and enthusiastic group of participants. Among them are engineers, physicians, scientists, school teachers, oceanographers, and professors. Ms. Carrion-Petersen says, “We were able to recruit younger, older and middle-aged participants, male and female.” In fact, the group even includes a father and adult daughter who both qualified and participated.

### RECRUITMENT EFFORTS

UCSD established several informal partnerships that helped with the recruitment efforts. The local school district helped distribute flyers to

teachers and support staff, and Kaiser Permanente physicians shared information about the study with patients whose blood sugars and BMI fell in the study range. The DPP team also coordinated with occupational health nurses at several companies to set up on-site screenings to identify employees at risk for diabetes.

---

***“Karen [one of the nurses at the San Diego site] is my “go-to” on any and all questions I have about being diabetic. She is the best cheerleader one could ask for. The information I have gathered through these years has been life-changing. I am able to make the right choices about my diabetic life,” says a San Diego DPPOS participant.***

---

For the first part of the study, Epidemiologist Elizabeth Barrett-Connor, MD, and Endocrinologist Jerrold Olefsky, MD shared the role of principal investigator. Three additional endocrinologists, Robert R. Henry, MD, Steven Edelman, MD, and Sunder Mudaliar, MD, helped during the recruitment and enrollment phase of the study, performing physical exams and fielding questions from participants.

“Our five faculty members came from different fields and complemented each other nicely,” Ms. Carrion-Petersen says. “Dr. Barrett-Connor



had more experience with population observational studies looking at diabetes and cardiovascular health issues, and the endocrinologists had strong diabetes and endocrinology backgrounds and were able to assess people's risk for diabetes and meet with them about the study."

In all, "we screened approximately 1,425 San Diegans," Ms. Carrion-Petersen says. In the process, they identified nearly 200 people who already had diabetes and did not know it. Another 366 were identified as having impaired glucose tolerance (IGT). One hundred sixty two individuals, ranging in age from 27 to 80 years of age, enrolled at the UCSD site.

In addition to Ms. Carrion-Petersen, staff at the San Diego site in 2013 include two research nurses (Jean Smith, RN, and Karen Vejvoda, RN, CDE), a medical assistant (Jonalle Dowden) and former study dietitian Javiva Home, all of whom work part-time. Two faculty members from the beginning of DPP still remain with the study. Dr. Barrett-Connor now holds the PI position on her own, and the co-investigator, Sundar Mudaliar, MD, acts as on-site medical officer.

---

***"With knowledge and assistance from my friends in the DPPOS program, I've dealt myself a winning hand. Almost seventeen years later, everything's changed for the better. The only thing that will never change is your DNA – but you can live and enjoy life with diabetes. I have, I will and I do, thanks to you." says a San Diego DPPOS participant.***

---

The staff have noted some common traits among the participants who have stuck with the study all the way through. First is altruism—a sense of wanting to contribute to medical discovery. Second is concern for their own health because they've seen the effects of diabetes on friends and family members.

"I feel like I am part of something really special and important, especially since so many of my families members have died or are victims of the ravages of type 2 diabetes," one participant says. "I believe my participation has improved my life and will help improve not only the lives of my children, but of diabetics everywhere."

Another common trait is the desire to spread what they have learned to others in their communities: "Our participants 'spread the gospel' to family, co-workers, church members and other organizations they belong to," Ms. Carrion-Petersen says.

## EDUCATIONAL ENHANCEMENTS

The staff members take advantage of the beautiful San Diego weather, the cultural and natural attractions of the area, and the rich resources of the academic and medical community to keep DPPOS activities educational and appealing. They've organized visits to the UCSD Birch Aquarium and San Diego Zoo and walking tours of the university's sculpture garden and

the historic Gaslamp Quarter, Mission Bay, and other areas of the city. They've explored a local organic farm and had a cooking demonstration on grilling techniques. Participants have taken Mediterranean and healthy cooking classes from the Cancer Center's Healthy Lifestyle Kitchen team and toured grocery stores to read labels and discuss healthful choices.

---

***"I lost 30 pounds in the first three months after joining, and I have kept most of it off. I owe my health and probably my life to DPP. The education I received from them is priceless," says a San Diego DPPOS participant.***

---

## PARTICIPANT PROFILE: QUINTEN "AL" PIERCE



DPPOS Participant Quinten "Al" Pierce

Quinten "Al" Pierce, an active volunteer at the USS Midway Museum in San Diego Harbor, has found that many of his fellow docents also have or at risk for type 2 diabetes. In addition to sharing stories of their days in the Navy, they trade tips on healthy eating and exercise ideas.

Work on the ship helps with the latter. Mr. Pierce estimates that he walks about 15 miles on a typical 10-hour shift showing tour groups around the aircraft carrier. Since he started volunteering five years ago, he's logged more than 6,000 volunteer hours and lost 20 pounds. He also earned the Top

25 Volunteer Award in 2012 from the Retired Senior Volunteer Program (RSVP) of San Diego. And, even better, his blood sugars are much improved through this added activity and attention to his health and weight.

Ms. Carrion-Petersen likes to bring in or visit experts in the field, whether it's someone with a medical, nutrition, or motivational background, an exercise specialist, or a physical therapist. She's even brought in different instructors to teach Zumba, tai-chi, stretching, and weight bearing and balance activities. "I think most participants appreciate it and look forward to coming to learn from various experts delivering the DPPOS healthful lifestyle message," Ms. Carrion-Petersen says.

---

***"What a difference DPPOS has made in my life. My only regret is this support and knowledge cannot be offered to everyone with diabetes in this same fashion. How much better it would be if everyone with diabetes met with this awesome staff as we have done on a regular basis and received the guidance and support we have all received," says a San Diego DPPOS participant.***

---

Study visits can be long, but staff members try to make them as educational and interesting as possible. Participants review with the study team their health and physical measure reports, including weight, blood pressure, EKG and laboratory results, and identify and discuss the feasibility of health risk factor improvements. Dr. Mudaliar is often available to answer questions and review the participants' progress, not as a replacement for their primary doctor, but as an additional resource.

Even with these educational events and support, sticking to the diet and exercise recommendations isn't easy. Many participants still occasionally wish for a "magic pill" that will do all the work for them. In fact, one participant admits she was initially disappointed when she was assigned to the lifestyle group. "I would have quit if I had not met Javiva at the beginning. She is a no-nonsense type of person who was not about to let me quit," she says. "I have come a long way from when I thought the four basic food groups were ice cream, cake, donuts and orange soda. I think of DPPOS as the angel on my shoulder fighting the junk food devil on my other shoulder."

---

***"All of the things that usually go undetected until it is too late for anything to help, have been detected in the early stages, and taken care of before any long lasting damage had occurred. I feel very fortunate to have been a part of DPP and feel that it has made my life better and that I may live longer than many with diabetes," says a San Diego DPPOS participant.***

---

# UNIVERSITY OF CHICAGO



## UNIVERSITY OF CHICAGO CHICAGO, ILLINOIS

When the Billings Hospital opened in 1927, it put the University of Chicago on the map as a world-class medical center. The buildings, adorned with spires and gargoyles, housed the medical school as well as clinic space, including its maternity ward. One of the doors to the building is still labeled in stone, “Chicago Lying-In Hospital.”

“Women would stay here for weeks when they had their babies in the 20s and 30s,” explains Margaret (Margie) Matulik, RN, CDE, Program Coordinator of the Diabetes Prevention Program Outcomes Study site here. In fact, Ms. Matulik says, at least one participant in the study had her children in this building before the maternity ward moved in the 1960s.

The University of Chicago DPP/DPPOS site has been in this historic building since the study began. At first, the site had a lot of staff to oversee recruitment, screening, data collection, and other study-related tasks. “We had a whole hallway,” Ms. Matulik remembers.

Now, Ms. Matulik and Case Manager Catherine DeSandre carry out all aspects of the study—from the participants’ twice-yearly visits to teaching lifestyle classes. Ms. Matulik, Ms. DeSandre, and Principal Investigator David Ehrmann, MD, have all been with the study since it started.

“We’re like family,” Ms. Matulik says about the staff’s relationships with the participants. “We’ve been together for 17 years. So now we know



A photo of the Chicago skyline taken from a DPPOS cruise outing.

their kids, the grandkids, the weddings...all that.” They get Christmas cards and even gifts from some of the patients. “I had a lady who came from Michigan—she gave me a big [container] of blueberries that she just picked,” she says. “Little things like that they do for us. It’s nice.”

---

***“We’re like family,” Ms. Matulik says about the staff’s relationships with the participants. “We’ve been together for 17 years. So now we know their kids, the grandkids, the weddings...all that.”***

---

### ONE CITY/TWO SITES

Located on Chicago’s South Side, the University of Chicago DPPOS site is just 15 minutes from the other Chicago site hosted by Northwestern University. But in a city like Chicago, 15 minutes can make a world of difference. While the





University of Chicago participants (from top): Victoria Franzese, Alonzo Dudley, Griscilla Moore.

Magnificent Mile is known for high end shopping and sightseeing, Chicago's South Side is more known for the Chicago Blues, the city's urban spin on the musical style that originated in the rural south.

It's also known for the South Side Irish Parade, which winds through the streets of Beverly, a traditionally Irish section of the city. One year, Ms. Matulik and her husband watched the parade with one of the DPPOS participants who lives near the parade route.

During recruitment for the study, staff attended health fairs and community screenings to let people know about the study, but their best draw came from mass mailings to residents in the surrounding neighborhoods. The study also got some news coverage on television, radio and newspaper. Many who responded had a family history of diabetes and had seen loved ones suffer with complications, such as blindness or amputations. They wanted to do what they could do to avoid diabetes—and wanted to help others to prevent the disease too.

The site now has about 115 participants, 62 percent of whom are African-American. While many are from Chicago's South Side, a few come from other parts of the state as well as Michigan. Those who have retired to other parts of the country now travel from as far away as Georgia, the Carolinas, Minnesota, California, and Arkansas. Most local participants drive, but some take public transportation. "We had one woman who was 87," recalls Ms. Matulik, "she would take three buses to get here by herself."

---

***"I think if you empower people with education, you'll get better outcomes," says Ms. Matulik.***

---

The staff enjoy talking with the participants about their health. "That's the thing I enjoy most," Ms. Matulik says, "teaching them about diabetes and talking to them about cholesterol or whatever's going on with their health. They don't get that kind of time with their doctor. We'll talk about risk factors and how the medicine works. I think if you empower people with education, you'll get better outcomes."

## LEARNING GOES BOTH WAYS



DPPOS participant Katherine Seaberry.

Participant Katherine Seaberry has certainly used what's she's learned through DPP and DPPOS to change the course of her life. Her entire family has had diabetes: her father was a double amputee, her mother lost a leg, and both her brother and sister passed away from the disease.

"So far, I'm the only member of my family who doesn't have diabetes," says Ms. Seaberry, who is now 84. "This study has helped me so much."

She says her favorite foods used to be cake, soda, and just about anything fried. Her new favorites are cauliflower, broccoli and especially tomatoes and peppers she grows in her garden. "I've learned how to eat healthy," she says. "I want to be able to take care of myself."

Ms. Seaberry walks with a friend for 30 minutes, six days a week. A few years back, the friend was diagnosed with diabetes. Ms. Seaberry was right there with information she learned from her participation in the study.

And the learning goes both ways, Ms. Matulik says. "I think I've learned as much from the participants." A few years ago, she had an injury and had to wear a "boot" on her foot. She was hobbling around, and maybe feeling a bit sorry for herself because she couldn't keep up with the workouts she enjoys so much. One of the participants told her, "Well Margie, everybody gets a turn. Right now it's your turn. Next time it will be mine."

"The people who have the best attitude seem the healthiest," Ms. Matulik says. "They sure don't let their illnesses get them down." She tells the story of a gentleman in his 80s who walks every day, no matter what the weather. He says he loves getting out and staying active.

"I've learned [from the participants] that if you have a good attitude and keep moving, that will serve you well in your older age," she says. "Don't let ailments get you down, it's just your turn. That's all."

Ms. Seaberry's attitude is an inspiration to those around her, including the DPPOS staff. "I tell Katherine I want to be like her when I grow up," Ms. Matulik says. In fact, they even joke that they're mother and daughter, since Ms. Seaberry's wedding anniversary is the same as Ms. Matulik's parents.

"This study is the best thing that ever happened to me," says Ms. Seaberry. "Even though I know I'm old, I don't feel old. Age is just a number. It's how you handle that number. I'm handling my number real well."

# UNIVERSITY OF COLORADO



## UNIVERSITY OF COLORADO AURORA, COLORADO

In 2010, after 14 years in a downtown office building, the Colorado DPPOS site moved to the new University of Colorado campus in Aurora, CO, 20 minutes outside Denver. Program Coordinator Lisa Testaverde, MS, worried that participants might not follow them to the new location. The staff even printed out customized directions to show participants exactly how to get to the new site from their home and where to park.

They needn't have worried so much. The Colorado DPPOS participants showed – again – that they were willing to do what it takes to continue their part in the study. "It's a testament to how dedicated our participants are," says Lifestyle Case Manager, Tonya Jenkins, RD, CDE.

The Colorado site has more than 130 participants who come from all over Colorado, from central Denver to Fort Collins to Colorado Springs, and the rural areas outside of the city. They represent a variety of backgrounds and professions, including teachers, masons, farmers, nurses and other health professionals. "We have a salesman who used to eat in restaurants for all his meals. He totally changed his lifestyle with DPP," says Ms. Jenkins. More than 15 percent of the participants at the site claim Hispanic heritage.

It's a well-informed, engaged group, the staff says. "They're the kind that read articles, send them to us and say, 'Have you seen this? Have you read

this?' They are very proactive about their health," Ms. Jenkins says. "We have so many participants who have had good success with changing their lifestyle, changing their habits."

I have such admiration for all our participants here in Colorado and nationwide," adds Sheila Steinke, Colorado Case Manager. "Some have been involved in DPP for more than 15 years and still want to know what is next."

---

***"DPP and all it has to offer—education, events, health screenings, eye photos, et cetera—means the world to me. All my counselors have been great, and I consider them friends," says Ann Lohmann, Colorado DPPOS participant.***

---

### THE KAISER PERMANENTE CONNECTION

The Colorado site is collaboration between the university and Kaiser Permanente (KP), an integrated delivery system with more than 500,000 members in the state. More than 70 percent of the DPP and DPPOS participants are members of a Kaiser health plan and get their healthcare from KP healthcare professionals.





DPPOS participants and staff join the American Diabetes Association walk.

KP's involvement started in the recruitment process by identifying members with a history of high blood sugar. The DPP staff also held recruitment events at Kaiser healthcare facilities. Kaiser physician David Price, MD, acts as co-investigator at the site, providing clinical consultation and acting as liaison between the study site and Kaiser. "Our partnership in DPP has been beneficial to both the university and KP. Our successes illustrate how academic medical centers and health care practice systems can work together to improve health," says Dr. Price.

The KP connection gives the program staff peace of mind. If KP participants develop diabetes during the course of the study, staff can refer them to Kaiser for diabetes education and treatment. "Kaiser runs a really wonderful diabetes education program," says Ms. Testaverde. "We feel confident knowing they're going back to Kaiser and getting good information there."

For its part, KP has integrated elements of the DPP findings into its patient care. In addition to its diabetes education, Kaiser now offers a prediabetes class that is built on the DPP lifestyle intervention.

It was at a Kaiser recruiting event that Carol Baden first heard about the DPP study. Recently retired from her job as a nurse-educator at a community college in Denver, she saw the DPP table set up in the lobby of a Kaiser facility. Although she didn't know anyone if she had a family history of type 2 diabetes, she was concerned about her health and about staying healthy. "I thought, well, I'll just go find out what my blood sugar is," she remembers. (Later, she found out that her mother probably had type 2 diabetes and didn't know it.)

The test showed she was at high risk for the disease. Her weight was a big factor. "I had gained a lot of weight before I retired," Ms. Baden admits. "I was up to 282 pounds when I entered the program."

---

***"I feel empowered to do the things I need to keep diabetes at bay for as long as possible. My father, my maternal grandparents and both of my children developed type 2 diabetes. So far, I have not. I attribute this 100 percent to my participation in the program," says a Colorado DPPOS participant.***

---

## STAYING ACTIVE

As luck would have it, Ms. Baden was randomized to the lifestyle intervention. The program was just what she needed. "The staff whom I worked with were just so genuine in their approach," she says. "I was really excited to do everything they said to do." She especially appreciated the walking groups organized by the staff. "I needed the encouragement and walking with other people really made it so much more interesting."

Through the years, the study participants have sampled many of the area's trails and hikes, including Sloan's Lake, Deer Creek Trail, and into the foothills of the Rockies. For several winters in a row, they organized a snowshoeing trip in Nederland, CO, just west of Boulder. "We hired a guide from the local outdoors store and he would point out jackrabbit tracks," and other sights along the way, Ms. Testaverde remembers.

Even though Ms. Baden says she had trouble staying active in the past, she caught right on to the walking routine. Soon she was a regular member of the group walks. She was also losing weight. Since the study started, she's lost 85 pounds and feels better than she did in high school.

Ms. Baden has re-arranged her life to make sure that exercise stays a central part of it. When she and her husband were looking for a new home in Denver, they chose a neighborhood near the High Line Canal, which has miles of walking trails and which they enjoy nearly every day.

"I'm so fortunate to continue in the program," she says "It's been the best thing in the world for me. If I hadn't gotten into it, I probably wouldn't even be alive."

## IMPACT BEYOND THEMSELVES

Beyond this type of personal impact—which is obviously significant—the participants and the staff are also aware that the study has reached far beyond themselves. That comes through loud and clear at the annual presentation entitled "Our Contributions Carry On" when the principal investigator presents the latest findings from the study.

"The participants realize they're part of something significant," Ms. Testaverde says. "They feel so proud of making an important contribution."

"Our participants are fantastic, giving people," Alexis Bouffard, Case Manager, adds. "I feel fortunate to work with such a great group."

And the staff feels similarly. Ms. Testaverde, who has been involved in other clinical studies, says the DPP experience stands out. "Other studies are not structured in a way where you can develop a relationship with the participants. In DPPOS, we have followed the same participants for 15 to 17 years, seeing them a minimum of two times a year.



They become like family. The science of the other studies is very interesting, but it's the relationships, and the incredible study results, that make DPPOS so special."

Richard Hamman, MD, DrPH, PI for the Colorado site as well as Vice Chairman of the study as a whole, recently retired after a career that spanned four decades and many important discoveries. When asked to name his most significant accomplishment, he answered: "Showing that type 2 diabetes could be delayed or prevented by lifestyle changes. The Diabetes Prevention Program, which I was lucky enough to be a part of, actually showed that risk factors could be changed and diabetes onset delayed."

---

*"DPPOS has taught me to...watch what I'm eating, and keep moving!"  
says a Colorado DPPOS participant*

---

## OUR CONTRIBUTIONS CARRY ON: CASE IN POINT



A DPPOS participant brings her daughter to her class.

As at other sites, Colorado participants sometimes bring their teenaged and young adult children to the lifestyle classes. These kids have grown up watching their parents change their habits and their health by participating in the study. And those habits tend to rub off after a while.

Ms. Jenkins tells a story of a participant's daughter who recently returned to class with her mother. Ms. Jenkins recognized her from several years ago and asked her how she was doing. The young woman told her, "When I got married a couple of years ago, I started to put on a lot of weight. I realized that

because my mom had diabetes, I was probably setting myself up for a bad situation in the future." Using what she had learned as a teenager tagging along with her mom, she started to change her habits and lose the weight.

"Seeing her mom participate in DPP helped her realize she was at risk and start to modify her behaviors," says Ms. Jenkins.

"Talk about 'Our Contributions Carry On,'" Ms. Testaverde adds.

# UNIVERSITY OF HAWAII



## UNIVERSITY OF HAWAII HONOLULU, HAWAII

Honolulu's population of 900,000 definitely qualifies it as a big city but, to long-time residents, sometimes it feels like a small town. Mae Isonaga MPH, RD and Narleen Baker Ladao, BS, Co-Program Coordinators for the University of Hawaii site in Honolulu, regularly bump into DPPOS participants at the mall or in downtown Honolulu.

Being on an island in the middle of the Pacific might have something to do with it. All but one of the site's 50 current participants live on the island of Oahu within a relatively short drive, at most an hour away from the study site in downtown Honolulu. "It's kind of a captive audience, so [for most] it's easy for them to come in for study visits," Ms. Isonaga says.

It's also easy for staff to travel to participants' homes. For those who can't make the trip downtown, staff regularly make home visits or even stop by on their way to and from work. (In exchange, participants might give staff a papaya, mango, or apple banana from one of the fruit trees in their yards.)

Like the participants, both Ms. Isonaga and Ms. Ladao were born in Hawaii and have lived here most of their lives. Ms. Ladao has been with the study from the very beginning, and Ms. Isonaga came on board at the end of DPP. Richard Arakaki, MD, Principal Investigator, was born in Okinawa, and moved to Hawaii at the age of seven.

"You always find someone you're related to or someone who knows your aunt or uncle or who

went to school with your cousin," Ms. Isonaga says. This lends to the small town feel of life in Hawaii. "We say in Hawaii that you can't say anything negative about anyone else or it will come back to you." Gossip travels quickly on what they call the "coconut wireless."

### COMMON CONNECTIONS

Island residents also share a serious concern about the high rate of diabetes in the state, especially among Native Hawaiians. According to the Centers for Disease Control, as many as one in four Native Hawaiian and Pacific Islander adults has diabetes. Many more residents are at risk and don't know it.

Vince Takano counted himself in that number before DPP staff showed up at his employers offering blood tests to screen for impaired glucose tolerance in 1997. Diabetes was "the farthest thing from my mind," he says, even though he knew his grandfather had had it. But the blood test showed that Mr. Takano was at risk, and further testing showed he qualified for the study.

From the very beginning, the design of the Diabetes Prevention Program called for special efforts to recruit ethnic groups at greatest risk for the disease. The University of Hawaii site was chosen to put a special emphasis on recruiting Native Hawaiians, Pacific Islanders and Asian participants.



Mr. Takano, a participant, built his own boat and invited DPPOS staff to attend the blessing.

During the recruitment phase of the study, DPP staff went to health fairs and events, especially in areas where these populations are greatest. For example, they went to the Waimanalo Health Center and Waianae Coast Comprehensive Health Center, both of which are located in communities populated predominantly by Native Hawaiians. They also posted ads in publications circulated in the Native Hawaiian community.

### MAKING CHANGES

Frances Tam saw one of those ads. Her doctor had recently diagnosed her with “borderline” diabetes (now called prediabetes). “He said, ‘If you don’t watch your diet, then you could have diabetes,’” Ms. Tam says. She figured she’d call to see if she qualified for the study.

***“It changed my lifestyle, and it changed my wife’s lifestyle too,” Mr. Takano says. “We never used to walk or exercise.”***

Both Ms. Tam and Mr. Takano have made major lifestyle changes as a result of their participation in DPP and DPPOS. Mr. Takano was randomized to the lifestyle group and started learning about how to make changes in his diet and exercise habits. “It changed my lifestyle, and it changed my wife’s lifestyle too,” he says. “We never used to walk or exercise.” Now they walk daily. Mr. Takano also gets exercise by boogie boarding and building boats. He’s lost weight and feels good.

Although Ms. Tam was originally assigned to the placebo group, she started to modify her diet and increase her exercise. But it wasn’t until the bridge between DPP and DPPOS that she took the lifestyle classes and made more radical changes.

The hardest part for Ms. Tam was giving up some of her favorite foods, like canned meat and white rice, which are very popular in Hawaii. “It’s a good thing I love my poi,” she says, referring to the most important food to Native Hawaiians. Made from taro root that is cooked and pounded, poi is high

fiber and low fat—and it fits right in with Ms. Tam’s new, improved diet.

The participants are eager to share what they learn with family and friends to help them lose weight, get more active and forestall diabetes. “Folks are always asking me for extra education materials,” says Ms. Isonaga. One participant asked for copies for his golf buddies, she says.

Over the years, strong bonds have formed between the staff and participants. When participants come in for visits, they exchange family news and share their photos of recent vacations or occasions. The staff work on other clinical studies, but nothing compares to the dedication of the DPPOS participants, they say.

Mr. Takano recently launched his 27-foot sport fishing boat that he designed and built himself. He invited guests to a boat blessing prior to the launch. Offerings of vegetables and sake (rice wine) were made, and water and salt were used for purification. The traditionally dressed Shinto priest conducted the ceremony and offered prayers to grant safe sailing for all who set foot on the boat. “I called all my good friends to partake in the Sake rice wine,” Mr. Takano says.

And the DPPOS staff were among them.

### MAKING A HEALTHIER “PLATE LUNCH”



Ms. Frances Tam

The “plate lunch” is Hawaii comfort food. Served on paper plates or in disposable containers from food trucks and luncheonettes, the plate lunch usually features two scoops of

white rice, macaroni salad, and a main dish, often fried chicken, a slice of canned meat or beef teriyaki.

“There’s not really anything green on the plate,” says Ms. Isonaga.

If she wanted to help the DPP and DPPOS participants adopt healthy eating habits, she knew she would have to re-invent the plate lunch into something healthier.

“You have to focus on the cultural foods that are eaten here,” she says. “The Hawaiian food, Chinese food, Japanese food, Korean food, Filipino food—those are the foods more commonly eaten here.”

Ms. Isonaga offers these suggestions for a healthier plate lunch:

- Replace the macaroni salad with a tossed salad
- Use one scoop of brown rice instead of two scoops of white
- Choose fish or lean chicken instead of fried meat
- Share your meal with friends and family
- Make several meals out of one plate lunch

Ms. Isonaga says the participants have responded well to these suggestions. “Our folks are so smart about what they need to do. With all of the classes, they know what they need to do to reduce the fat.” In fact, she adds, “they could be the ones teaching the classes!”



# UNIVERSITY OF MIAMI MILLER SCHOOL OF MEDICINE



## UNIVERSITY OF MIAMI MILLER SCHOOL OF MEDICINE MIAMI, FLORIDA

With its warm climate, thriving business center, and magnificent beaches, Miami draws people from the northern United States as well as people from Latin and Central America. The result is a sophisticated, bilingual, global city.

So it makes sense that the DPPOS site at the University of Miami Miller School of Medicine also has an international flair. More than 40 percent of the participants are native Spanish speakers from a variety of cultures, including Cuba, Venezuela, Colombia, and Puerto Rico. Several participants have dual citizenship and a number travel quite a bit.

To meet the needs of this culturally diverse group, most of the staff are bilingual. In addition, since the very beginning of the study, the site has had a foreign-born physician serve in the role as clinical coordinator and foreign residents who rotate through the clinic as part of their program.

“Miami is placed in a strategic position as a United States city in relation to Central and South America,” says Ron Goldberg, MD, Principal Investigator for the Miami site. “There is a continuous stream of foreign medical students who get opportunities to come and work at U.S. hospitals. Frequently, Miami is their top choice because many of the faculty and many of the patients at the hospital are Spanish speaking.”

The first foreign physician to work on the study from the Miami site was Hermes Florez, MD, a Venezuelan physician who first joined the DPP

site as a research fellow and later became clinical coordinator, seeing participants when they came in for their regular visits. When he moved on to other duties within the study and at the university, the site continued the tradition of filling the role of clinical coordinator with a foreign physician. In fact, Dr. Florez’s wife, also a doctor, served in this role.

“The beauty was that our participants felt so at home with fully bilingual staff,” says Dr. Goldberg. “The physicians were fully Spanish speaking and had a deep knowledge of diabetes and risk for diabetes. It really enriched our program and helped to bond our participants to us even more intensely than might have happened otherwise.”

---

***“Our participants are our missionaries in many respects. They go out and talk to their friends, speak in their communities and extol the virtues of this program,” says Ronald Goldberg, MD, DPPOS Principal Investigator, University of Miami Miller School of Medicine.***

---

### EMOTIONAL CONNECTION

To recruit participants for the study, the staff “spread the net out all around the community,” through employers, newspaper ads, and direct mail, says Juliet Ojito, RN, Program Coordinator for the site.



DPPOS is represented at a local walk, proudly wearing their t-shirts.

Many were interested, but fewer could commit to a long-term study. “Miami is very fast-paced, and everybody is busy,” Ms. Ojito says. Many people in the area come for a job or school or some other short-term reason.

But, she says, those participants who did commit to the study had a deep personal connection to diabetes. Because participation required a long-term commitment, “this study wasn’t for the average person,” Ms. Ojito says. “Most of the participants had an emotional reason to join the study, because of their health, because they had a brother, a sister, a mother, a friend who had diabetes.”

“We have one lady that who has five siblings and she’s the only one who has not developed diabetes,” adds Jeanette Gonzalez-Calles, Lifestyle Coach and Co-coordinator for the Miami site. “She’ll talk about it in tears, how she lost a brother, lost her parents. It’s a very emotional thing for a lot of participants.”

The staff is bonded by that connection and by their common dedication to the study. “We have a group that is very supportive of each other,” says Ms. Gonzalez-Calles. “We’ve been seeing each other for 10, 12 years. Our spouses even know each other.”

The participants are also bonded to the staff. Both Ms. Ojito and Ms. Gonzalez-Calles have been with the study from the very beginning. “There’s an element of consistency that I think people really appreciate,” says Dr. Goldberg. “You come to your appointment, and it’s the same person you know and trust and who has shown you how much they care about you. That works its way into people’s lives.”

“Even though this is research, there are also valued friendships,” adds Ms. Gonzalez-Calles.

### STATE-OF-THE-ART FACILITY

In 2007, the Miami DPPOS site moved to the University of Miami’s brand new Clinical Research Building in downtown Miami. The energy-efficient, state-of-the-art building has earned LEED certification as a “green building.” Opened in 2006, it was designed specifically for clinical research studies into such important areas as patient safety, pediatrics, and clinical pharmacology.

### SPREADING DPP TO VENEZUELA

The success of DPP inspired Hermes Florez, MD, to adapt the program for his native Venezuela, where the rates of obesity and diabetes are similar to the United States. He secured funding from several international health organizations as well as the Venezuelan government to start a program called BRIDGES, or ‘Bringing Research in Diabetes to Global Environments and Systems.’ “We are implementing the same core curriculum as DPP,” Dr. Florez explains, “but instead of being delivered through case managers, dieticians or nurses, we are using lay people.”

After testing the program in Miami, the group is now training people in Venezuela to carry out the program there. “Those who were successful in achieving weight loss [in the training], now they’re going to become the masters. They are going to help train other people and hopefully this will lead to reduction of diabetes in Venezuela.”

At first, Ms. Ojito admits, the staff didn’t really want to move; the new location is a bit of a trek for staff and participants alike. But now that they’re settled in, “We love it and the participants love it,” she says. “The building is very eco-friendly and energy efficient. It’s smarter than we are.”

Because the building is devoted to research, the DPPOS staff have an opportunity to share what they’ve learned with others in the field. “We get a lot of people who are interested in our study and how well it has been run and performed,” says Ms. Gonzalez-Calles. In fact, the Institute for Clinical Translational Studies just moved in right next to the DPPOS offices. In a recent training for researchers, they used DPP as an example of how to standardize clinical research.

The DPPOS staff also make use of the facilities for their lifestyle classes. They’ve had exercise classes in the onsite Wellness Center as well as cooking classes. They also hold events at the university’s campus in Coral Gables, which is just outside the city. “It’s in a gorgeous, residential part of

town, so we try to use that when possible,” says Ms. Gonzalez-Calles.

And, of course, there’s the beach. DPPOS staff and participants often join walk-a-thons or other community events that encourage activity while also raising awareness of diabetes and other health issues.

But what participants appreciate most, Ms. Ojito says, is “the attention and care and the cutting-edge information” about their health, such as the bone density scans and the carotid artery scans. “They value it because they know that healthcare is so incredibly expensive and difficult to come by, even if you have insurance,” she adds.

So, in a city that’s always changing and a population that’s constantly on the move, the Miami participants stick with the study.

“It been amazing,” says Dr. Goldberg. “Twelve to 16 years after the study started, the enthusiasm of the participants is very evident. ‘We want to stay with you. We want to continue,’ they say.”

# UNIVERSITY OF NEW MEXICO AT ALBUQUERQUE



## UNIVERSITY OF NEW MEXICO AT ALBUQUERQUE ALBUQUERQUE, NEW MEXICO

Although she's been the program coordinator of the University of New Mexico DPPOS site in Albuquerque since 2006, Penny Hyde, RN, says she's still a newbie. "I'll always be the newbie."

That's just the way it is around here. Her colleagues—including Principal Investigator David Schade, MD; Case Manager Janene Canady, RN; Secretary Ysela Gonzales and Data Entry Clerk Doris Hernandez McGinnis—have worked on the study since the Diabetes Prevention Program started.

And, of course, the participants have also been involved since the late 1990s. They've been rock steady, too: 95 percent of the current participants haven't missed an appointment since DPPOS started in 2001 and no one has missed more than one appointment. That's dedication. The other staff might have to retire before Ms. Hyde can claim seniority at the site, but that's okay with her; this is where she wants to be.

"I started my nursing career in the emergency room," Ms. Hyde says. "What I saw right away was that, for all of my patients—unless they were there for a car accident or something—diabetes was in some way involved." She decided at that point that she wanted to be a diabetes educator. "My big thing is prevention," she says.

She's in the right place.

### DPP HAS BECOME "HOME"

The University of New Mexico site is located on the North Health Sciences Campus of the University of New Mexico, in the center of Albuquerque. "We have our own building that was built specifically for Dr. Schade and his diabetes research," Ms. Hyde explains, referring to David Schade, MD, Principal Investigator for the site. With parking right at the front door and public busses nearby, the site is easy to get to for the participants. "We make sure every little thing is handled for their visits," Ms. Hyde says.

Most of the participants live in the city and the surrounding area. They come from a variety of backgrounds, including Hispanic as well as several American Indian tribes, such as Navajo, Zuni, Hopi, Laguna, and Isleta. The variety of cultures represented in the group keeps the work interesting, staff say.

Most of the participants have relatives or loved ones who have had diabetes. "They've had relatives on dialysis, or a mother or father die of a heart attack" brought on by diabetes complications, Ms. Hyde says. "They came because someone else had been sick and they were afraid that might happen to them. They also want to take the information back" to other relatives who may have diabetes.





Loretta, an American Indian participant.

Ms. Hyde and Case Manager Janene Canady, RN, each work with a group of DPPOS participants. Both Ms. Canady and Ms. Hyde are Certified Diabetes Educators, and they each take care of most of the data collection from their participants. “We do all the EKGs, the blood draws—the nurses do nearly everything,” Ms. Hyde explains. The participants “get really good one-on-one nursing when they come in here.”

This setup lets the staff really focus on the participants. It also turns each visit into an education session and helps them build long-term relationships with the participants.

When they review their lab results with the participants, the staff show them what their levels are and how that compares to the national average and the range recommended by the American Diabetes Association or other expert source.

“It sometimes surprises me how endeared they are to us, how strong the connection is between the staff and the participants,” Ms. Hyde says. “They tend to trust us before their doctors. Their doctor will tell them something they don’t understand, so they’ll call us to have us explain it.”

But then again, she adds: “Where in our lives do we get this level of continuity”—especially in healthcare? Many of them have been through numerous primary care physicians during their years in DPPOS, Ms. Hyde says. “It’s just a cold world out there, and DPP has become home to them.”

## EMPHASIS ON LEARNING

Staff believe part of their role is to help participants navigate that world. “We talk with our participants about how to talk to their doctors,” Ms. Hyde explains. “We always send them two copies of their labs—one for them, and one for their doctors. If you teach the participant how to contact their doctor, you give them more than if you do it for them. We’re teaching them how to have their voice and how to take care of themselves.”

That emphasis on continuous learning starts with the site’s PI. Every Tuesday, after the weekly staff meeting, Dr. Schade and the staff have “journal club” where they review a current research article on diabetes care. They go through the article, evaluate the research design and the findings, and share



Doris McCann, 92, the site’s oldest participant.

their thoughts. They recently looked at some research on coronary artery testing similar to that recently performed as part of DPPOS. The article explored the potential cost savings of routine screening for at-risk populations.

“Dr. Schade is a teacher, and he wants us to be, too,” Ms. Hyde explains. Reviewing the journal articles “gives the staff helpful information when we’re talking to our participants.”

## THE CYCLE CONTINUES

The cycle continues when the participants share what they’ve learned with their families and friends. Several participants have helped get adult children or other relatives to early diagnosis and treatment for diabetes because they learned in the study what signs and symptoms could spell trouble. “Then, they bring those people to the HELP sessions,” Ms. Hyde says. “There’s a huge ripple effect.”

The staff usually hold the HELP and BOOST sessions on campus or at local venues where they can combine an event with the learning session. They’ve held sessions at the Museum of Natural History, minor league ball games, or local restaurants. They get a good turnout at the events—especially if there’s food involved.

They can always count on the presence of Doris McCann, the site’s oldest participant. A retired nurse, Doris now uses a wheelchair to get around, but she’s at every HELP session with her daughter or her aide at her side. “She makes the most of those sessions,” Ms. Hyde says. At 92, she still doesn’t have diabetes.

“The story we hear over and over again is how much the study means to the participants, how much it’s changed their lives,” Ms. Hyde says. “They wonder where they would be if they hadn’t been in DPP.”

And although most probably weren’t thinking about public policy or how the study’s findings might impact the standards of care when they joined back in the 1990s, they are certainly proud of their role in changing the public health messages about diabetes. They love to see the national coverage of DPP and DPPOS, like a television interview with study chair David Nathan, MD, or the director of NIH talking about DPP in his budget justification to Congress for medical research.

“DPP has made a difference for these participants,” Ms. Hyde says. “I wish everyone could have this level of care.”

# UNIVERSITY OF PITTSBURGH



## UNIVERSITY OF PITTSBURGH PITTSBURGH, PENNSYLVANIA

When most people think of Pittsburgh, they think of steel and of industry. But the people who live and work in the city know that it's a diverse city of hills and rivers, parks and bike trails, artists and scientists, universities and technology. That diversity comes through at the University of Pittsburgh site of the Diabetes Prevention Program Outcomes Study.

"Our participants reflect our country and the history of Pittsburgh," says Sue Jeffries, MSN, one of two program coordinators with the site. Among the current 128 participants, "We've got professors, lawyers, dentists, engineers. We have people who worked in the mills when they were younger. We have teachers, hairdressers, massage therapists, policemen, firefighters, restaurant owners and homemakers. One person is a champion weight lifter. He is also an actor and a bus driver."

The site is located on the campus of the university of Pittsburgh in the neighborhood of Oakland, near the landmark "Cathedral of Learning," a 1920's skyscraper that symbolizes the university. Participants come from different areas of the city and the suburbs, as well as surrounding states. No matter where they come from, Ms. Jeffries says, everyone "needs to cross a bridge or drive through a tunnel to get here."

Many of them know each other from different parts of their lives—from their neighborhoods, churches, schools, military service or work place.

One participant found out that his boss was also part of the study.

---

*"Our participants reflect our country and the history of Pittsburgh," says Sue Jeffries.*

---

They share a common concern about diabetes and a common goal to do what they can to prevent the disease and lessen the impact on themselves, their families, and their communities. "I have seen what diabetes can do to people," one participant said, "and I don't want that to happen to me. Because I love my husband, my children, and my grandson, and I want to grow old and healthy with them." Another said she got involved in the study "to help my children—and theirs."

### NATIONAL AND LOCAL TWIST

Ms. Jeffries shares the program coordinator role with Marie Smith, BSN. Trevor Orchard, MD, currently serves as the principal investigator at the site. They work closely with the group that developed and authored the lifestyle component for DPP and DPPOS, which is also housed at the University of Pittsburgh. The Lifestyle Resource Core is currently led by Elizabeth (Beth) Venditti, PhD, with assistance from Linda Semler, MS, RD, Valarie Weinzierl, BS, and Andrea Kriska, PhD. Based on evidence from previous





In the summer of 2011, the Pittsburgh site partnered with Venture Outdoors, a local non-profit organization that promotes outdoor recreational activities, to give DPPOS participants a chance to try three outdoor activities: biking, kayaking and walking. Venture Outdoors brought the kayaks and bicycles, DPPOS brought the people. The beautiful weather helped make the day a rousing success. As a result of that outing, several participants bought kayaks or bicycles to change up their exercise routine.

studies combined with input from a national advisory committee, the group creates the curriculum and the materials that are used at all of the DPPOS sites across the country.

A tricky aspect of designing the curriculum is making sure that it is structured enough to meet the scientific protocol standards of a national study, but also flexible enough to meet the unique needs of each site. It not only has to work in Pittsburgh, Dr. Venditti says, it has to work in Shiprock, Miami, Boston, Seattle and each and every one of the DPPOS sites.

Although their work reaches nationally, Dr. Venditti, Ms. Semler and Ms. Weinzierl also consider themselves part of the

Pittsburgh site. In fact, they organize and present the lifestyle classes to the local participants. “We’ve always had this national and local twist to our site,” Dr. Venditti says.

Ms. Smith remembers the excitement in the air the day the DPP results were announced. “We had a big party and everybody came to celebrate a successful trial,” Ms. Smith says. While everyone was thrilled that both interventions showed positive results, the Pittsburgh group felt a special connection with the lifestyle results. Rena Wing, PhD, Pittsburgh’s principal investigator during the first part of the study, had spearheaded the lifestyle program, and she announced the results to the gathered group. “There really was this sense that we showed the health community that we could do something to forestall diabetes,” says Ms. Smith.

Knowing they’ve been part of this is a big boost to the participants and the staff, says Ms. Jeffries. “They love it. They feel special. They didn’t really realize what they were getting into at first, but they are part of something that is really timely and important. We feel that way, and they do too.”

Dr. Venditti adds, “That collective sense of belonging to the DPP has been a defining moment for many of us.”

## UNEXPECTED BENEFIT

Danny Kuhn probably wins the award for the farthest drive among the Pittsburgh participants. When he started in the trial, he drove more than four hours to the site from his home in West Virginia. Sometimes he took his elderly father, a retired coal miner, along with him for company. “You know, you have conversations in a car on a long drive that you just don’t have otherwise,” he says. “We learned things about one another and had conversations about his growing up and all that we just wouldn’t have had.” Mr. Kuhn’s father died of lung cancer several years into the study. He calls that time with his dad a “secondary benefit” of the study, “but it is just priceless to me now.”

“When you’re involved for 13 years the way I have been with the folks at Pittsburgh, you go through all these life changes,” Mr. Kuhn says. Not long after his father died, his wife also passed away in an accident. He called the DPP staff to cancel his upcoming appointment. “They could not have been more caring and compassionate,” he says.

Recently retired and moved to South Carolina, Mr. Kuhn continues to travel back to Pittsburgh for his appointments. “[The study] has definitely been a good thing for me. It’s caused me to be more aware and take more control,” he says. “And here I am, all these years later, and I have not developed type 2 diabetes.”

## PATIENT PROFILE: JOHN HELD, NUMBERS GUY



John Held

John Held admits he originally felt a pang of disappointment when he learned that the “medicine” he had been taking for the three years of DPP was a placebo. But that disappointment turned to opportunity when the study organizers offered all participants the lifestyle intervention during the “bridge” period. Because he had examined the data that showed the intervention worked, Mr. Held worked hard at increasing his exercise and improving his diet.

As a retired metallurgist in the steel industry, Mr. Held used his sense for science and statistics to track his progress. “I love to play with data,” he says. When he first started the program, he used a personal digital assistant (PDA—the precursor to today’s smartphone and tablets) to track what he ate and how much he weighed. “If I made soup, I knew what I put in it, and then I could break it down and know that a cup and a half of soup had this many calories and this many grams of fat,” he explains.

In addition to tracking calories, at age 82, Mr. Held maintains a full schedule of activities: On Mondays, he tap dances; he plays golf Tuesdays and Wednesdays; he volunteers at a local school on Thursdays, and on Fridays he “pushes wheelchairs at St. Clair Hospital for four and a half hours.”

“On Tuesdays, I play 27 holes of golf. I walk and carry my own bag. I’m 82 years old,” he says proudly.



# UNIVERSITY OF TENNESSEE AT MEMPHIS



## UNIVERSITY OF TENNESSEE AT MEMPHIS MEMPHIS, TENNESSEE

Memphis, Tennessee, with 650,000 people and 2,000 churches, may have more churches per capita than any other United States city. So, when the University of Tennessee Health Sciences Center started recruiting participants for the Diabetes Prevention Program study in 1996, it made sense to start with the city's churches.

"Memphis has a deep faith community," says Mary Beth Murphy, who was program coordinator for the Memphis DPP site from the beginning of the study through November 2012. Over the years, Ms. Murphy and other healthcare professionals in the area have built a strong and mutually beneficial relationship with the area churches.

Many faith communities make it part of their mission to promote their members' physical as well as spiritual health. In Memphis, it's common for churches to have a health minister—sometimes a healthcare professional who goes to the church, sometimes a minister who has a special interest in health—who helps coordinate health-related activities, such as setting up presentations and distributing teaching materials. "They set up the health fairs and then come to us if they want teaching materials or other support," Ms. Murphy explains. "Since we know them so well, we work together. If they need someone to come to their church and help out, we have several nurses and residents who help."

The Memphis site built on these relationships from the beginning of DPP. Principal Investigator Abbas Kitabchi, PhD, MD, and other DPP staff visited churches, met with healthcare ministers, and participated in church health fairs. Because one of the missions of DPP was to recruit minorities most affected by diabetes, they especially reached out to African American church leaders. "We went over the study in detail," Ms. Murphy remembers. Through these meetings, and through the candor of Dr. Kitabchi and others involved in DPP, they answered questions and built support and trust for the endeavor.

"When you go with the support system that's already there, there's a trust that's built up," Ms. Murphy says. Many of the site's participants were recruited through these church contacts.

They also worked with local hospitals and clinics for their recruitment outreach. Both Dr. Kitabchi and Ms. Murphy know the local healthcare community well and have contacts at the city's public health hospital and community-based clinics. In addition, there are several faith-based healthcare providers in the community, including the Church Health Center, located just a few blocks from the DPP offices. Started in the 1980s by Scott Morris, MD, a physician who is also an ordained minister, the Center offers affordable primary care, wellness classes and a workout facility and shares many of the goals of DPP.



DPPPOS participants visit the Botanical Gardens.

## SPECTRUM OF PARTICIPANTS

The Memphis site currently has about 120 participants who come from a variety of professions and backgrounds. “We have a spectrum of participants—all the way from one end to the other,” Ms. Murphy says. The group includes lawyers, teachers, principals, biomedical engineers, nurses, home health aides, travel agents, prison guards, and payroll clerks. They work for the university, large distributors, and utility companies. One participant is a talented photographer, another is a local singer, another is a well-respected cantor and another is a local Memphis

and Civil War historian.

“It is amazing to me the commitment the volunteers have for the study,” says Ms. Murphy. “It’s a win-win situation. They see the results, and they truly feel like they’ve benefited from being in this study.”

Laura Taylor, RN, who took over as program coordinator when Ms. Murphy moved on to another study emphasizes the benefits come not from the honoraria or blankets or other tangible items (Although participants like those, too!).

“It’s not *anything* that you give them,” Ms. Taylor says. “What we do is to try to take care of the whole patient. We get to know them and their families and what’s important to them. We make them feel special because they are special.”

Ms. Murphy tells the story of one gentleman who, each time he came to his appointment, weighed a little more and felt a little worse. Over the course of one appointment, he talked about his grandson, who was just getting old enough to visit without his parents. He told about taking the boy to enjoy outdoor activities, such as walking, hunting and exploring the countryside. “He loved that grandchild,” Ms. Murphy says. “That was the center of his life. But he was getting so he couldn’t walk as far” with his grandson.

And then came the a-ha moment. Ms. Murphy suggested that if he lost a little weight, got a little healthier, he could do more with his grandson. He could

be there longer for his grandson. “He made a miraculous change,” Ms. Murphy says. “This man turned around on something as simple as wanting to be there and be active with his grandson.”

## HISTORIC LINE-UP

The Memphis staff have offered a great lineup of events to participants over the years, but one in particular stands out for its creativity. “Each staff member took an element of Memphis history and gave a talk about it,” Ms. Murphy, former Program Coordinator, remembers. “Afterwards we had a quiz.”

Harriet Ricks, Lab Technician—whom, Ms. Murphy says, is the “glue that sticks everything together” at the site—talked about important African American leaders in the community. Jennifer Dolgoff, RN, another nurse, talked about the history of the city’s medical community.

Ms. Murphy chose to talk about the historic Elmwood Cemetery, where notables from Civil War soldiers to politician Edward Hull “Boss” Crump are buried. And Debbie Clark, Outcomes Specialist, spoke about none other than Elvis Presley!

## PARTICIPANT PROFILE: ARUN GANDHI



Arun Gandhi

Arun Gandhi, grandson of Mahatma Gandhi and a social justice and peace activist in his own right, moved to Memphis in 1990 to establish the M.K. Gandhi Institute for Nonviolence, which was originally hosted by Christian Brothers University.

When he saw an advertisement for the Diabetes Prevention Program in the newspaper in 1996, it piqued his interest. He

had seen the debilitating effects of diabetes on his mother’s health and wanted to do what he could to prevent the disease. He was also uninsured.

“When I saw that the study was offering free medical checkups twice a year, I thought this was a God-sent opportunity,” he says.

With his schedule of worldwide lectures on nonviolence and conflict resolution, Mr. Gandhi at first found it difficult to build exercise into his routine. However, in recent years, he has joined a YMCA and now enjoys regular spinning classes and strength training sessions. “I have lost a little weight and I feel fitter and healthier. I intend to continue this routine as long as I can,” he says.

He also intends to keep coming to the Memphis site, even though he and his Institute have moved to Rochester, NY. “The staff are marvelous,” he says. “That’s why I chose to remain attached to the Memphis site. It is always a joy to come to my old haunt and see the staff.”

# UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT SAN ANTONIO



## UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT SAN ANTONIO SAN ANTONIO, TEXAS

The San Antonio Zoo is located in Brackenridge Park, a historic gathering spot just north of downtown San Antonio. Since prehistoric times, people have gathered on this spot near the headwaters of the San Antonio River to enjoy the cool shade of pecan trees and the springs that bubble up from underground. Archaeologists have found American Indian artifacts here dating back to 9200 BC. Spanish settlers in the 1700s built elaborate ditches to channel river water to irrigate their fields; from the Civil War to the early 20<sup>th</sup> century, the River served as the city's main water source. The San Antonio River also connects all the historic missions starting with the Alamo.

Through the years, the University of Texas Health Science Center at San Antonio has held a catered lunch for DPPOS participants at the San Antonio Zoo as part of their retention efforts. It's a leisurely afternoon of food, friends and socializing. In addition to the zoo, participants can enjoy the park's gardens, fountains, playgrounds, theaters and museums that are connected by an elaborate collection of bridges, stairs and walking paths.

Can there be a better way to sneak in your exercise? Wandering from the Japanese Garden to the Sunken Garden and enjoying the beautiful foliage and koi ponds, "the setting is kind of upstairs, downstairs," says Maria M. Montez, Program Coordinator for the San Antonio site. "People get their activity without even realizing it."

This fits well with the goals of the DPP/DPPOS. "Walks in the park and things like that encourage physical activity. For people who are more sedentary, they actually realize, 'Hey. This is not so bad. I can actually do this.'" The key, she says, is to make it fun. "Get out to the park and just walk until you start building up your stamina."

All staff members at the San Antonio site have been with the study from the beginning. The participants have also been very steady, Ms. Montez says. Ninety percent moved from DPP to DPPOS.

"People just bought into the DPP, and they've been very loyal," she explains. DPP and the now twice-annual visits to the clinic are just part of the participants' way of life. It's gotten to the point, Ms. Montez says, where they wonder what they'd do if the study ended. "They're asking me, 'If this goes away, what's going to happen? We're so dependent on seeing the staff and visiting them every six months.'"

Most of the San Antonio participants live close by the study site. Although the site offers participants cab service if they need it, most drive to the facility, which is located just north of downtown, about a mile from the Health Science Center. The site has one of the highest levels of participation for the HELP and BOOST sessions.



## HISPANIC HERITAGE

With its Spanish heritage and its location close to Mexico, San Antonio was a logical site for recruiting Hispanic participants. Ms. Montez, who—like the rest of the DPP staff—is bilingual, appeared on both English and Spanish television and radio shows to let people know about the study and the need for volunteers. “Whenever there was a special event, like a run or a marathon in town, I’d take shoes and food props to show people what they needed to do before their big race if they had diabetes,” Ms. Montez says.

---

**Me da gusto verla (Spanish).  
It’s my pleasure to see you.**

---

The staff also attended health fairs at churches and community centers and even at the regional home and garden show that takes place in San Antonio every year.

Whatever they did, it worked. “Our recruitment ended early because we already had all of our participants,” Ms. Montez says. The current participant pool is 70 percent Hispanic, 25 percent non-Hispanic whites, with a few African Americans and Asian participants.

The staff clearly appreciates the dedication of this group. “They’re very loyal, and when they believe in something, they will go to the ends of the earth to accomplish it. They have a great work ethic, which really translates into working with the DPPOS because they take it to heart. They’re incredibly grateful because they feel that they’ve learned so much and they’ve benefitted so much from being in the program.”

Lorene Juarez had at least three risk factors for diabetes when she joined the study: “I was more overweight than I am now, I had had gestational diabetes, and I am Hispanic.” In fact, within six months of joining the study, she became diabetic. While most people would have seen this as bad news, Ms. Juarez was thankful that she knew right away. “I know to the date when I became a diabetic. How many people really know when they become sick?” she asks. In fact, most people with diabetes don’t get diagnosed for five to 10 years—when complications have already started to develop.

Once diagnosed, Ms. Juarez started taking medication to control her diabetes. Despite getting diet and exercise advice during the bridge period, she still struggled with her weight. After gastric bypass surgery, she finally dropped the pounds and since then has been able to go without medication.

“Being in contact with the DPP staff every six months had just opened my eyes to take care of myself,” Ms. Juarez says. “Now when there are different issues that come up in my life, I go ahead and take care of them, instead of hiding.”

---

***“If you get up and move, why, you’re going to live longer. My mother was go, go, go all the time. She passed away in December 2012 at age 106,” says Richard Haines, lifestyle participant at the University of Texas, San Antonio site. “I’m going to try to outlive my mother. I’m 80 now, so I have another 27 years to go!”***

---

## SHARED EXPERIENCE: UT SITE HELPS DEVELOP BILINGUAL PATIENT EDUCATION MATERIALS

Because of their experience with Hispanic participants, Ms. Montez and the rest of the San Antonio site have helped design the bilingual patient education materials for the National Diabetes Education Program, an NIDDK program that helps disseminate high-quality patient education materials and clinician guides to primary care providers across the country.

“The materials had to be useful—not the same old thing,” says Maria Montez, RN, Program Coordinator for the San Antonio site. “You have to cater to the population you’re serving. If you create a document that’s useful in Philadelphia, it may not be useful in Texas.”

Ms. Montez brought her Texas experience to the national committee that designed the bilingual patient education materials for the National Diabetes Education Program (NDEP). With input from clinicians who have worked with different populations, the NDEP materials go beyond the standard diabetes education materials.

It’s important that patients feel comfortable with the materials and be able to use them easily, Ms. Montez says. “If they look at them and think, ‘Well, I’m not going to be able to do that,’ they won’t even attempt it.” But by breaking it down into smaller steps and ensuring, for example, that spaces in the food diary accommodate different handwriting and note taking styles, “little by little you start getting people to use those types of tools. Then they become addictive, and people think, ‘Oh, I’ve got to write that down.’”

# UNIVERSITY OF WASHINGTON



## UNIVERSITY OF WASHINGTON SEATTLE, WASHINGTON

In 1997, the University of Washington and VA Puget Sound kicked off their recruitment efforts for the Diabetes Prevention Program (DPP) study at the Wing Luke Museum of the Asian Pacific American experience, located in the heart of the city's Chinatown-International district. The purpose of the event was to get the word out about the study to minorities at greatest risk for diabetes, especially Asian Americans.

"We had people from the community talking about what diabetes was and what the risk factors were in their community," says Brenda Montgomery, RN, MS, DCE, Program Coordinator for the DPP in Seattle. For example, the speakers explained that Japanese Americans are at high risk for diabetes even if they are not as overweight as other Americans.

The event may have looked like the beginning of the study effort to those gathered, but it was actually the culmination of an effort that started the moment the Seattle site received word that they had received the DPP grant. "We were asked to focus on the Asian American community," Ms. Montgomery remembers. The DPP staff took that charge and ran with it. "That was our charge from day one."

Wilfred Fujimoto, MD, a Japanese-American and a co-investigator at the Seattle site at the time, spearheaded the effort. "He helped us make history in minority inclusion in the study nationwide," Ms. Montgomery says. He also helped design the local approach.

---

*"We were asked to focus on the Asian American community," Ms. Montgomery remembers. The DPP staff took that charge and ran with it. "That was our charge from day one."*

---

The first step was to get the Asian American communities involved in the effort. DPP staff formed advisory boards of community leaders for each nationality—Korean, Japanese, Chinese, and Filipino. Then, they established a main Community Advisory Board, which was comprised of a few members of each of the other boards. That main advisory group drove the site's approach to outreach to the area's Asian Americans.

"The Board was formed in 1996, and they're still advising us," says Ms. Montgomery. Board members continue to attend the site's events—including the annual appreciation dinner and educational offerings.

The involvement of these community members in the planning process helped build recognition and trust. When DPP staff showed up at community fairs and events (including the Seattle Cherry Blossom Festival and the Japanese Cultural Festival), people already had some knowledge of the study and its goals.



Bettye Atkinson, DPPOS participant.

The approach worked. The Seattle site screened 14,000 people in the area and surpassed its original recruitment goal by signing up 196 participants. And, not insignificantly, the effort raised awareness of diabetes even among those who did not get screened or recruited into the study.

“We were able to go back to the [Filipino-American] community and say, ‘Of the people we screened, your population had a greater incidence of diabetes versus anybody else,’” says Ms. Montgomery. This gave community leaders valuable information and helped them raise awareness of the disease. They were also able to report to newer immigrants from Southeast Asia that they were also at risk. Armed

with that knowledge, people in that community could take steps to protect themselves against the disease.

The Seattle site’s groundbreaking work also caught the attention of the Washington State Department of Health, and the Community Advisory board members were asked to serve on a similar board to advise the state’s diabetes control program.

## PARTNERS IN PREVENTION

---

***“We tell all of our staff, we’re the Nordstrom of research,” Ms. Montgomery says with a laugh, referring to the site’s emphasis on “customer service.” If participants are busy and have lots going on in their lives, the site accommodates their schedules. “No one ever waits,” she says. “We want them to always know they are our priority.”***

---

The Seattle site shines in many other ways, too. Data collection methods, quality reports and staff training techniques developed here form the basis of the study’s Protocol Oversight Program (POP) used by all the DPP study sites nationally.

“We tell all of our staff, we’re the Nordstrom of research,” Ms. Montgomery says with a laugh, referring to the site’s emphasis on “customer service.” If participants are busy and have lots going on in their lives, the site accommodates their schedules. “No one ever waits,” she says. “We want them to always know they are our priority.”

Located on the campus of the Veterans Affairs hospital in Seattle, the site is easy to get to for most participants, but staff also do home visits and Saturday clinics when needed to make sure that everyone can continue in the study.

The participants appreciate this, and, close relationships have developed between the participants and the staff. At the twice annual study visits, DPP staff catch up with participants not only on their health but on family news and other details of their lives.

“Our greatest accomplishment,” says Ms. Montgomery, “is our relationship—our friendships—with our participants. They see themselves as partners with us in improving the knowledge about diabetes risk factors.”

Bettye Atkinson, a retired director with the U.S. Economic Development Administration, takes that role seriously. When asked who in her family had diabetes, she starts listing relatives: her parents, grandparents, siblings, uncles and aunts. But the loved one who inspired her to join the study was her son, who was 10 years old at the time. “I thought I should do something to ensure that, if diabetes is going to impact his life, I’ve done something to help,” she says. Ms. Atkinson watches what she eats now and gets in her exercise by walking daily around Seattle’s Green

Lake. She also shares what she’s learned through DPP with anybody and everybody she meets. “I’m not shy about talking about it,” she admits. When a co-worker complained of increasing thirst, she urged him to see his doctor. When a friend was diagnosed with diabetes, she started taking her to her DPP classes. She’s recruited several people to her daily walking habit. Even her pharmacist comes to her for advice.

And, her involvement in the study has influenced her son, now 24 and living in another city. “He eats healthier because I talk about this,” she says. “He’s using his bike more, and he takes time to walk. He told me he walks over four miles a day.”

---

***“Our greatest accomplishment,” says Ms. Montgomery, “is our relationship—our friendships—with our participants. They see themselves as partners with us in improving the knowledge about diabetes risk factors.”***

---

## THE LIFETIME ANSWER

Another enthusiastic participant is Jeanette Blankas Clayton. Diabetes was already weighing heavily on her mind when she heard about the DPP study on local television 16 years ago.

Both of her parents had already been diagnosed with the disease. She thought diabetes was “in the cards” for her as well. So, when she saw the DPP study featured on the evening news, she paid close attention. Among the groups most at risk, the newscaster reported, were those of Asian descent.





Jeanette Clayton, DPPOS participant.

As the daughter of a Filipino mother and a Japanese father, this fact hit home.

She also knew her diet and her weight were risk factors. Ms. Clayton describes her former self as a “fried-chicken-two/three-times a week girl.” “Given the choice, I’d pick something fatty and fried over something crisp and green,” she remembers.

Her participation in DPP changed all that.

“I remember going to the initial meetings and thinking to myself, ‘Please, please, I hope I’m randomized into the lifestyle group,’” she says. “I knew that would be the lifetime answer.”

Now she piles her plate high with colorful vegetables. “I’ve developed a real love for high-iron and cruciferous vegetables— like broccoli and high-iron spinach,” she says. She also has become interested in healthy cooking and transforming recipes. And, although she admits she’s not as good about exercise as she should be, she’s much more active than she used to be.

---

*“I remember going to the initial meetings and thinking to myself, ‘Please, please, I hope I’m randomized into the lifestyle group,’” Ms. Clayton says. “I knew that would be the lifetime answer.”*

---

But Ms. Clayton gained more than a new lifestyle from DPP. She also found a group of supportive friends who have carried her through some difficult times. Since the study started, Ms. Clayton lost both parents to diabetes complications.

“I have found a lifelong group of friends through the program,” she says.

Ms. Montgomery has been involved in many different clinical studies and she agrees there’s a special energy and excitement about DPP and DPPOS. True bonds and friendships have been forged among the participants and staff.

---

*“I think it’s because we’re trying to understand and prevent something in future generations,” Ms. Montgomery says. “We’re all just so connected. I can’t imagine having the study end.”*

---

# WASHINGTON UNIVERSITY SCHOOL OF MEDICINE



## WASHINGTON UNIVERSITY SCHOOL OF MEDICINE ST. LOUIS, MISSOURI

Located on the campus of Washington University School of Medicine, the St. Louis DPP site seems tailor-made for the study. Three of the city's top hospitals sit just blocks away, making it easy for participants to get their DEXA scans, eye exams and other medical tests that are part of the study. The site is also right next to Forest Park, a historic urban park that hosted both the World's Fair and Summer Olympics in 1904.

"Back in the days of the 16-session life balance sessions, DPP staff would take participants to walk in Forest Park to get in their physical activity," says Prajakta ("PJ") Khare-Ranade, MSc, RD, LD, one of the co-program coordinators for the St. Louis site.

More than 80 participants come to this site for their bi-annual study visits and other DPPOS events. They range in age from 45 to 90, which means some still have youngsters at home while others now live in nursing homes.

### ONE STEP FURTHER ALONG

Interestingly, this DPP site is housed in the pediatrics department. This quirk can be traced back to Julio Santiago, MD, the original principal investigator for Washington University. Although he specialized in pediatric endocrinology, Dr. Santiago also saw adult patients and was a leader in exploring new ways to treat the disease

in people of all ages. Current PI Neil H. White, MD, carries on this tradition.

"Dr. Santiago was very involved with the design of the entire DPP," says Ms. Khare-Ranade. He was also part of another large, groundbreaking diabetes study, the Diabetes Control and Complications Trial, which looked at the effects of tight blood sugar control in people with type 1 diabetes.

Known for his positive attitude and his charismatic presentations, Dr. Santiago was a huge asset during the recruitment stage of the study. He appeared on local television and radio talking about the study. "It prompted a tremendous response from the public," remembers his wife Ana Santiago, RN, who helped with recruitment and who is now a DPPOS case manager. In fact, the response was overwhelming. "We had to hire temporary help to take all the telephone calls and screen all the people," Ms. Santiago says.

---

***"What DPP means to me: Early diagnosis, peace of mind, professional staff, knowing that this research is meaningful to others as well as me," says a Washington University DPPOS participant.***

---



Barbara Harris, DPPOS participant.

While that was a crazy busy time, Ms. Santiago learned something that she's reminded of often as she continues to work on DPPOS. "A lot of what we do is repetitive—paperwork, phone calls. But ultimately all of these minute details go into extremely important studies. Even if your hypothesis is not proven, it still puts you one step further along the road to being able to solve that problem."

And, in the case of DPP and DPPOS, the hypothesis that diet and exercise could forestall diabetes proved correct.

The St. Louis participants are pleased to be a part of this effort. "For many participants, DPP is like a special place in their lives. The look forward to their visit and they share what's going on," says Tamara (Tammy) Stich, RN, MSN, CDE, Co-Program Manager.

"They are happy to be contributing," Ms. Santiago adds.

---

*"Diet and exercise is the beat," says a Washington University DPPOS participant.*

---

## GETTING THE MESSAGE ACROSS

For Ms. Santiago, the results of DPP and DPPOS hit especially close to home. Dr. Santiago was diagnosed with diabetes soon after the launch of the study. He died from complications of the disease a year later. Now she worries about their adult children who are at increased risk, one of whom has already been diagnosed with the disease.

She wonders how best to get the message about diabetes prevention and early detection to those at risk. "This is something that's extremely important for us as educators to deal with," Ms. Santiago says. "How do we get through? How can we present the diet and exercise information so that our people understand there is no reason they can't lead a healthy life?"

The key, the DPPOS staff believe, is in consistent caring and follow-up. "The fact that we care about them, that we call just to see how they're doing and ask about that graduation," or other big events in their lives, Ms. Santiago says. Eventually, the message gets through.

Participant Barbara Harris agrees. After three decades as a social worker, Ms. Harris knows something about human nature and making choices and changes. "Everyone has to have their own realization," she says. "You've got to go through the journey to know and realize the benefits."

In fact, she's lived that journey herself with her own health.

When Ms. Harris first started with the Diabetes Prevention Program study back in 1997, she was juggling a full time job in social work with raising her two teenage children. Soon after the study started, her mother was diagnosed with diabetes and started suffering from complications. Her life revolved around caring for others.

Although she remained dedicated to the study and felt "very supported" by the DPP staff, Ms. Harris had trouble integrating the study's diet and exercise advice into her busy life. "Looking back, I attribute this to my stress," she says. "That's why I couldn't acclimate myself to the program like I should have."

It took her own diabetes diagnosis as well as knee surgery in 2007 and 2008 to get her to take a hard look at her activity and eating habits. Her illness and her injury forced her to focus on her own needs. That's when the lessons of DPP and DPPOS finally paid off for her. Soon, she was participating in an exercise program for an hour a day three times a week. "Things were beginning to be the way they should be. All that information [the DPP staff] had given me was working. I started feeling better."

---

*"DPP has improved the quality of my life, lengthened my life, made my attitude more positive, given a technical basis for diet and fitness, and reduced anxiety about potential disease. All in all, a great program to overcome diabetes," says a Washington University DPPOS participant.*

---

While rheumatoid arthritis prevents her from keeping up that vigorous routine, Ms. Harris keeps up with chair exercises and choosing her foods carefully. "I still try to keep that principle going," she says, noting with pride that her last A1c reading was 5.5. "I'm not in a position to count myself out. I can still take care of myself and keep pressing on."

## SECRET INGREDIENT

What keeps St. Louis participants coming back? Ms. Stich says the key is to keep the participants engaged with fresh and interesting content. She finds that the materials developed by the Life Balance Core in Pittsburg help tremendously. "It's not the same thing over and over again," she says. She and the other St. Louis staff also keep changing it up with different activities, including cooking demonstrations and presentations in different parts of the city.

It also helps to have engaged participants. The St. Louis participants like to stay current with health news and diabetes research in particular. "They'll call us and ask, 'Hey, did you read that in the newspaper today?'" Ms. Khare-Ranade says.

They also like carrot soufflé.

"Every year, they look forward to the carrot soufflé," served at some study events. "They all say no one can make it like that," Ms. Stich says with a laugh. It's not particularly healthy, Ms. Stich admits, but it's okay once a year to indulge.



# THE IMPACT OF THE DIABETES PREVENTION PROGRAM OUTCOMES STUDY



## THE IMPACT OF THE DIABETES PREVENTION PROGRAM OUTCOMES STUDY

The Diabetes Prevention Program came just in the nick of time. In 1994, surveys indicated that more than 5 percent of adults over age 20 had type 2 diabetes and the numbers were on the rise. Less than a decade later, the rate had almost doubled. In some groups, including American Indians, Pacific Islanders, Hispanics and African Americans, the rates were even higher. In 2001, analysts at the Centers for Disease Control were projecting a dramatic increase in type 2 diabetes diagnoses by 2050—perhaps rising as high as one in three adults in the United States.

“The only way to reverse that was to reduce the number of people getting diabetes,” says Dr. Sanford (“Sandy”) Garfield, PhD, who was NIDDK Project Scientist for the Diabetes Prevention Program (DPP) and its follow up, the Diabetes Prevention Program Outcomes Study (DPPOS).

Of course, that’s what the Diabetes Prevention Program was all about. **The results of the DPP are a big, bright shining light pointing the way to a better future.**

By spreading the word that people can reduce their risk of type 2 diabetes by changing their diet, increasing exercise and losing weight, it might actually be possible to prevent or at least delay people from developing type 2 diabetes.

That’s where translation comes in.

### HANDS-ON TRANSLATION

In most clinical studies, there’s a separation between those who actually carry out research and those who get into the nitty-gritty of integrating the findings into practice, also called translation. The researchers conduct their clinical trial, report on the results, and then let other experts figure out what to do with those results.

But, considering the important results that came out of the first phase of the Diabetes Prevention Program (DPP) and the increasing epidemic of type 2 diabetes, no one wanted to leave the translation of DPP up to others. The researchers wanted to make sure that the findings of DPP benefited as many people as possible—and as soon as possible.

A committee formed to tackle the task. Chaired by Dr. David Marrero, PhD, Principal Investigator for the Indiana site, members included Dr. Elizabeth Venditti, PhD, Director of the Lifestyle Core and other program coordinators and study representatives. These members worked with staff from NIDDK, CDC, Indian Health Service (IHS), as well as state governments and other organizations to extend the reach of DPP. Through the following programs, the findings of DPP have reached hundreds of thousands of people around the globe, changing lives and, indeed, saving lives.



The National Diabetes Education Program created their “Small Steps, Big Rewards” campaign to reach hundreds of thousands of people about diabetes prevention and risk.

### INDIAN HEALTH SERVICE AND AMERICAN INDIAN AND ALASKA NATIVE COMMUNITIES

The Indian Health Service (IHS) got involved with the Diabetes Prevention Program in order to find ways to address the growing problem of type 2 diabetes among American Indians and Alaska Natives. Translation—building programs based on clinical research—was their intent all along.

This dedication to making new developments widely available warms a researcher’s heart. “IHS is so eager to learn from research,” says Dr. William Knowler, MD, PhD, Principal Investigator for the Southwest American Indian Center sites in Shiprock, Zuni, Gila River and Salt River. “DPP is the best example of that. One of the things that’s so satisfying to me is knowing that the research findings are being implemented more quickly in the IHS than practically anywhere else.”

Based on the findings of DPP, Congress appropriated funds—**more than \$30 million**—specifically to implement DPP in American Indian communities. So far, **more than 25 different tribes and communities** have started programs based on DPP. Staff from the Southwest American Indian Center have provided in-person and web-based training to help them with the implementation.

In addition, IHS now uses the DPP interventions—both the lifestyle program and metformin—as the standard of care for patients who are diagnosed with prediabetes. This means that American Indians, outside the research study, are now receiving treatment that may delay or even prevent the onset of diabetes.

### NATIONAL DIABETES EDUCATION PROGRAM: SMALL STEPS, BIG REWARDS

In 1997, just as the Diabetes Prevention Program study was recruiting participants and getting underway, the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health joined together to launch the National Diabetes Education Program (NDEP). The aim was to improve diabetes management, reduce complications from the disease, and help people with the disease live longer.

After the results of DPP were released in August 2001, NDEP added a new goal: to help *prevent* diabetes by making sure people at risk know they can prevent or delay the disease through modest weight loss and regular physical activity.

Members of the translation committee as well as other DPP staff worked with NDEP to launch a multi-cultural campaign called “Small Steps, Big Rewards,” which included public service announcements, fact sheets and a “game plan” that helps people figure out their diabetes risk and start taking steps to improve their diet and increase their physical activity. Since its launch in 2005, **hundreds of thousands of people** have downloaded the materials, some of which are available in **16 different languages**.

By all counts, the campaign has had a major role in raising awareness of diabetes as a preventable condition. Just six years later in 2011, a survey showed that **84 percent** of the public realized that type 2 diabetes is a serious

disease, and **77 percent** understood that diabetes is preventable. In addition, **60 percent** of people with prediabetes recognized their risk for developing diabetes.

“There’s a huge change in people’s awareness of prediabetes as a condition of its own,” says Dr. Marrero. “All that’s happened in the lifetime of this study. We put prediabetes into the public focus.”

---

*“Not only is this a great study from the standpoint of loving what we do, but the work is so important. It’s like a double whammy. We take great pride in the work, and we have so much fun doing it. It’s a win-win. Not only does the staff feel that way, but I think the participants feel that way too,” says Ms. Sue Shapiro, RN, DPPOS program coordinator, MedStar Health Research Institute.*

---

### ADAPTING THE LIFESTYLE CORE FOR WIDER DISTRIBUTION AND THE YMCA’S DIABETES PREVENTION PROGRAM

To make the DPP Lifestyle Program easier to use in communities, a lifestyle committee pared the 16 study lessons down to 12 group sessions that could be taught by trained lay people. The next step was to identify a way to get the course out to communities across the country.

That’s when Dr. Marrero ran into the executive director of the YMCA in Indianapolis at a meeting

to discuss translation of DPP into the community. “There was an ‘a-ha’ moment,” Dr. Marrero remembers. Before they knew it, they were planning a pilot program called Diabetes Education and Prevention with a Lifestyle Intervention Offered at the YMCA, or DEPLOY, which took place in 2004 with 92 participants. “To make a long story short, we trained YMCA staff to deliver a modified version of the DPP. And to make an even longer story short, it worked!” The participants’ body weight decreased by 6 percent and their cholesterol also went down.

The DEPLOY pilot became the basis for a national program launched by the YMCA, which has branches around the country. The Y’s program started in 12 states in 2009 and captured the attention of not only the Centers for Disease Control and Prevention (CDC) but also United Health Group (UHG), one of the largest health plans in the country. UHG recognized that a low-cost intervention that helped participants lose weight and prevent diabetes could reduce healthcare costs while improving quality of life for members at risk for diabetes.

Currently the program is offered for a modest cost (about \$120, often covered by insurance) by **92 Y’s at 684 locations in 39 states**. More than **1,500 lifestyle coaches** have received training and **14,250 participants** have attended sessions and lost an average of nearly 5 percent of their body weight. By 2017, the Y plans to have the program started in more than 300 locations.

---

*“The DPPOS Study has kept me aware of my health. My sessions with Ms. Levy have helped me and guided me in making good food choices, maintaining my weight at a good level. Thanks, Pennington, for taking such good care of me,” says DPPOS participant, Pennington Biomedical Research Center.*

---

## HEALTHY PEOPLE 2020 GOALS

Every 10 years since 1980, the U.S. Department of Health and Human Services has issued new goals for health promotion and disease prevention for the nation. The Healthy People goals and objectives act as “the nation’s

roadmap” and help set priorities for government agencies as well as for health care organizations.

The Healthy People 2020 goals and objectives were released in 2010, and they clearly reflect the results of the Diabetes Prevention Program. In fact, the first objective under diabetes reads: “Reduce the annual number of new cases of diagnosed diabetes in the population.” Another objective cited is to “increase prevention behaviors in persons at high risk for diabetes,” including increased physical activity, weight loss and improved diet. The supporting evidence for these objectives comes straight from DPP.

## CDC’S STATE-BASED DIABETES PREVENTION AND CONTROL PROGRAMS/NATIONAL DIABETES PREVENTION PROGRAM

As the government agency most focused on disease prevention and public health, the Centers for Disease Control and Prevention (CDC) has taken a lead role in informing the public about diabetes prevention.

As part of the Affordable Care Act, the CDC established the National Diabetes Prevention Program (NDPP), inspired by the promising results of DPP. Headquartered at the CDC in Atlanta, NDPP encourages collaboration among federal agencies, community-based organizations, employers, insurances and healthcare providers to develop these programs.

For this public-private partnership, the CDC has joined up with the YMCA, United Health Group, Viridian Health Management, Inc. (a worksite health promotion company) and Emory University in

Atlanta to continue spreading the ideas behind DPP and DEPLOY. The program trains lifestyle coaches to deliver a year-long lifestyle change program. So far, more than **2,100 lifestyle coaches** have received training through NDPP partner organizations, and more than **400 organizations** have agreed to offer the NDPP lifestyle program based on DPP. Soon programs based on DPP will be available in **every state in the country** as well as the District of Columbia, Puerto Rico, the U.S. Virgin Islands and six Pacific territories/former territories.

## STATE PROGRAMS

All states now have some type of program aimed at preventing type 2 diabetes, but a few have gone farther to implement a DPP type program. These include:

*Minnesota:* Minnesota has implemented the Individuals and Communities Acting Now (ICAN) to Prevent Diabetes, a program based on DPP. The program has certified more than 90 lifestyle coaches who now offer a 16-week course and have adapted it for different groups including Hmong, Somali, American Indian, Hispanic and people with hearing impairment. Participants in the classes have lost an average of 5.7 percent of their body weight and reduced their risk of converting to diabetes.

The program also works with healthcare providers and insurers to make sure that providers are screening for diabetes risk and that insurers reimburse for the cost of preventive treatment. Since the program started, prediabetes diagnoses in the state have doubled—and more people are getting the care they need to reduce and delay diabetes onset.



*Montana:* In the rural state of Montana, a state initiative resulted in the training of 60 coaches, enrollment of more than 2,700 participants and completion of the program by more than 1,800 people. Those who completed the program logged an average of more than 200 minutes of physical activity a week. Two-thirds of the participants reached their physical activity goals and nearly half reached their weight loss goals. The addition of a telehealth intervention (classes delivered via the internet or other televised method), meant that the program reached people in small, rural communities who otherwise would not have had the opportunity to take a similar class close to home.

## INTERNATIONAL PROGRAMS

DPP has also had an impact beyond the United States with programs in countries around the world, including Sweden, Costa Rica, Russia and Venezuela. The University of Miami site has been closely involved with replicating DPP in Venezuela by training lay volunteers to act as lifestyle coaches.

## AND IT ALL STARTED WITH YOU...

The impact of the Diabetes Prevention Program has extended far beyond anything anyone imagined back in 1992 when the National Institutes of Health started planning the study or in 1994 when the 27 sites received funding to start the investigation. It has spread to Maine and Hawaii, to large cities and small towns, to people of all races and backgrounds, to residents in Russia and Costa Rica, changing **hundreds of thousands of lives around the globe.**

And, it all started with the participants who signed on to take part in the Diabetes Prevention Program back in the mid-1990s.

It all started with **you.**

Thank you.

# ACKNOWLEDGEMENTS



## ACKNOWLEDGEMENTS

The DPP/DPPOS was funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), with support from the following Department of Health and Human Services Operating Divisions:

Centers for Disease Control and Prevention

Indian Health Service

National Institutes of Health

*Eunice Kennedy Shriver* National Institute of Child Health and Human Development

National Cancer Institute

National Eye Institute

National Heart, Lung, and Blood Institute

National Institute on Aging

Office of Research on Women's Health

The NIDDK gratefully acknowledges the contributions of the participants, clinical site staff and researchers of DPP/DPPOS.





