

Diabetes Control and
Complications Trial / Epidemiology
of Diabetes Interventions
and Complications Study
DCCT / EDIC



Inside Front Cover (Blank)

TABLE OF CONTENTS

Introduction	2
From the Study Chairs	3
NIDDK Director's Update	4
Featured Results of the DCCT/EDIC: 2013 – 2023	8
Cardiovascular	8
Eyes	9
Cognition	10
Glycemic Control	11
Hearing.....	13
Kidneys.....	13
Mortality	13
Nerves	14
Physical Function / Frailty	15
Skeletal Health	16
DCCT/EDIC Publications: 2013 – 2023	17
DCCT/EDIC AT 30 YEARS (2013)	17
Publication Update 2013 – 2023	18
Brain/Cognition	18
Cardiovascular	18
Diabetes Treatment	19
Economic	19
Eyes	20
Glycemic Control	20
Hearing.....	21
Kidneys	21
Mortality	21
Nerves	22
Other Autoimmune Diseases	22
Physical Function	22
Quality of Research Data	22
Sexual Function & Bladder Health.....	23
Skeletal Health	23
The Story Continues... DCCT/EDIC Study Visits: 2023 – 2027.....	24
DCCT/EDIC Over Time: Participant Characteristics & Follow-up	25
Continued Participation Despite Distance & Relocations	25
DCCT/EDIC Clinical Center and Participant Locations.....	26
What Has ~40 Years Of The DCCT/EDIC Meant To The Participants?	27
Acknowledgements	53

INTRODUCTION

When the ***Diabetes Control and Complications Trial*** (DCCT) began in 1983, thoughts of the DCCT celebrating a 40th anniversary were unimaginable. The DCCT ended in 1993 and in 1994, the ***Epidemiology of Diabetes Interventions and Complications*** (EDIC) study started. In 2013, DCCT/EDIC celebrated its 30th year milestone, which was memorialized in a book created for study participants. Now, 10 years later, DCCT/EDIC celebrates its 40th anniversary. This booklet highlights the study's accomplishments over the past 10 years.

The DCCT/EDIC achievements would never have been possible without the loyal commitment and unwavering participation of the research volunteers. Together with a dedicated team of investigators, study coordinators, colleagues in laboratories and special reading centers, and the steadfast support of the data and clinical coordinating centers, the DCCT/EDIC has positively impacted the scientific understanding and the medical care of type 1 diabetes worldwide. The continued support from NIDDK project scientists and leadership has continued to make this ***journey of discovery*** possible . . . and the journey continues.

With deep gratitude, this booklet is dedicated to the DCCT/EDIC research participants and their families.

Created by:

*Annette Barnie, Matt Bott, Kaleigh Farrell, Patty Gatcomb, Susan Hitt,
Mary Larkin, Gayle Lorenzi, Cathy Martin, and Victoria Trapani,
on behalf of the DCCT/EDIC Research Group.*





FROM THE STUDY CHAIRS



**David M. Nathan,
MD**

**Rose Gubitosi-Klug,
MD, PhD**

Dear loyal participants of the DCCT/EDIC,

HAPPY 40th ANNIVERSARY! It's hard to believe that the first DCCT participant was enrolled over 40 years ago in 1983. The remarkable story of our scientific journey has been chronicled in the medical literature and repeated by physicians to patients, lecturers to medical trainees, and reporters to the public. Your efforts have forever improved our world of type 1 diabetes management and bring hope and inspiration to all people with type 1 diabetes.

In June 2023, we had the opportunity to update the international scientific community at the American Diabetes Association Meeting held in San Diego, California. It was wonderful to have a few of you in the audience, respond to your questions, shake your hands, and listen to your personal journeys living with diabetes and participating in the DCCT/EDIC. Indeed, study-wide, we were moved by your sentiments and reflections on 40 years of belonging to the DCCT/EDIC family. You will find your comments in this booklet, alongside the pages that tell the story of our research findings.

DCCT/EDIC has been an incredible long-term partnership between you and our study staff, and we have more to come! You might ask, what more can we learn after 40 years of study? Owing in part to your contributions, the lifespan of people with type 1 diabetes should no longer be reduced compared with the non-diabetic population. Therefore, the impact of type 1 diabetes across the lifespan has become a major theme of DCCT/EDIC. No other study has the long-term follow-up of people with type 1 diabetes as we have. DCCT/EDIC has followed you during more than 95% of your diabetes duration and for 65% of your lifetime. Our current grant cycle continues to explore the effects of diabetes on the eye, kidney, and nerve using some of our usual methods but harnesses new methods including evolving imaging technology for eye vessel and nerve disease. We are also expanding our studies of the heart and vascular system at rest as you push the pedals (or pace on a treadmill) to better understand the impact of diabetes with exercise. Finally, we are the first and largest study in type 1 diabetes to examine the liver, which has been an organ of interest in type 2 diabetes. Our overall goal is to continue to identify and describe the effects of type 1 diabetes - and other risk factors- over time. Better understanding of the course of type 1 diabetes over the lifespan will inform guidelines for continued improvement in diabetes management for generations!

Happy 40th Anniversary. Together we will continue to expand understanding and improve the care of type 1 diabetes.

Our warmest regards,

David M. Nathan, MD



Rose Gubitosi-Klug, MD, PhD



NIDDK Director's Update

Fall 2023

Celebrating 40 years of DCCT/EDIC

By Alyssa Voss for NIDDK

Not every day can a person say they helped change modern medicine, but staff and participants involved in the **NIDDK-supported Diabetes Control and Complications Trial (DCCT)** got that opportunity in June at the 83rd American Diabetes Association (ADA)'s Scientific Sessions in San Diego.

In a symposium marking the 40th anniversary of DCCT and its long-term outcome study, the Epidemiology of Diabetes Interventions and Complications (EDIC) study, a panel of study investigators, including study chair Dr. David M. Nathan, director of the Diabetes Center at Massachusetts General Hospital, and NIDDK project scientist Dr. Ellen Leschek, gave tribute to the study's participants and its long-lasting impact on type 1 diabetes treatment and people living with the disease.

Thirty years ago, in 1993 and after 10 years of study, the initial DCCT study results were presented at the ADA Scientific Sessions in Las Vegas. For the first time, the study demonstrated that early-stage complications



DCCT/EDIC 40th Anniversary ADA Symposium Presenters 2023

of type 1 diabetes could be reduced by between 35-76% through intensive management of blood glucose levels. **The New England Journal of Medicine** published the primary findings in 1993, and the paper remains among the most highly cited in diabetes literature to this day. In total, DCCT/EDIC has published nearly 400 papers, each helping to advance understanding of type 1 diabetes and its complications.

DCCT and the glucose hypothesis

The DCCT was recommended to Congress in 1975 by the National Commission on Diabetes (<https://babel.hathitrust.org/cgi/pt?id=uc1.31210023083353&view=1up&seq=4&skin=2021>) to test the "glucose hypothesis"—the idea that targeting diabetes treatment to

The New England Journal of Medicine

©Copyright, 1993, by the Massachusetts Medical Society

Volume 329

SEPTEMBER 30, 1993

Number 14

THE EFFECT OF INTENSIVE TREATMENT OF DIABETES ON THE DEVELOPMENT AND PROGRESSION OF LONG-TERM COMPLICATIONS IN INSULIN-DEPENDENT DIABETES MELLITUS

THE DIABETES CONTROL AND COMPLICATIONS TRIAL RESEARCH GROUP*

PARTICIPANT REFLECTIONS

The EDIC program has provided me numerous testing protocols that have confirmed my ongoing diabetes care is very stable, giving me confidence in my care. Arlington, TX

Gratitude ... Fabulous ... Caring ... Supportive ... Educational ... Exceptional. I am so grateful to be part of this incredible study. I have personally benefited with care I could never afford and the results have helped share diabetes care for all. Collingswood, NJ

bring blood glucose levels as close to non-diabetic levels as possible would prevent or delay long-term complications of diabetes.

“At the time, diabetes was the third leading killer in the United States, with incidence rates on the rise, and most people with diabetes died by their late forties. By testing the glucose hypothesis, we hoped to improve the quality of life and reduce significant complications including blindness, kidney failure, stroke, amputation, and heart attack for people with diabetes,” said Nathan.

And so it began. In 1983, the DCCT launched at 21 centers across the United States and Canada, later expanding to 28 centers and enrolling 1,441 people between ages 13 and 39 with type 1 diabetes, with an average age of 27. One-half of those enrolled received intensive diabetes treatment, which involved three or more daily injections of insulin or use of brand-new insulin pump technology; four or more blood glucose tests daily; monthly visits with study investigators with frequent phone calls between visits; and the goal hemoglobin A1c (HbA1c) level of less than 6.05%. The other one-half of participants received conventional diabetes treatment, which involved one to two daily injections of insulin; blood or urine glucose testing daily with no specific glucose targets; and one visit with study investigators every three months.

After six and a half years, the intensive therapy group maintained HbA1c levels around 7%, compared to around 9% in the conventional therapy group. The difference produced dramatic results. Compared to conventional therapy, intensive therapy reduced the development of diabetic eye disease by 76% among participants with diabetes for less than five years; the progression of diabetic eye disease by 54% among participants with diabetes who already had signs of retinopathy; and the development of kidney and

nerve disease by 43% and 57%, respectively. Glucose control was the dominant factor underlying these benefits.

The news of these findings had immediate translational effects. The ADA sent a letter to 40,000 clinicians in the United States to update the standards of care for type 1 diabetes. In addition to changing clinical practice, DCCT also spurred decades of new research avenues to improve diabetes management. Innovations in diabetes care included the development of insulin analogues, new insulin delivery methods, treatment algorithms, and other new technologies, all to further improve blood glucose levels with less risk of hypoglycemia and to make intensive therapy more accessible.



EDIC and the lesson of metabolic memory

At the end of DCCT, the study team transitioned the cohort to the EDIC long-term study in which participants would visit study clinics annually. Participants in the conventional therapy group were taught intensive glucose management, and all diabetes care was transferred back to their own clinicians. HbA1c levels quickly steadied at about 8.0% in both DCCT treatment groups. During EDIC, the team expected participants to reach ages and duration of diabetes that would allow for the study of more advanced complications including cardiovascular disease.

After four years, the EDIC study demonstrated ‘metabolic memory,’ in which the effects of the original treatments persisted even after the HbA1c levels had become similar in both treatment groups. This finding further reinforced the clinical recommendation to start intensive therapy as early in the course of type 1 diabetes as possible.

continued >

PARTICIPANT REFLECTIONS

The DCCT/EDIC gifted me health and hope. I could stop there, as each expanded my world in ways that defy description. They brought me a career, a spouse, a family and an immensely increased respect for research, patients and health care systems. Thank you! High River, Alberta, CAN

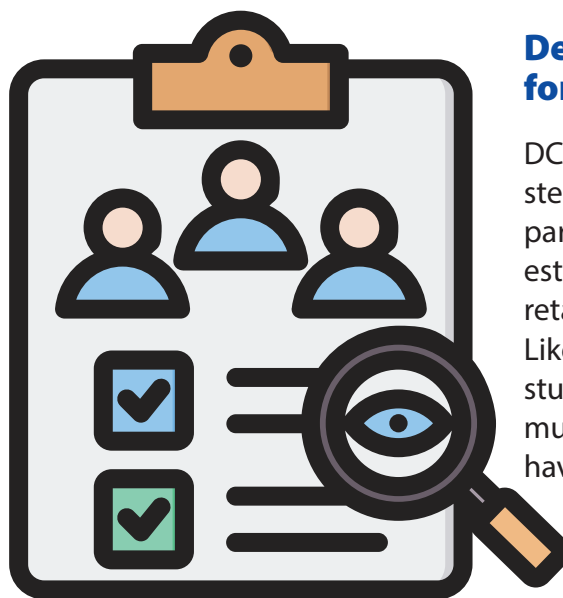
I was diagnosed with diabetes as a college student and joined the DCCT 9 months later. The care, education and support I received in the DCCT saved my life! Johnstown, PA

As EDIC continued, ongoing analyses elucidated the crucial role of glycemic control and HbA1c in promoting long-term health and preventing serious diabetes-related conditions. From the first analyses looking at diabetes-related complications, HbA1c was the single most important modifiable risk factor for microvascular and cardiovascular disease. And more recently, analyses have shown that intensive therapy and glycemic control play important roles not only in preventing severe complications but also in maintaining cognitive health, hearing function, mobility, and skeletal health.

“The implications of these findings are so important because it means it’s never too late to improve glycemic control. Lower HbA1c has a durable effect over time, and intensive intervention should be started as early as possible after diabetes diagnosis because having better control – even if delayed – helps prevent or slow the development of all outcomes we’ve studied in EDIC,” said panelist Dr. Bruce Perkins, study vice chair and professor of medicine at the University of Toronto, Canada.

Long-term follow-up in EDIC has also shown that the increased risk of death that had accompanied type 1 diabetes in the past had also been eliminated by intensive therapy. The original intensive therapy group’s rate of death is now no different than that of the general population. This result clearly showed that intensive diabetes therapy made a meaningful impact on preventing serious life-threatening complications and extending length of life in people with type 1 diabetes.

The next phase of EDIC will examine the effects of long-duration type 1 diabetes in its aging population. The average diabetes duration of EDIC participants is now 42 years and their average age is 63, a time at which age-related issues commonly arise. In addition, the proportion of the cohort with overweight and obesity is similar to the general population. EDIC will now look at the interaction of diabetes-related conditions and complications, weight-related issues including liver disease and sleep apnea, and age-sensitive factors including heart failure, cognitive and physical function, self-care, health economics, and quality of life.



Dedicated participants for the long haul

DCCT/EDIC is well-known for its steadfast group of dedicated study participants, who remain the largest type 1 diabetes study cohort retained for the longest time. Likewise, its dedicated staff and study coordinators, credited with much of the retention success, have remained committed to the study, many for decades. The majority of participants have remained engaged over the last 40 years,

and today, 90% of surviving cohort members are still enrolled. EDIC has studied them for 60% of their lifespans and about 90% of their time with diabetes.

The more than 1,000 remaining participants travel from across the United States, Canada, and as far as Europe, the Middle East, Australia, and New Zealand to complete their study visits at one of the remaining 27 clinical centers. They have completed more than 120,000 study visits.

PARTICIPANT REFLECTIONS

When I was randomized (age 14), I knew nothing about type 1 diabetes. So thankful to be part of the study because they gave me all the knowledge and tools I needed to maintain a healthy life. We formed some life-long bonds and I know that even now, we will stand by each other in times of need. Thank you to all the staff and fellow participants from the bottom of my pancreas (and heart!) Bronxville, NY

The cutting-edge tests, annual evaluations, and desire to help others are among the reasons participants give for being involved in the study for so long.



“I am so appreciative to be able to be part of the study, to get my test results and monitor my health, and to be at the cutting edge of what’s new with diabetes management,” said Elizabeth Murphy who’s participated in the study for 39 years and attended the ADA session.

More contributions to modern medicine

Equally important to advancing the understanding of diabetes complications, DCCT/EDIC has been instrumental to the development of innovative screening techniques and fine-tuning screening schedules.

Recently, the team reported new methods for diagnosing cardiovascular nerve damage and other microvascular complications, made possible by analyzing the multiple measurements taken at different points during EDIC. By assessing changes over time, the study was able to show which patients were at risk for developing these complications.

DCCT/EDIC has used its robust data to inform personalized, evidence-based screening guidelines across the lifespan from adolescence to adulthood, for retinopathy and more recently, kidney disease. Personalized screening schedules are now also incorporated into diabetes standards of care, which help identify how frequently or infrequently people with diabetes need screening, often minimizing the screening burden and need for tests.

The study has also influenced how clinical trials are conducted and set a precedent for implementing NIDDK-funded multi-center clinical trials and designing patient-oriented research. DCCT/EDIC created a network of diabetes clinicians and researchers that grew and generated many fruitful scientific ideas and opportunities. The network stimulated further NIDDK research on diabetes that yielded groundbreaking results, including the Diabetes Prevention Program, TrialNet, LookAHEAD, TODAY, GRADE, and RISE.

“I cannot overstate the enormous impact of the DCCT/EDIC study”

said NIDDK Director Dr. Griffin P. Rodgers.
“The entire diabetes community is forever indebted to the dedicated participants who made the study possible and the study team, whose endless energy and commitment keep propelling the research forward.”

PARTICIPANT REFLECTIONS

At the age of 27 with an A1C of 12+ I was accepted to the DCCT and within 3 years I had a 6.5 pound baby girl. Diabetes is a disease that you can live with and does not have to control your life. Don't let it – diabetes does not define you, you are more than a disease. Jamestown, TN

FEATURED RESULTS OF DCCT/EDIC: 2013 – 2023

The results of the DCCT/EDIC Study have made a dramatic impact on the understanding and care of type 1 diabetes world-wide.

The summaries that follow represent a sample of important findings published by the DCCT/EDIC Research Group during the period 2013 – 2023.

CARDIOVASCULAR



Risk Factors for Cardiovascular Disease

Cardiovascular disease is a primary cause of mortality in type 1 diabetes. In the DCCT/EDIC, age and average HbA1c over time are the strongest predictors of cardiovascular disease (CVD) in type 1 diabetes. This article describes other factors that are associated with a lower risk of CVD. Normal blood pressure and lipid levels (cholesterol, triglycerides, HDL, LDL), and use of ACE inhibitor medications (prescribed for blood pressure control and protection of kidneys from diabetes) were the factors identified as reducing the risk for developing heart disease.

Risk Factors for First and Subsequent Cardiovascular Diabetes Events

The study aimed to better understand the risk factors contributing to the first and to subsequent cardiovas-

cular events. Age, followed by higher HbA1c levels (measure of glucose control) over time were identified as the two strongest risk factors for all CVD events. For the first CVD event, age and glucose control as measured by HbA1c, were the most important risk factors. Similarly, the risk factors associated with subsequent CVD events included age and level of glucose control, along with previous occurrence of any CVD event. While age, duration of diabetes and family history of CVD are not modifiable (cannot be changed) risk factors, factors such as blood glucose, blood pressure and lipid control, and smoking are modifiable factors (can be changed). Bottom line: efforts to achieve optimal control of glycemia, blood pressure and lipid levels are important to reduce the risk of the first and subsequent CVD events.



PARTICIPANT REFLECTIONS

So proud, so appreciative to be involved in extraordinary research driving knowledge and improved diabetes care. Trumbull, CT

EYES

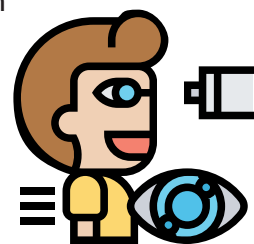


Evidence-Based Recommendations for Frequency of Retinopathy Screening

Diabetic retinopathy is the most common cause of blindness in the US and Canada. The current eye recommendations advise people with type 1 diabetes to be screened annually for diabetic retinopathy starting 3-5 years after diagnosis of diabetes. Using the photographs from the DCCT/EDIC over the past 30+ years, the DCCT/EDIC study developed more efficient, evidence-based retinopathy screening schedule guidelines. The recommendation models from this paper encourage health care providers to establish individualized schedules for retinopathy screening based on the person's current state of retinopathy and HbA1c. Ultimately, this approach would reduce the frequency of eye examinations without delaying the diagnosis of diabetes-related clinically significant eye disease.

Intensive Diabetes Therapy and Ocular Surgery

The DCCT/EDIC study showed that better blood glucose control early in the course of type 1 diabetes reduces not only the occurrence of earlier stages of eye disease, but also the need for eye surgery, such as LASER treatment, vitrectomy (procedure to remove fluid from the eye that is filled with blood due to retinopathy), cataract extraction and others. These results reinforce the importance of controlling blood glucose as close to the non-diabetic range as is safely possible, and that tight control should begin as early as possible after type 1 diabetes diagnosis. This study also highlights that improved glucose control reduces the future burden and costs of ocular surgery in people with type 1 diabetes.



PARTICIPANT REFLECTIONS

I feel so lucky to have been randomized early in my diagnosis. I have benefited from the cutting-edge results. And, although my A1C isn't perfect, my understanding of diabetes management is huge due to my involvement. Leveraging a team approach and multiple techniques, including a blood sugar alert dog, I've maintained excellent health for over 30 years with type 1! Seattle, WA

Answering the ad my Mom saw for DCCT was the best decision I made. It is a blessing to have been provided the opportunity to be a part of the study. Mentor, OH

COGNITION



Cognitive testing was initially included in the DCCT to evaluate the impact of diabetes treatment and frequent hypoglycemia (low blood glucose) on an individual's ability to process and remember information. At the end of the DCCT, we learned that cognitive function was not affected by randomization to either treatment group or by the number of severe episodes of hypoglycemia requiring the assistance of another person. At EDIC year 12 (2005), cognitive testing was repeated to understand the longer-term impact of glucose control and severe hypoglycemia on brain health. While there was no evidence of a significant decline in cognitive function related to DCCT treatment group assignment or the frequency or severity of hypoglycemia, it appeared that better glucose control showed some subtle long-term benefits on cognitive ability. We also found that tests that measure how the brain processes and uses information quickly and efficiently



were more sensitive to the effects of blood glucose control. Cognitive testing was repeated during EDIC years 25-26 (2017-2019), and we learned that the change in cognition was greater than seen in previous years of the DCCT/EDIC testing, but not different between the DCCT treatment groups. However, some change was expected due to aging. The most significant decline was found on tests that required flexible thinking and rapid responding, while smaller declines were seen in measures of immediate and delayed memory. More changes were seen among those who were older. Higher HbA1c, higher blood pressure and a history of severe/frequent episodes of hypoglycemia were associated with greater changes in cognitive function over time. The results continue to emphasize the importance of striving to improve overall blood glucose control, controlling blood pressure and reducing the frequency and severity of hypoglycemia.

PARTICIPANT REFLECTIONS

I am so proud to continue in the DCCT/EDIC for the last four decades. It is the reason I have been able to live a very good life and to provide the opportunity for all people with diabetes to do the same. Dallas, TX

I am grateful for the advances we have accomplished in the last 40 years! The staff has cared for me like I was family. I'm grateful specifically for my long-time DCCT/EDIC doctor. Haines City, FL

This study has meant more to me than I can put into words. I am proud to say I am a part of it. Thank you to everyone that has been involved in this program over the years. Newark, DE

GLYCEMIC CONTROL



Equivalence of Age and Duration of Diabetes to Glycemic Control Relative to the Risk of Complications

Hyperglycemia (high blood glucose), age, and longer duration of T1D are major risk factors for diabetes-related complications and mortality among individuals with T1D. This paper describes the impact of glucose control compared to the effects of additional years of age and duration of diabetes on the risk of diabetes-related complications and mortality. Using statistical methods, the authors quantified or measured the risk associated with higher glucose levels (as measured by HbA1c) on diabetes complications that was equivalent to the risk of added years of age or duration of T1D. For example, the risk of any cardiovascular disease associated with a 1-percentage point increase in HbA1c (i.e., from 7% to 8% i.e., or from 53 mmol/ml to 64 mmol/mol) was similar to the risk associated with an additional 4.3 years of age or with an additional 5.6 years of T1D. For mortality, a 1-per-

centage point increase in HbA1c resulted in the same increase in risk as an increase of 12.9 years of age. These analyses may provide individuals with T1D and the medical community with a useful way to better understand risk and consider methods to reduce this risk.

Risk of Severe Hypoglycemia over 30 years

During the DCCT, randomization to intensive diabetes therapy helped participants achieve a mean HbA1c of ~7% (53 mmol./mol). However, intensive therapy was also associated with a three times higher rate of severe hypoglycemia (defined as hypoglycemia requiring assistance from another person) compared to those randomized to conventional diabetes therapy. After ~30 years of follow-up, approximately half of all DCCT/EDIC participants have reported at least one episode of severe hypoglycemia that required assistance. During EDIC, rates of severe hypoglycemia were similar between the former DCCT intensive treatment group and the former conventional treat-

continued >

PARTICIPANT REFLECTIONS

DCCT/EDIC has had a profound impact on my life. I have received excellent care, developed lifelong friendships and learned a tremendous amount about diabetes and my own health status. Without this study, the odds of me being alive at this stage would be slim. I am as healthy or healthier than most of my age group. Thank you to all for everything you have done for me personally and for people with diabetes around the world. Mercer Island, WA

ment group. The most powerful predictor of severe hypoglycemia was having experienced a previous episode of severe hypoglycemia. Additionally, those participants who entered into the DCCT study as adolescents regardless of the treatment group had increased risk of severe hypoglycemia compared to those who entered as adults. Participants who use insulin pumps experienced a lower risk of severe hypoglycemia. Overall, severe hypoglycemia remains a challenge for individuals with type 1 diabetes across their life span.

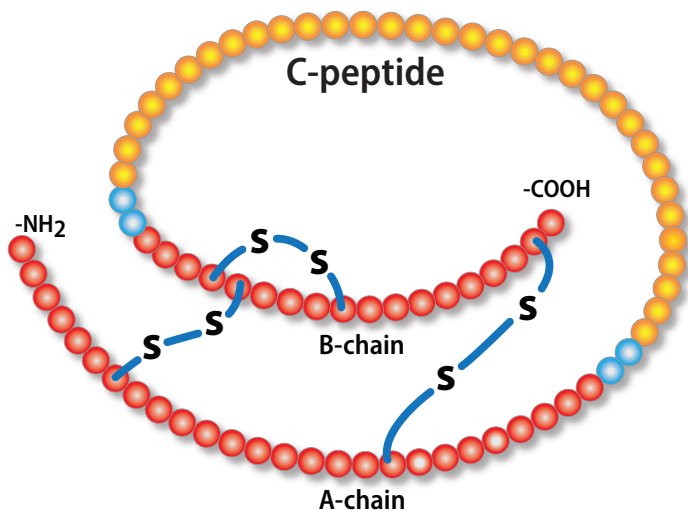
Residual β -cell Function Associates with Reduced Incidence of Hypoglycemia

In most individuals with type 1 diabetes (T1D), the ability of the beta (β) cells in the pancreas to secrete insulin declines as the duration of diabetes increases. Yet, it has been shown that continued insulin secretion (referred to as “residual insulin secretion” or “residual β -cell function”), can be detected in some individuals despite long duration of diabetes by measuring circulating C-peptide levels in the blood after a standard meal test. In this DCCT/EDIC study, we found that 12.4% of DCCT/EDIC participants, with an average of 35 years of T1D, were still producing some insulin (“C-peptide responders”). Among these C-peptide responders, there was a lower history of any

severe hypoglycemia (low blood glucose) and there were clinically meaningful reductions in the frequency of severe hypoglycemia when compared to those that did not continue to secrete some insulin. This study also found that continued β -cell function over 35-years was associated with factors that occurred early in the course of T1D, such as lower HbA1c, lower daily insulin dose and higher C-peptide level at the start of the DCCT. Further study is needed to better understand what occurs in the body and if that information can help identify future treatments to preserve the body’s ability to continue to make some insulin over time.

Oral Health

Periodontitis (a chronic inflammation of the gums and supporting structure of the teeth) is one of the main causes of tooth loss in adults. People with diabetes are at higher risk for periodontitis and tooth loss than people without diabetes, but few studies have looked at type 1 diabetes specifically. The purpose of this study was to understand the relationship between tooth loss and other diabetes related factors, such as HbA1c and diabetes-related complications. Based on annual responses to questions related to tooth loss (including unexpected tooth loss and/or dental extractions) reported between 2015 and 2019, 17% of participants (165 people) reported 221 tooth loss events. Those that experienced tooth loss were more likely to have diabetic peripheral neuropathy while those with controlled cholesterol levels had a lower risk of tooth loss events. This study also confirmed the well-established association between tobacco use and tooth loss. These findings suggest that some other diabetes-related complications may be directly associated with unexpected tooth loss and/or dental extractions and underscore the importance of preventive lifestyle and medical interventions to reduce oral health risks.



PARTICIPANT REFLECTIONS

The dedicated researchers have extended the lives of so many! I am grateful for 38 years of quality of life. Special Thanks to the amazing staff at my center. New Smyrna Beach, FL

DCCT/EDIC is the extended family you look forward to seeing. I am healthy today because of the knowledge gained and occasional nudges and encouragement from the staff. YAY! Queens, NY

HEARING



Hearing Impairment

Previous studies have suggested that individuals with diabetes have greater hearing loss than individuals without diabetes of similar age and gender; however these studies have not distinguished between individuals with type 1 and 2 diabetes. Using the data from the audiogram (hearing test) and information obtained from the questionnaires completed by participants, the EDIC Hearing study demonstrated that individuals with type 1 diabetes are NOT at an increased risk of hearing impairment compared to individuals without type 1 diabetes. Among those with diabetes, this study also showed that higher values of HbA1c over time were associated with hearing impairment. This article stresses the importance of controlling blood glucose as close to the non-diabetic range as is safely possible.

KIDNEYS



Risk Factors for Kidney Disease

Diabetic kidney disease is the leading cause of end-stage renal disease in North America and is defined by the development of albuminuria (protein in the urine) or by a decrease in the rate the kidneys filter blood, known as glomerular filtration rate (GFR). This DCCT/EDIC study identified risk factors associated with progression to advanced stages of kidney disease. Long-term higher glycemic (glucose) control was most strongly associated with the development of more advanced kidney disease, specifically macroalbuminuria (increased amounts of protein in the urine) and reduced GFR (filtration by the kidney). Higher triglyceride levels and higher blood pressure also increased risk of these more advanced stages of kidney damage. These results support the importance of glycemic control in reducing the occurrence and progression of advanced stage diabetes-related complications.

MORTALITY

Mortality in the DCCT/EDIC Versus the General Population

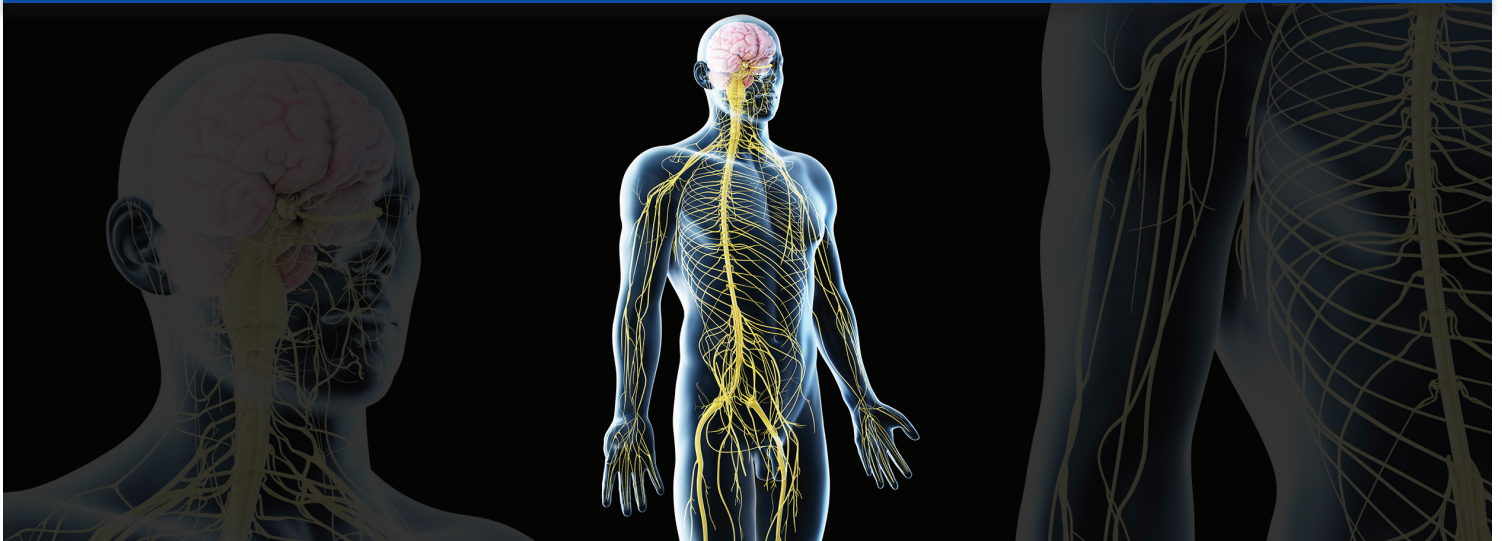
Historically, mortality in type 1 diabetes has been greater than in those without diabetes. In the DCCT/EDIC, overall mortality was similar to the general

population. Intensive treatment was associated with a slightly lower mortality rate. Factors associated with higher mortality rates were higher average HbA1c levels, more so among women than men, and especially when the average HbA1c over time was above 9%.

PARTICIPANT REFLECTIONS

Being in the DCCT/EDIC has given me the opportunity to see my children grow up and be successful, as well as doing the same for untold numbers of people with type 1 diabetes. Boston, MA

NERVES



Risk Factors for Diabetic Peripheral Neuropathy and Cardiovascular Autonomic Neuropathy

DCCT/EDIC has showed that intensive glucose control lowered the risk of developing diabetic peripheral neuropathy (DPN) and cardiovascular autonomic neuropathy (CAN). During DCCT/EDIC, 33% of participants developed DPN and 44% developed CAN. For DPN, higher mean HbA1c was the most impactful risk factor, followed by older age, longer duration of T1D, being taller, having macroalbuminuria (increased urine protein), having a higher mean pulse rate, using beta blockers (certain blood pressure medications), and having sustained albuminuria (continued increased levels of urine protein). For CAN, the most impactful risk factor was older age, followed by having a higher mean HbA1c, followed by sustained albuminuria, longer duration of T1D, higher mean pulse rate, higher mean systolic blood pressure, using beta blockers, having an estimated glomerular filtration rate (eGFR) <60 mL/min/1.73 m², and cigarette smoking.



Risk of Foot Ulcer and Lower-Extremity Amputation

People with diabetes are more likely to develop foot ulcers than people without diabetes, and diabetic foot ulcers (DFU) are the main cause of lower extremity amputations (e.g., toes, feet). Hyperglycemia (high blood glucose) has been shown to increase the risk of developing complications of diabetes, but it is unknown whether intensive glucose control lowers the risk of DFU and lower extremity amputations. This study investigated whether there were differences in DFU and lower extremity amputation outcomes between participants who were randomized to intensive versus conventional diabetes treatment during the DCCT, as well as the associated risk factors. Over 23 years in EDIC, 195 participants developed at least one DFU and 36 amputations occurred. We found that intensive glycemic control was associated with a significant risk reduction for DFU, while having retinopathy and higher HbA1c was associated with higher risk of both DFU and lower extremity amputation. These results support the importance of maintaining glucose control closer to the non-diabetic range in reducing DFU and lower extremity amputations.

PARTICIPANT REFLECTIONS

I am proud that because of this study, people with type 1 diabetes can now avoid many of its complications and lead long, fulfilling lives while waiting for a cure. St. Charles, MO

PHYSICAL FUNCTION / FRAILITY



Musculoskeletal Complications

Cheiroarthropathy is a condition of thickened skin and limited joint mobility, with common signs and symptoms that include decreased mobility in the shoulders (including “frozen shoulder”) and fingers, trigger finger and contractures in the palm of the hand. These problems have generally received less attention in the medical community, compared to other complications of diabetes (e.g., complications of the eyes, kidneys, nerves, and heart). The EDIC study showed that cheiroarthropathy is common in people with type 1 diabetes and was associated with age, sex, diabetes duration, advanced glycation end-products, neuropathy and retinopathy (nerve and eye disease related to diabetes). This article stresses the need for routine screening and discussion between individuals with diabetes and their health care providers to promote early identification and treatment of cheiroarthropathy to reduce pain and functional disability.

Physical Function and Frailty

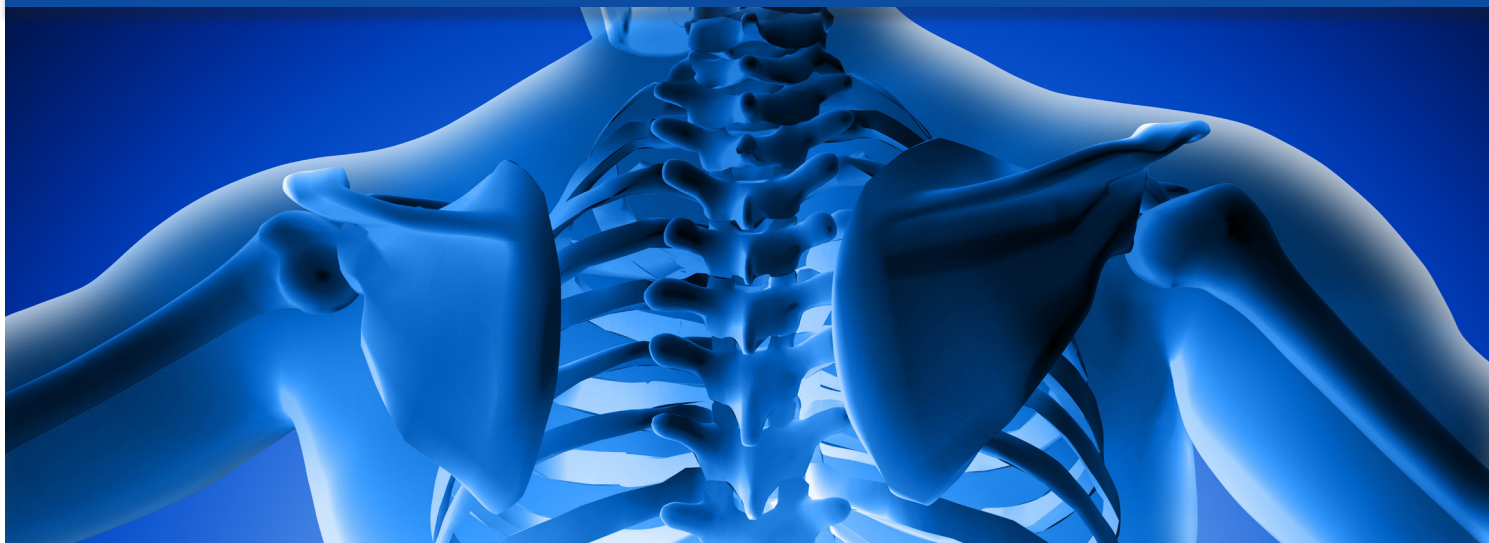
The ability to perform certain physical activities is expected to change with age. It may be harder to climb stairs, lift or move heavier objects, and even walking speed can start to slow. Some people may

have difficulty with routine activities, like getting dressed, preparing meals, or managing their money. While age-related changes in physical function are not unique to diabetes, we wanted to better understand the impact of type 1 diabetes on measures of physical function. EDIC participants were asked to balance with their feet in different positions, to get up from a chair without using their arms, and to walk a short way down the hall while being timed. Grip strength and shoulder flexibility were also measured, and questionnaires were used to better understand if people were having trouble doing their regular daily activities. We found that about 1 in 5 people with type 1 diabetes had some trouble with physical function (based on balance, walking speed, and chair stands), compared to about 1 in 14 people of a similar age but without diabetes. Overall, about half of EDIC participants reported some limitations in day to day functioning. People who had higher HbA1c values over time (since the start of the DCCT), who had higher body mass indexes (BMI, a marker of weight), people who had higher levels of psychological distress (including depression) and people with cardiac autonomic neuropathy were the most likely to experience reduced physical functioning.

PARTICIPANT REFLECTIONS

*I am thankful to the DCCT/EDIC for the opportunity to be my best medically, physically and mentally.
Canmore, Alberta, CAN*

SKELETAL HEALTH



Risk Factors for Lower Bone Mineral Density

With older age, the risk of a fracture increases. The consequences of a fracture vary widely but hip fracture in particular can be debilitating. Some reports have found that half of older adults who have had a hip fracture are no longer able to live independently. Type 1 diabetes increases the risk of hip and other fractures, and type 1 diabetes is also associated with lower bone density which contributes to fracture risk. However, little has been known about why bone density is lower. The purpose of the EDIC Skeletal Health

study was to identify diabetes-related factors, such as glycemic control and complications that contribute to lower bone density. Three factors were consistently associated with lower bone density: higher average HbA1c over time, reduced kidney function, and higher levels of advanced glycation end products (AGE). AGEs are molecules that form naturally in the body from a reaction between sugar and protein. They are thought to contribute to diabetes-related complications by altering the elasticity of blood vessels. Maintaining target glycemic control is one way to reduce AGE levels.

SPECIAL THANKS



We are grateful for the participation of several spouses, family members and friends of DCCT/EDIC participants who participated as control subjects without diabetes in the EDIC Hearing, Skeletal Health and Brain MRI studies. These studies would not have been possible without their enthusiasm and support!

PARTICIPANT REFLECTIONS

DCCT/EDIC has been life-changing for all those with type 1 diabetes. It has improved our ability to manage this disease every day and over the long-term, and I'm proud and grateful to have participated. Scarsdale, NY

DCCT/EDIC AT 30 YEARS (2013)

Since 1983, over 369 academic manuscripts have been published in scientific and medical professional journals.

In 2014, in recognition of the 30th anniversary of DCCT/EDIC, the American Diabetes Association published a special edition dedicated to this study in the Diabetes Care Journal. The articles included are listed below.

The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications study at 30 years: Overview. Diabetes Care 2014, 37(1):9-16. PMC3867999.

Diabetic retinopathy and other ocular findings in the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications [DCCT/EDIC] study. Diabetes Care 2014, 37(1):17-23. PMC3867989.

Renal disease and related findings in the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) study. Diabetes Care 2014, 37(1):24-30. PMC3867994.

Neuropathy and related findings in the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) study. Diabetes Care 2014, 37(1):31-38. PMC3868000.

Update on cardiovascular outcomes at 30 years of the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications study. Diabetes Care 2014, 37(1):39-43. PMC3868002.

The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications study at 30 years: Summary and future directions. Diabetes Care 2014, 37(1):44-49. PMC3867991.

continued >



PARTICIPANT REFLECTIONS

The study was a lifesaver when I was young and uninsured, and again later when I switched to tight control due to its findings. I've made friends with many staff members and look forward to seeing them every year and catching up. Lake Tapps, WA



PUBLICATION UPDATE: 2013 – 2023

Approximately 140 manuscripts have been published to date during the past 10 years. A partial listing of DCCT/EDIC published manuscripts during this period follows.



BRAIN / COGNITION

Brain structure among middle-aged and older adults with longstanding type 1 diabetes in the DCCT/EDIC study. Diabetes Care 2022, 45(8):1779-87. PMC9346989.

Cognitive performance declines in older adults with type 1 diabetes: results from 32 years of follow-up in the DCCT and EDIC study. Lancet Diabetes Endocrinol 2021, 9(7):436-45. PMC8583716.



CARDIOVASCULAR

Cardiometabolic risk factors and incident cardiovascular disease events in women vs. men with type 1 diabetes. JAMA Netw Open 2022, 5(9):e2230710. PMC9459657.

Utility of using electrocardiogram measures of heart rate variability as a measure of cardiovascular autonomic neuropathy in type 1 diabetes patients. J Diabetes Investig 2022, 13(1):125-33. PMC8756321.

Coronary artery disease events and carotid intima-media thickness (IMT) in type 1 diabetes. J Am Heart Assoc 2021, 10(24):e022922. PMC9075257.

Associations of microvascular complications with the risk of cardiovascular disease in type 1 diabetes. Diabetes Care 2021, 44(7):1499-1505. PMC8323173.

Risk factors for longitudinal resting heart rate and its associations with cardiovascular outcomes in the DCCT/EDIC study. Diabetes Care 2021, 44(5):1125-32. PMC8132325.

PARTICIPANT REFLECTIONS

I thank the staff of NIDDK and EDIC and all wonderful personnel who over the past 40 years have done so much to help me understand my diabetes and its complications. Because of these studies and knowledge, we have been given a longer and happier life. May God bless all who participated in this study. Lynden, WA

What I think of when I think of the 40 years of DCCT/EDIC is the impact each individual has had on this study. Each person is a gift. Rochester, MN

Risk factors for first and subsequent CVD events in type 1 diabetes: the DCCT/EDIC study. Diabetes Care 2020, 43(4):867-74. PMC7085803.

The association of coronary artery calcification with subsequent incidence of cardiovascular disease in type 1 diabetes: the DCCT/EDIC trials. JACC Cardiovasc Imaging 2019, 12(7 Pt 2):1341-49. PMC6612565.

Impact of excessive weight gain on cardiovascular outcomes in type 1 diabetes: results from the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) study. Diabetes Care 2017, 40(12):1756-62. PMC5711332.

Association of cardiovascular risk factors and myocardial fibrosis with early cardiac dysfunction in type 1 diabetes: the DCCT/EDIC study. Diabetes Care 2017, 40(3):405-11. PMC5319473.

Cardiovascular autonomic neuropathy and cardiovascular outcomes in the DCCT/EDIC study. Diabetes Care 2017, 40(1):94-100. PMC5180458.

Co-progression of cardiovascular risk factors in type 1 diabetes during 30 years of follow-up in the DCCT/EDIC study. Diabetes Care 2016, 39(9):1621-30. PMC5001148.

Risk factors for cardiovascular disease in type 1 diabetes. Diabetes 2016, 65(5):1370-9. PMC4839209.

Intensive diabetes treatment and cardiovascular outcomes in type 1 diabetes: the DCCT/EDIC study 30-year follow-up. Diabetes Care 2016, 39(5):686-93. PMC4839174.



DIABETES TREATMENT

Continuous glucose monitoring in adults with type 1 diabetes with 35 years duration from the DCCT/EDIC study. Diabetes Care 2022, 45(3):659-65. PMC8918229.

The beneficial effects of earlier versus later implementation of intensive therapy in type 1 diabetes. Diabetes Care 2021, 44(1):2225-30.



ECONOMIC

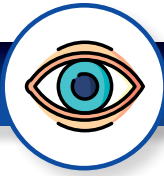
The 30-year cost-effectiveness of alternative strategies to achieve excellent glycemic control in type 1 diabetes: an economic simulation modeled by the results of the DCCT/EDIC. J Diabetes Complications 2018, 32(10):934-39. PMC6481926.

What are the clinical, quality-of-life, and cost consequences of 30 years of excellent vs. poor glycemic control in type 1 diabetes? J Diabetes Complications 2018, 32(10):911-15. PMC6459401.

PARTICIPANT REFLECTIONS

I feel the DCCT/EDIC made a giant leap into managing type 1 diabetes and preventing complications. I'm grateful as a volunteer to help people better manage T1D. Austin, TX

DCCT / EDIC and me. How I love the A1C! I was the president of the Saul Genuth Fan Club! I am the president of the David Nathan Fan Club! Free club, no membership fee, join me. Wear the eyebrows! Avon, OH



EYES

Retinopathy during the first 5 years of type 1 diabetes and subsequent risk of advanced retinopathy. Diabetes Care 2022, 45(12):2943-49. PMC10090905.

Screening eye exams in youth with type 1 diabetes under 18 years of age: once may be enough? Pediatr Diabetes 2019, 20(6):743-49. PMC7217664.

Risk factors for retinopathy in type 1 diabetes: the DCCT/EDIC study. Diabetes Care 2019, 42(5):875-82. PMC6489114.

Frequency of evidence-based screening for retinopathy in type 1 diabetes. N Engl J Med 2017, 376(16):1507-16. PMC5557280.

Effects of prior intensive insulin therapy and risk factors on patient-reported visual function outcomes in the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) cohort. JAMA Ophthalmol 2015, 134(2):137-45. PMC4825807.

Effect of intensive diabetes therapy on the progression of diabetes retinopathy in patients with type 1 diabetes: 18 years of follow-up in the DCCT/EDIC. Diabetes 2015, 64(2):631-42. PMC4303965



GLYCEMIC CONTROL

Relationships between the cumulative incidences of long-term complications in type 1 diabetes: the DCCT/EDIC study. Diabetes Care 2022, 46(2):361-68. PMC9887612.

Weight gain trajectories and obesity rates in intensive and conventional treatments of type 1 diabetes from the DCCT compared with a control population without diabetes. Diabet Med 2022, 39(5):e14794. PMC9144023.

Type 1 diabetes and oral health: findings from the EDIC study. J Diabetes Complications 2022, 36(4):108120. PMC9241440.

Understanding metabolic memory: the prolonged influence of glycemia during the Diabetes Control and Complications Trial (DCCT) on future risks of complications during the study of the Epidemiology of Diabetes Interventions and Complications (EDIC). Diabetes Care 2021, 44(10):2216-24. PMC8929187.

An observational study of the equivalence of age and duration of diabetes to glycemic control relative to the risk of complications in the combined cohorts of the DCCT/EDIC study. Diabetes Care 2020, 43(10):2478-84. PMC7510046.

PARTICIPANT REFLECTIONS

The DCCT/EDIC study has been a great study. We now have pumps, continuous glucose monitoring and lead a much more normal life. I don't have to worry about low sugars because the pump will alarm and I know 30 minutes before an extremely low sugar or an extremely high sugar. I've met a lot of wonderful people over the almost 40 years of the study. Tallahassee, FL



HEARING

Risk factors for hearing impairment in type 1 diabetes. Endocr Pract 2019, 25(12):1243-54. PMC7217092.

Hearing impairment and type 1 diabetes in the DCCT/EDIC cohort. Diabetes Care 2018, 41(12):2495-2501. PMC6245203.



KIDNEYS

Optimal frequency of urinary albumin screening in type 1 diabetes. Diabetes Care 2022, 45(12):2943-49. PMC9763027.

Early trajectory of estimated glomerular filtration rate and long-term advanced kidney and cardiovascular complications in type 1 diabetes. Diabetes Care 2022, 45(3):585-93. PMC8918200.

Risk factors for kidney disease in type 1 diabetes. Diabetes Care 2019, 42(5):883-90. PMC6489116.

Intensive diabetes therapy and ocular surgery in type 1 diabetes. N Engl J Med 2015, 372(18):1722-33. PMC4465212.

Renal outcomes in patients with type 1 diabetes and macroalbuminuria. J Am Soc Nephrol 2014, 25(10):2342-50. PMC4178441.

Effect of intensive diabetes treatment on albuminuria in type 1 diabetes: long-term follow-up of the Diabetes Control and Complications Trial and Epidemiology of Diabetes Interventions and Complications study. Lancet Diabetes Endocrinol 2014, 2(10):793-800. PMC4215637.



MORTALITY

Association between 7 years of intensive treatment of type 1 diabetes and long-term mortality. JAMA 2015, 313(1):45-53. PMC4306335.

Mortality in type 1 diabetes in the DCCT/EDIC versus the general population. Diabetes Care 2016, 39(8):1378-83. PMC4955932.

PARTICIPANT REFLECTIONS

Being a part of the study has been truly a Godsend! I was a single mom of two grade schoolers, working full time, always exhausted and totally not in control of my diabetes. The study changed and saved my life! I am now an active, pretty healthy nearly 75 year old. I am forever grateful to everyone in the DCCT/EDIC group. Thank You! Minneapolis, MN



NERVES

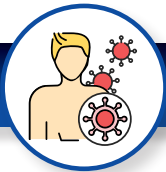
Risk of foot ulcer and lower-extremity amputation among participants in the DCCT/EDIC study. Diabetes Care 2022, 45(2):357-64. PMC8914413.

Risk factors for diabetic peripheral neuropathy and cardiovascular autonomic neuropathy in the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) study. Diabetes 2020, 69(5):1000-10. PMC7171957.

Delayed gastric emptying is associated with early and long-term hyperglycemia in type 1 diabetes mellitus. Gastroenterology 2015, 149(2):330-9. PMC4516593.

Risk of severe hypoglycemia in type 1 diabetes over 30 years of follow-up in the DCCT/EDIC study. Diabetes Care 2017, 40(8):1010-16. PMC5521975.

Association of glycemic variability in type 1 diabetes with progression of microvascular outcomes in the DCCT. Diabetes Care 2017, 40(6):777-83. PMC5439414.



OTHER AUTOIMMUNE DISEASES

Self-reported autoimmune disease by gender in the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) study. Diabetes Care 2014, 37(2):e28-29. PMC3898756



PHYSICAL FUNCTION

Physical function in middle-aged and older adults with type 1 diabetes: long-term follow-up of the DCCT/EDIC study. Diabetes Care 2022, 45(9):2037-45. PMC9472495.

Musculoskeletal complications in type 1 diabetes. Diabetes Care 2014, 37(7):1863-9. PMC4067398.



QUALITY OF RESEARCH DATA

Quality control measures over 30 years in a multicenter clinical study: results from The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) study. PLoS One 2015, 10(11):e0141286. PMC4631458.

PARTICIPANT REFLECTIONS

DCCT/EDIC has been a lifetime learning experience. As the world has become technology savvy so have our diabetes care and resources. However, the connection to the DCCT/EDIC community has been a true support for me. Garfield, NJ



SEXUAL FUNCTION & BLADDER HEALTH

Longitudinal patterns of urinary incontinence and associated predictors in women with type 1 diabetes. Neurourol Urodyn 2022, 41(1):323-31. PMC8738144

Diabetic peripheral neuropathy and urological complications in type 1 diabetes: findings from the EDIC study. Diabetes Care 2021, 45(1):119-26. PMC8753757.

Risk factors for orgasmic and concomitant erectile dysfunction in men with type 1 diabetes: a cross-sectional study. Int J Impot Res 2021, 33(1):59-66. PMC7483362.

Blood pressure, anti-hypertensive medication use, and risk of erectile dysfunction in men with type 1 diabetes. J Hypertens, 2019, 37(5):1070-76. PMC7223638.

Burden of urological complications in men and women with longstanding type 1 diabetes mellitus in the DCCT/EDIC cohort. Diabetes Care 2018, 41(10):2170-77. PMC6150428.

Longitudinal patterns of emergence and remission of erectile dysfunction in men with type 1 diabetes. J Sex Med 2017, 14(10):1187-94. PMC5624836.

Cardiovascular autonomic neuropathy, sexual dysfunction, and urinary incontinence in women with type 1 diabetes. Diabetes Care 2016, 39(9):1587-93. PMC5001143.

Glycemic control and risk of incident urinary incontinence in women with type 1 diabetes: results from the DCCT/EDIC study. Diabet Med 2016, 33(11):1528-35. PMC5045319.

Glycemic control and urinary tract infections in women with type 1 diabetes: results from the DCCT/EDIC. J Urol 2016, 196(4):1129-35. PMC5025347.

Effect of glycemic treatment and microvascular complications on menopause in women with type 1 diabetes in the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) cohort. Diabetes Care 2014, 37(3):701-708. PMC3931380.



SKELETAL HEALTH

Risk factors for lower bone mineral density in older adults with type 1 diabetes: a cross-sectional study. Lancet Diabetes Endocrinol 2022, 10(7):509-518.



A FULL LISTING OF DCCT/EDIC PUBLICATIONS CAN BE FOUND AT THE LINKS BELOW:

DCCT/EDIC Website:

<https://edic.bsc.gwu.edu/publications>

Google Scholar DCCT/EDIC page:

<https://scholar.google.com/citations?user=fEcOxwUAAAAJ&hl=en>

THE STORY CONTINUES...

DCCT/EDIC STUDY VISITS: 2023 – 2027



DCCT/EDIC OVER TIME: PARTICIPANT CHARACTERISTICS & FOLLOW-UP

AS THE YEARS HAVE GONE BY, THE PARTICIPANTS ARE OLDER, HAVE LONGER DURATION OF DIABETES, AND CONTINUE TO PARTICIPATE IN THE DCCT/EDIC.

	DCCT 1983-1993	EDIC 1994-Present	
	Baseline	1994	2023
Total participants (% participating)	1441	1375 (96%)	1045 (89%)
Male vs female (%)	53 vs 47	52 vs 48	52 vs 48
Average age (min – max) years	27 (13-39)	35 (19-51)	64 (48-79)
Average T1D duration (min – max) years	6 (1-15)	14 (6-26)	42 (30-54)

CONTINUED PARTICIPATION DESPITE DISTANCE & RELOCATIONS

When participants entered the study, many but certainly not all, lived relatively closer to their DCCT clinic. Not surprisingly, over the 40 years participants have moved, sometimes requiring that they transfer from one DCCT/EDIC site to another one that is closer to their new home. For others, the moves have meant longer distances to travel to complete the study visits. Without this dedication, the study would not have survived to celebrate 40 years!

Participants now live across many regions in the US and Canada. In addition, several participants now live outside of the US or Canada yet continue to participate in the study at one of the 25 clinical centers in the US and 2 in Canada.

DCCT/EDIC CLINICAL CENTER AND PARTICIPANT LOCATIONS



Additional Participants
Located in:

- England
- France
- Israel
- New Zealand
- Saudi Arabia

- ★ Clinical Centers
- Participant Locations

*Approximate location of DCCT/EDIC participants using US zip codes and Canadian postal codes, as of 2023

WHAT HAS ~40 YEARS OF THE DCCT/EDIC MEANT TO THE PARTICIPANTS?

Each DCCT/EDIC participant has a unique and very personal perspective about how participation in the DCCT/EDIC has impacted them personally and influenced their lives. An invitation to share was extended to all study participants and over 220 responses from all areas were received. (Minor editing was necessary for some of the submissions due to space constraints.)

PARTICIPANT REFLECTIONS

The DCCT/EDIC taught me to accept my life with diabetes. Through participation, I embarked on a lifelong journey of discovery of health, instead of succumbing to potential sickness. I am forever grateful. Westfield, NJ

Being a participant in the DCCT/EDIC for 37 years has been life-changing. The study has educated me on blood sugar levels, food intake, exercise and the effects they have on my body. Boston MA

At my last visit with my cardiologist, he said, "Getting involved in DCCT and EDIC are probably the smartest things you ever did for your health. I don't know many others your age with type 1 who are as knowledgeable and active as you!" Philadelphia, PA

I learned that diabetes does not control me, or my life. But sometimes, I can use some help. I got a lifetime vial from DCCT/EDIC! Santa Monica, CA

In the 45 years since my diagnosis, I've watched with awe the advances being made in the treatment of diabetes. If my participation in DCCT/EDIC has helped, then I'm grateful and proud! Philadelphia, PA

The EDIC study has been a wonderful experience. I feel as though I have been on the cutting edge of new treatments and innovations in the treatment of diabetes. I have met super people in this study and have been blessed to be part of this study. Oaklyn, NJ



PARTICIPANT REFLECTIONS

Participating in this study has been amazing, interesting, empowering and a privilege. Amazing and interesting because of the information learned to better understand this disease and improve the care of so many people, which can result in a positive prognosis. It is empowering to think that I could give back to humanity in such an important role. It has been a great privilege to know so many wonderful and caring nurses and doctors who display such grace and passion with their patients. Brimfield, OH

My participation in the DCCT/EDIC study has allowed me not only frontline education and research, but has also made me strive to keep myself in good physical and emotional health. Staff was always very supportive and helpful. Henderson, NV

EDIC is a wonderful continuation of my experience with the DCCT. The nurses and doctors associated with the study have always been the backbone of these studies and remain so for me today - always there to encourage and assist whenever they can. My heartfelt thanks to all of them not only for the care they provide for me but for the work they are doing to help fight this disease through their research. Clayton, GA



The DCCT kept me informed on advancements in diabetes care. I have received testing in four DCCT clinic locations. No matter the location, the DCCT staff has been OUTSTANDING! Medford, NJ

Being in the DCCT/EDICT has enabled me to live my life as a "normal person". Many people are not even aware that I have diabetes. Thanks to the STUDY, I will turn 70 this year. I am enjoying time with grandkids, kids, husband, family and friends and traveling overseas to enjoy the culture of other countries. Thanks DCCT/EDIC for a wonderful, fulfilling life. Dale City, VA

DCCT/EDIC has been a game changer. With round the clock insulin pump and CGM, I can travel anywhere. Plano, TX

PARTICIPANT REFLECTIONS

It is an honor and privilege to be part of this comprehensive study. It has provided me the health information I needed over the past 38 years that kept me in control and free of complications. Thank you to all the doctors, nurse educators and techs that provide such excellent and professional service. Lewis, DE

I remember two pre-study interviews with Dr. Genuth. He was very serious. Clearly one of the best decisions I have ever made was signing on the dotted line. Thank you! Cleveland Heights, OH

I have been in the study since the very beginning and hope that with each participant they will come closer to a cure to diabetes. The research team has been professional and helpful in my needs and care. Thank you. Lacey, WA

I am certainly convinced that significant and meaningful work has been done, and I'm sure my health and that of many others, now and in the future, has benefited almost immeasurably from this work. Well done! Belleville, IL

I volunteered for a diabetes study and got a lifetime of friends who share the latest research. It's great. Reminderville, OH

Over 37 years in DCCT/EDIC (starting age 13), I have most appreciated the relationships with staff who have become genuine friends and who have taught me much about T1D! Monroe, NC

I started the study at one DCCT center and during EDIC, I was pleased to learn I could continue with it at another DCCT/EDIC center. My father had type 1 DM and ANYTHING I can contribute to foster better understanding and management of this dreadful disease, I am happy to do. Heartfelt thanks to ALL the teams of this study. Lutz, FL

I thank God for the DCCT/EDIC studies. I owe quality of life and good health to all the staff at my center. Hermitage, TN



PARTICIPANT REFLECTIONS

I read an article about the DCCT study, then applied and was accepted on my son's birthday. I have thoroughly enjoyed meeting all of the doctors, nurses and other participants in the study. The testing and evaluations have given me very rewarding knowledge about diabetes. I look forward to keeping in touch with all of the awesome people I have met. Thank you so much for this excellent opportunity. Big Lake, AK



DCCT/EDIC has been a great family member to me. I know there is always someone I can contact for support if I need someone to vent my diabetes frustration to. I know I am not fighting this "diabetes battle" alone. Thank you DCCT/EDIC for being a positive family member for me. London, ONT, CAN

My mother cut out this small newspaper ad that asked for participants in a new diabetes study. I scheduled my visit and remember how concentrated the tests were but glad knowing we would know if anything was wrong. There was an issue with my eyes. I entered the DCCT in 1984. I can sum up my tenure in the DCCT/EDIC - it made me a much healthier person. I am so grateful I, thanks to my mom, had the opportunity to be in the study. Murfreesboro, TN

I appreciate everything the study has taught me and all the wonderful testing that has been provided in the study. I'm thankful for the continued funding support we receive in this long-term study. I am thankful for all the work the study staff have done. Fayetteville, AR

I was diagnosed in 1987 at age 26 with type 1 diabetes and was advised of the DCCT immediately. I knew nothing about diabetes. I have learned so much and been able to keep my A1C often below 7%. I am truly thankful for all that I have and continue to learn – and for all the suggestions and knowledge provided to me. Maple Ridge, BC, CAN

I feel so fortunate to have been a part of the study. I learned more from the staff and doctors over the years than I could have any other way. I'm glad I was selected. Sammamish, WA

Every day I am grateful that I saw the advertisement for the DCCT study. Anderson, SC

PARTICIPANT REFLECTIONS

The most important outcome for me was proving that good control of my blood sugars meant less complications. This was my first question for my Endocrinologist when diagnosed with diabetes. Fergus, ONT, CAN

The knowledge I have gained has enriched my life and the lives of other diabetics around me as I share the same! St. Louis, MO

For the last 35 years, the DCCT/EDIC has improved my quality of life by giving me access to testing and better healthcare. I'd like to give a special thanks to my coordinator. Whitehouse, TX

The DCCT/EDIC study has saved my life and has given me the knowledge and understanding to live my life to the fullest possible extent. I trust the coordinator to give me straight answers based on her 37 years of helping me be the best diabetic I can be! Granite Bay, CA

Forty years ago I received a tremendous gift by being selected to join the DCCT. I didn't realize what a humongous life changing experience it would be. Lutz, FL

DCCT/EDIC has been a lifesaver for me. My life would have not been the same if I hadn't been accepted to take part in this great study. I'm healthier and happier than I would have expected 40 years ago. Thank you for saving my life. Lakewood Ranch, FL

Being accepted into the study turned out to be one of the best things I did in my life. It helped me see how important taking care of myself is and I have no major issues with my diabetes. The great people I have met are still my friends. I'm so proud to be a part of medical history. Butler, PA

I'm ALIVE thanks to DCCT, 'fer sher'. And EDIC has absolutely cemented my cognizance of all things T1D forever. Lakewood, OH



PARTICIPANT REFLECTIONS

Getting involved in DCCT/EDIC has been one of the most important decisions in my life. I do not believe I would still be alive without the care and support that I have received from the outstanding doctors and nurses over all these years. Thank you, thank you! Naples, FL

Being part of DCCT and EDIC changed my life. Early awareness of tight control and personal care from field leaders. Appreciate being part of game-changing research. Thank you all! Seattle, WA



A DCCT/EDIC HAIKU: Forty years of blood-letting, probing, pumping—and a low A1C! Cody, WY

Because of the DCCT/EDIC studies, I have learned to live my life as normal as anyone could possibly hope for with T1D. These studies have saved my life! Modesto, CA

From the first human insulin trials and the DCCT/EDIC study, they've left me more intelligent and healthier. Thank you all. Ely, MN

I wouldn't trade my life for one without diabetes. It's part of who I am and I've been able to give back and show others that life can be well lived with diabetes. Bozeman, MT

I am proud to have been a part of an amazing study that has improved the lives of so many who live with diabetes. I have had the pleasure of working with amazing personnel whom have become trusted friends and I am grateful for them all. Lynwood, WA

38 years ago, I was randomized into the DCCT as a 15-year-old girl. The DCCT shaped how I would learn to care for myself and my diabetes. The DCCT/EDIC truly changed my life! Boston, MA

I truly believe that getting into DCCT/EDIC saved my life. The study has provided many updates regarding my health. The ability to contact a professional with questions is invaluable. Leesburg, FL

PARTICIPANT REFLECTIONS

*It's a remarkable project and experience. Congratulations and thanks for the hard work.
London, ONT, CAN*

DCCT/EDIC has taught me so much about type 1 diabetes. All the people involved have taught me how good healthcare can be if everyone cared as much. Most importantly without DCCT/EDIC, I'd likely be dead, so thank you! Seattle, WA

As a newly diagnosed diabetic, I was excited to join the DCCT and then EDIC studies to learn how to better control my diabetes. The talented team of diabetes health care specialists I met along the way have truly changed my life. I am forever grateful for their dedication to improving our health. Thanks for an amazing forty years! Alexandria, VA

I want to thank the DCCT/EDIC for the advancements in diabetes and for my continued health. The many professionals I have worked with over the years have helped me with continued good health. Mt. Lebanon, PA

DCCT/EDIC has been life-giving for me. I learned strategies that allowed me to live a healthy fulfilled life-celebrating birthdays, loving my family and 54 years with my soulmate. Ashland, MO

I feel extremely fortunate to be a participant in the EDIC study. Not only has it given me an opportunity to make a meaningful contribution to diabetes research, but the care, support, and wisdom of the EDIC team help me navigate the challenges of living with type 1 diabetes. Many thanks! Hubbardsville, NY

1983, the year I graduated from high school! It's not always easy or comfortable, but we did it! We've shown the world tight control matters, saves bodily damage, and is possible. Tight control/tight team members/long happy lives - Teamwork! A little cheesy – but sincere. Thank you all! It DOES take a village (sometimes happy, sad, tearful, scared, confused village people) – but a village bonded together for success. Florence, AL



PARTICIPANT REFLECTIONS

I feel so fortunate to have been part of this DCCT/EDIC research. The benefits of being in this study have been so valuable to me as a diabetic - as well as the friendships I have made. Thanks to all who have kept this research going for 40 years! Williamsport, PA



To participate in the DCCT/EDIC has been life changing for me. I learned so much and feel that the study has contributed to my well-being. I am lucky and thankful! Livonia, MI

I have been in the EDIC/DCCT study since the start. I have learned a lot about having type 1 diabetes and understand more about diabetes. Along with the knowledge, I'm being cared for by the very best. Thanks to everyone who participates. Lakeland, FL

When I joined the DCCT, I believed in the strategy the doctors and nurses were trying to figure out - if keeping diabetes under control would eventually lead to fewer or no complications and to a better life for all diabetics around the world. Thank you to everyone involved. London, ONT, CAN

I was incredibly lucky to become a part of the study within one year of being diagnosed with type 1 diabetes. Using the pump has made such a huge difference! I will always be thankful for my DCCT-EDIC 'family' - the coordinators and physicians!! Sanford, FL

I am glad to be a part of the EDIC study over the years. Knowing that by me being part of all of the different research done has helped 100% of people. Tuscumbia, AL

I feel so privileged to be part of this life-saving study! And THANK YOU to all the dedicated medical professionals who have given so much to help guide our way! Sleepy Hollow, NY

I am proud to have been the first DCCT/EDIC volunteer at my center. The skill and dedication of the doctors, nurses, and staff is awe inspiring, and the study has overwhelmingly improved my- and my family's life. Nashville, TN

PARTICIPANT REFLECTIONS

The DCCT/EDIC study has been a great experience. Living with T1D for 53 years, being part of this study has benefited me and millions of T1D's around the world. T1D care has dramatically changed over time and a big part of these changes is because of this study. Thanks to all the study staff for their outstanding commitment to improving life for those with T1D. The progress of research is amazing. Toronto, ONT, CAN

It's a win:win - determining the best diabetes care for all through research, and helping me manage my own. Simcoe, ONT, CAN

I was randomized in March of 1987 at age 31, remember being excited, but I did not know how significant it would be. It saved my life. I had no clear idea of the impact of diabetes and the potential hazards. The DCCT/EDIC taught me how to use the equipment, anticipate highs and lows, and everything else. The staff was/is tremendous - they cared, helped and listened. When EDIC started, the doctors I saw were not familiar with the DCCT results. At times, I felt like I had to train my doctors! Despite moving away, I insisted on returning each year to my clinic. The people are that good. THANK YOU! Galt, CA

I really appreciate the DCCT/EDIC study. This study has helped me understand how to best control and manage my blood sugar levels. Thank you to the staff for your support and sharing the information of control & complication findings. The progress is a big help for future diabetes. Sachse, TX

What a privilege it is to be part of DCCT/EDIC Study. Thank you to the nurses, doctors, and staff, for your support throughout the study helping us live normal lives. West Plains, MO

When I tell medical people or others with type 1 diabetes that I am a participant in the DCCT/EDIC study, the reaction I get is like I am a celebrity. Boston, MA



PARTICIPANT REFLECTIONS

I am so grateful to the DCCT/EDIC study. I came from a family of four children: 3 of us have diabetes. I am the only surviving sibling with diabetes. This would have never happened without the many benefits and education I received from this amazing life changing study. Sandusky, OH

I have been in the DCCT/EDIC study since I was 16. I have grown up with most of the doctors and nurses here. A couple came to my wedding in 1991. It has been a pleasure being in the study. I have developed so many friends here. Federal Way, WA

DCCT/EDIC has meant: Gratitude in teaching me to maintain tighter blood sugar control; encouraged me to keep up the good fight in rough times; and blessings in knowing I'm helping future individuals with diabetes. Windsor, ONT, CAN



The DCCT/EDIC has been critical to my ability to lead an active life, travel the world, and succeed in a career of 40+ years. I owe my ability to go through life almost unimpeded by the deadly effects of type 1 diabetes to this fabulous team and the other DCCT/EDIC participants. Thank you all from the bottom of my heart. Here's to 40 more highly successful years! Boston, MA

My DCCT/EDIC journey started by replying to an ad in the Boston Globe. Who would imagine that simple action would result in belonging to a lifetime community of amazing people? I'm incredibly proud of what we've accomplished together. Boston, MA

The DCCT/EDIC study has saved my life. Without it I would be blind, on dialysis or dead by now. Katy, TX

The DCCT/EDIC has meant life! I have such gratitude for the dedication, knowledge & support gifted to me through this study. I feel honored to be part of this important work. Taylor, MI

PARTICIPANT REFLECTIONS

My family and I have been blessed! The study replaced my fear of diabetes and the possible complications with knowledge. I have a passion to encourage others with diabetes to follow their doctor's guidelines and live an abundant life! I am grateful to God. Kingston Springs, TN

Being in the study has allowed me to:

- *Keep control of the disease;*
- *Gain valuable education about my body and how diabetes affects it;*
- *Reduce long term complications from the diabetes;*
- *Help others in the world with diabetes.*

Monaca, PA

Because of the DCCT/EDIC staff knowledge and the study (and my Lord) I have made it to 73 years "old" and have no complications!! Iowa

The DCCT/EDIC study made me realize how serious diabetes is. The study encouraged me to focus on my treatment of diabetes in a very positive way. I shall always be grateful for joining the study. Tempe, AZ

I did not imagine how long my association with the DCCT was going to be, nor that the results would change the treatment for diabetes. I have done some wild things for research, usually committed to the gain of knowledge for the greater good. I have always felt I have gotten the best care possible, from the most kind and professional people.

Boston, MA

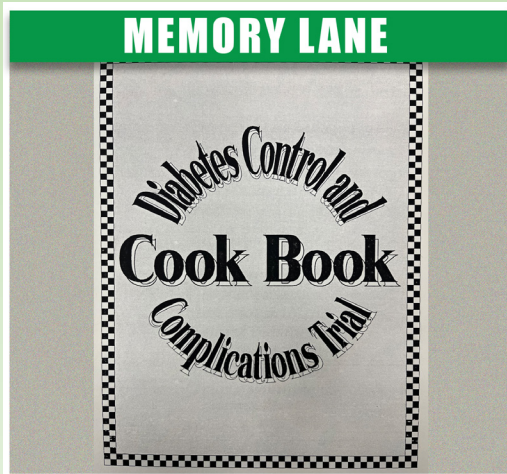
Learning about the DCCT was life changing. The study gave me an incredible knowledge about living with diabetes and I've shared my knowledge to maybe help someone else living with diabetes. After over 30 years of having diabetes I am now learning how to live with autonomic neuropathy. I am just trying to make the best of every day. Hope, ID

It felt rewarding to be proving what I felt was true - tight control is valuable. And what I hoped - that it is safe. And we're still learning! Hayward, CA



PARTICIPANT REFLECTIONS

I have had type 1 diabetes for nearly 40 years. I believe that I am alive today because of the education, guidance, support and care provided by the physicians, nurses and staff connected with DCCT/EDIC. Thank You! Ocean View, DE



*The DCCT/EDIC study is invaluable to me. I experience fabulous staff who patiently answer all my questions. Also, I like being part of history. Why would I ever quit?
Iowa*

*The DCCT program was life changing for me. I met some great friends and was connected to others with diabetes. It proved what I always believed - control eliminates complications. The DCCT/EDIC kept everybody connected and continues to keep us healthy with the tests and blood work. I owe my life to this study.
London, ONT, CAN*

I was one of the youngest nationwide when the study started. I have participated every year, testing and helping advance technology for those newly diagnosed. We have more understanding of how the disease affects our bodies and how we can manage the day-to-day high and low blood sugars and still live a "normal" life. Gainesville, MO

I want to thank all the people who have worked in the study. One of the first volunteers, I begged to get in! I feel it saved my life. Thank you all. Apache Junction, AZ

I feel so fortunate to be a DCCT/EDIC volunteer. Beyond the positive impact the study results has had on patient outcomes, the coordinator and other clinicians have always made me feel like their patient, not just a research participant. I have learned so much and participating in new tests to help answer more questions has been an important reminder and incredible motivator for me to follow best practices and beat the odds. Burlington, ONT, CAN

"DCCToday for a Better Tomorrow" is here now, for me, 40 years later. I have excellent health with absolutely NO diabetes side effects. I am grateful. Thank You. Boston, MA

This study is so important and has kept me on track for years. It saved my life with one of its tests that discovered an issue with my heart. THANK YOU!!! Portland, OR

PARTICIPANT REFLECTIONS

The DCCT/EDIC taught me to accept my life with diabetes. Through participation, I embarked on a lifelong journey of the discovery of my health, instead of succumbing to potential sickness. I am forever grateful. Westfield, NJ

Participation in the DCCT/EDIC was life-saving and hugely impactful. I obtained an in-depth understanding of the techniques and foundation needed to live well despite diabetes. I explored other techniques to live radiantly and build energy despite blood sugar challenges. I am extremely grateful for the dedication and tireless help of the team. Seattle, WA

This study has kept me alive and healthy for 35 years. The study allowed me to contribute to humanity and the welfare of many for which I am truly grateful and thankful. Gallatin, TN

Our family always says the DCCT saved my life. I was 13, taking 1 shot a day and strictly urine testing when I got randomized. DCCT changed EVERYTHING we knew about controlling diabetes and saved my life! Franklin, TN

When I walked into my first DCCT clinic, I never imagined, in a million years, that we'd change the world. Boston, MA

This is about 1/100,000th of what I'd like to write! To have an incredibly skilled team dedicated to our health for 40 years, with access to new technology and a wealth of experience, has been an unimaginable gift. Such appreciation to all of you. Niagara on the Lake, ONT, CAN

The key to ending diabetes is education. The DCCT and EDIC have been instrumental in teaching me wellness and managing a busy life having diabetes. Hire more diabetes educators globally. Stony Point, NY

My life was changed by DCCT/EDIC. Before I had minimal knowledge of treatments for type 1. I've gone from two shots a day and multiple BG tests to an insulin pump and CGM and thanks to all of you for your encouragement. Lansing, MI



PARTICIPANT REFLECTIONS

As the years go on, being part of this study has made me feel proud, fortunate and hopeful. My small part can make a difference in beating this disease. It has been an amazing trip with the best leaders in this field. Boston, MA



THANK YOU to the DCCT/EDIC staff and all volunteers who made this long-term commitment a reality. Without all of us, we'd very likely still be stuck with the 1-2 injections a day vs the tighter control we have now with the pump or MDI. CONGRATS TO ALL OF US!! Fort Eerie, ONT, CAN

Thankfully, DCCT/EDIC SAVED MY LIFE by training me to control my diabetes and the correct ways to do so! I feel extremely fortunate that I got in! Iowa

It is a lot more than being part of ground breaking, diabetes research and helping others with diabetes. It has been my pleasure to work with such loyal, dedicated researchers, who have provided and continue to provide advice, direction, support, and great preventive and predictive care. Thank You. MN

If it wasn't for the DCCT/EDIC study, for the care and education I received, I'd be dead. The free supplies were nice also. Seattle, WA

Type 1 diabetes @14 years old, from a small town. Struggled with control being a wild teen and no local endocrinologist. After being accepted into the DCCT, I was rewarded with quality health care. Transferred to another DCCT/EDIC for same quality care. 51 years with type 1 and still kicking. Thank You. Mossyrock, WA

I made the mistake of reading an old book in 1983 which talked about blindness starting 9 years after onset of type 1 diabetes. In February 2023, my eye doctor saw NO mild retinopathy after 40 years. I thank everyone in the DCCT/EDIC Study for amazing care. NC

DCCT-EDIC means the world to me. Life-saving study! Thank you to all!!! Monona, WI

PARTICIPANT REFLECTIONS

As a participant since '86 and now personally benefiting from some of the very same devices we helped test, it is very rewarding to see diabetes improvements both for the patients and caregivers. Minneapolis, MN

The DCCT changed my life and may have saved it! I was newly diagnosed at age 36 with no clue how to live with T1D. The constant oversight during the first 10 years and follow-up later were invaluable in helping me learn to stay healthy. The supporting professionals were fantastic and made life much easier. Thank you! Memphis, TN

I have learned that keeping very tight control of our blood sugar can prevent complications associated with type 1 diabetes. 1441 of us donated our time and efforts to answer important questions. No long term complications after 40 years. The study is very much worth the effort. Type 1 diabetes is a full time job, it's not going away, no cure in site, and it's complicated. It's up to me to take full control of my glucose control. Perfection is not possible. The effort is worth it. Fort Worth, TX

Being in the study has meant the world to me. I am so much more knowledgeable about diabetes and how to manage my disease. The study coordinators I have had the privilege to work with have become friends and a great source of knowledge. Always available to help me with any needs or questions. The entire study is first class. Lehigh Acres, FL

My Dad died of diabetes complications at 42. When I was diagnosed at 29, I thought that was my death sentence. Thanks to DCCT/EDIC, I'm still here at 65 and NO Complications! Round Rock, TX

Being part of DCCT/EDIC was the best thing that could have happened! I got so much out of it and I didn't do anything. The very best diabetes care and all you had to do was show up. I've had diabetes for 51 years, no complications and we have helped others with diabetes. The staff did all the work and became so friendly. All fond memories of being part of the study! I highly recommend being part of any medical study...you can add so much to others' lives. Thank you to all. Merrick, NY



PARTICIPANT REFLECTIONS

Being in the DCCT/EDIC has given me a chance to help others with diabetes while also helping myself. I have loved being a participant and have met some special people. Monroe, NC

I'm both grateful for and proud of being a DCCT/EDIC participant for all these years. I joined two years after my T1D diagnosis, at age 18. Participating in the study helped set me on a course for a happy, healthy life. Frederick, MD



The DCCT/EDIC has been truly life saving for me and my family. I have been educated on the importance of control and monitoring. I have been blessed with wonderful and supportive doctors, administrators and nurses. I will never be able to pay back what has been given to me. Nashville, TN

Being a participant in DCCT/EDIC has been life changing for me. My father and 3 of his 4 children had type 1. My father told his doctors that he would participate for any type 1 diabetes research. His volunteer attitude was instilled in us. I am committed to this study for the rest of my life or the end of this research. Thank you to all the staff who have and are taking this journey with us! Arden, NC

*LIFE CHANGER, LIFE GIVER. Thank you DCCT!
New Haven, CT*

Through the study, I receive beneficial medical test results and education that help me stay healthy. I work with nurses and doctors who care deeply about their patients. And, I rest well knowing that I am contributing to science. DCCT/EDIC is transformational to understanding diabetes and improving diabetic care! Here's to 40 more years! Chico, CA

What has the DCCT meant to me? Pretty much everything. Wendell, NC

Forty years ago, I was grateful just to have been selected to join this very special and dedicated group of elite skilled health care professionals called DCCT/EDIC. Thanks to all of them, the best is yet to come! Israel

PARTICIPANT REFLECTIONS

I am sincerely grateful for learning about DCCT shortly after I was diagnosed. I am certain I would not be complications free after 39 years with diabetes without the education and support of DCCT/EDIC staff. Thank you all. Escondido, CA

I am ecstatic the study results have provided a solid comprehensive foundation about the disease that is constantly with us, on our minds, 24/7. Management has progressed to closed-loop pump therapy, made possible, in part, because of the extraordinary commitment of NIDDK, participants and all the clinic staff. Because of the study, those newly diagnosed today can have significantly more confidence they can live longer, more productive lives, with less fear of debilitating complications. I am gratified with the progress towards that goal achieved to date, which I am confident will continue well after the study concludes. Lutherville, MD

The DCCT/EDIC is, without a doubt, the most important endeavor of my life! It has benefited not only me and my generation but also many generations to come. NY

I am so happy to have participated in the DCCT study. I have been under the guidance of some top level experts in endocrinology and at the cutting edge of diabetes care. Thanks can't express my gratitude. I'm still benefiting from this study. Special thanks to my study team who have been at my side for 40 years. Love you all. MN

Having been a DCCT participant since 1987, I have had the good fortune to receive multiple therapies at a far earlier time than if I had just been in the regular medical system, without all the exceptional screening this study has done. Hopefully our contributions as a group will continue to improve the lives of all with diabetes. Lasqueti Island, BC, CAN

I offer my thanks to the many for their skills and dedication. Ottawa, ONT, CAN

I have had tests and procedures that never would have happened!!! Very thorough and very thankful!! Leawood, KS



PARTICIPANT REFLECTIONS

Being in the study has given me the feeling of contributing to the new treatments for diabetes, and also contributing to finding a cure for diabetes. Holly Hill, SC

*By volunteering and being a small part of research that not only helped me personally, but will benefit others with diabetes in the future is awesome! Thank you, DCCT/EDIC!
Minneapolis, MN*

Being a participant in DCCT/EDIC helped me to stay current with improvements in therapy and medical technology. I appreciated the ongoing relationship with study coordinators and the contributions to science. Brooklyn, NY

As a 17-year-old kid, I raised my hand for the DCCT and changed my life forever. It's still hard to understand the impact on so many other lives! Boston, MA



Absolutely hated the mental tests, but 40 years later I have zero doubt about this trial being the only the reason I am still alive. Scottsdale, AZ

It has meant an extension to a productive, normal life. The oversight, accountability and support have been a gift from God. I am eternally grateful! Sun City, AZ

With many thanks to two clinical center teams plus the DCCT/EDIC teams we never see for your support and flexibility over the 40 years. Who would have known where this would and where it continues to take us. Kamloops, BC, CAN

My greatest achievement is helping the world to be a better place for countless people. Westminster, CA

The DCCT/EDIC study has basically meant Life or Death for me! I do not think I would be alive today without the study! I was a young kid who had no cares in the world until I became ill with diabetes! Thankfully I had a wonderful boss who knew of the study nearby and helped me get involved. Bonita Springs, FL

PARTICIPANT REFLECTIONS

Being part of DCCT/EDIC is the most meaningful thing I've done in my life! The study influenced two of my children to choose careers in medical fields. Thanks so much! Boston, MA

I admit I've always struggled with my diet and controlling my BS, but the EDIC team has always shown unconditional support and encouragement to help me reach my goals. I feel honored to be a part of this monumental study. Chesterfield, MO

My decision to get randomized into the DCCT was based solely on the fact that I wanted 2 injections of insulin/day. Little did I know how my entire life would change because of this landmark study. Thank you to my team! Seymour, CT

The first word that comes to mind is freedom. Freedom regarding the diet, monitoring of blood sugars, and learning about how my body reacts to diabetes. I have really enjoyed the knowledgeable staff, the information learned, and the new technology. I enjoy helping others gain knowledge by studying the different areas of the body that are affected by diabetes through this study. Florence, SC

It is hard to find the words to say what each of you have meant to me over the last 35 years! Your words of encouragement and correction have given me a good and healthy life! God blessed me with relationships with each of you, which are priceless! May we all continue to be for each other what you have been for me! Thank you and many blessings! Willmar, MN

When diagnosed in September 1983, my doctor told me that I should apply for disability and not expect to live beyond 30 years of age. A death sentence at age 24! I was randomized into DCCT in 1987. The amount of information gathered and shared with me has allowed me to learn much more than my non-diabetes doctors about my condition. The study has given me a suspended sentence instead of certain death. I believe all with T1 diabetes around the world have and are benefiting from the studies. I am extremely grateful and proud to be a participant. Thank you DCCT/EDIC. I am alive because of YOU! Pompano Beach, FL



PARTICIPANT REFLECTIONS

DCCT/EDIC has helped me and my endocrinologist manage my diabetes because of extensive testing and the result reports I receive. All of the tests performed and questions asked has added extra years to my life. The DCCT/EDIC staff have been wonderful, caring, and thorough and I always felt like I was seeing friends rather than medical staff. Thank you DCCT/EDIC. We all have a better life and more profound knowledge of this disease. Spokane, WA



Would not have taken as good of care of my type 1 diabetes without the education, testing, and moral support from the DCCT/EDIC research. An absolute joy to work with the DCCT/EDIC staff throughout those 40 years. Bremerton, WA

I was diagnosed in 1989 and enrolled immediately into DCCT at Vancouver General Hospital. I have learned how to control everything from my blood sugar to diet and exercise. All nurses, doctors, and staff have been exceptional in helping me manage my diabetes. Thank you. Maple Ridge, BC, CAN

I was fortunate to be in the DCCT. The care, concern, testing & supplies I received were amazing. The extraordinary doctors, nurses, coordinators, and attention to me made me feel so needed and appreciated. Upper Montclair, NJ

It's been an honor to be a part of this amazing research program. I have experienced compassion, dedication, and guidance to stay healthy and grow my family. Thank you. Cheyboygan, MI

Being able to participate meant healthy children and taking better care of myself from all the knowledge gained over the years. THANK YOU to ALL the nurses, doctors, techs, coordinators and everyone who participated, for making a healthy way of life possible! Port Hadlock, WA

Being a participant of the DCCT Study and then the EDIC Study since the beginning is most likely the reason I've made it to 70 years old. Still planning to be around for a while. Rogue River, OR

PARTICIPANT REFLECTIONS

Involvement in DCCT/EDIC has transformed my life with type 1 diabetes. I learned how to self-manage as a DCCT participant. I now have 44 years with type 1 and no complications, praise God! Arlington, TN

When diagnosed, I had visions of a shortened and probably physically challenging future. The knowledge and support I received from the DCCT/EDIC staff enabled me to live a full life, excel physically and do things I never thought I could do. The always smiling and helpful people I met along the way have made my participation an enjoyable, memorable and important part of my journey. I am so thankful for the medical advancements that have been made because of this program. Vancouver, BC, CAN

DCCT/EDIC saved my life. My family is a statistical nightmare for diabetes. I lost my dad, brother, 2 sisters, and a niece to diabetes complications. Because of DCCT/EDIC, I am 65 and going strong. My thanks to DCCT/EDIC and its precious staff. Oak Hill, FL

I love that the study is researching the long term effects of type 1 diabetes. I wish I could donate my body along with records to study when I am deceased. Buffalo, NY

Everyone shared welcoming smiles, wisdom, patience, and guidance that changed my entire outlook on self-care, thus avoiding life-limiting complications. I owe my present quality of life to the DCCT/EDIC team. Columbia, MO

Type 1-50 years! Thank you DCCT, EDIC, and my center's team for your educational & impactful dedication and support! Bradenton, FL

Being one of the youngest randomized into DCCT, I have been able to see first-hand what a true comparison of treatment can result in. I am so proud to see the study cited in package inserts in the A1C reagents that we use in the clinical lab that I currently manage. Newport, WA



PARTICIPANT REFLECTIONS

My connection with the DCCT 36 years ago was a life-changing encounter. At that time, my health was slowly suffering. The professionalism and expertise of the staff have been phenomenal and being on the cutting edge of diabetes care has been exciting and rewarding. The DCCT/EDIC staff have been partners on my journey with diabetes. I couldn't be more grateful. Cadillac, MI

Even in the standard group, I got excellent treatment and learned so much as a result. I am as proud of being in the study as I am of anything else I accomplished in my career. Minneapolis, MN



The DCCT/EDIC studies have changed so many things for the better for those with diabetes. These studies have made my medical care smoother, my life has become easier, and I am so glad I have been able to be a part of these studies. I cannot contain my praise because of all the changes that have come about. Tacoma, WA

*What does the DCCT/EDIC mean to me? It means . . .
... I am living longer and more educated than I could have ever imagined
... I am living a much happier life than I could have ever imagined
... I continue to dream about the future, and am grateful for every day. Cresco, PA*

The DCCT/EDIC study has given me a great sense of accomplishment and pride that I have contributed to the best health possible for future generations. Jacksonville, FL

I am grateful for EDIC/DCCT primarily for the relationships formed. In the middle of the DCCT, I was going to drop out. Under the guise of a medical lecture, my doctor drove to my hometown and brought me back into the fold. I will never forget his devotion to the research and his personal kindness to me. Hannibal, MO

I truly believe that this study gave me tools I'd have never known I needed. It helped me understand the whys. I was 13 when I joined, so I'm not sure I'd have understood the best ways to care for myself if I'd not joined. The study was a GAME CHANGER! Clover, SC



PARTICIPANT REFLECTIONS

My own physician at the time discouraged me from getting into the DCCT, but my mother stood behind me all the way. I know that I would not be where I am today without the best support, testing and up- to-date information, and we are able to help teach the medical field and others. I am proud to be a continuing contributor. My daughter now has type 1 diabetes and she is doing well because of this very study. Thank you for changing my outcome in life and carrying this legacy on. Erie, PA

DCCT/EDIC has saved my life! When I got into the study, my A1C was one of the worst. I was told at my first annual visit that had I not gotten in to this study, I would not have made it to the 1st annual visit!! There are no words to express my gratitude for being able to participate in this study! New Smyrna Beach, FL

As the wife of a DCCT/EDIC participant, I've watched from the outset as this extraordinary undertaking has changed what we know about and how we manage diabetes, and I've felt thankful to have cheered from the sidelines. Philadelphia, PA

40 years — it's like it was yesterday. When you mention an insulin pump, my first thought is 1985 and DCCT. Can't believe pump treatment all started due to this study and it is still going. Can't wait to see what the future treatment will be . . . or maybe we won't need to worry about how to treat. North Bethesda, MD

I'm so glad I was randomized into the DCCT! I know this is why I'm still solo hiking and backpacking with fairly few and mild complications. Prescott, AZ

Having the opportunity to be an actual "lab rat" has actually been a huge blessing! I truly am grateful for having all the care and attention from my team! Their attention to detail, concern for our/my wellbeing has been remarkable. When diagnosed at age 27, with three young kids and a wonderful wife, I prayed I'd live long enough to see them grow up and get married. I'm still kicking and enjoying our nine grandkids! God has blessed me with incredible care! Thank you so much for the great training, accountability and help over the years. Soli Deo Gloria. Spring Village, AR

DCCT/EDIC helped me learn control of diabetes. Because of amazing support, after 40 years I have no retinopathy, neuropathy or kidney disease. I can live my best life because of this great study! Alvarado, TX

Life saving!! Minneapolis, MN





PARTICIPANT REFLECTIONS

Being a part of the DCCT/EDIC study has meant improved health, access to treatments, enhanced decision-making, a new sense of hope living with diabetes, and a much better life. Bloomington, IL

Living with diabetes is not always fun, but it is definitely a blessing. I've been honoured to help make that blessing less "not fun" for those who follow. Whitby, ONT, CAN

DCCT and EDIC have given me the education and motivation to live with diabetes. Riverview, FL

The DCCT/EDIC study has been one of the best things ever to happen to me. Everyone that I've been connected with has become like part of my family. I feel eternally grateful and blessed to be a part of this amazing study! Iowa

The study may have been a research project but the discipline I learned as a participant have made my quality of life at my age to be far beyond what was expected when I was first diagnosed. The staff I have worked with over the years have been awesome and I feel they are friends. My thanks to all! Coquitlam, BC, CAN

I was diagnosed in 1975. My 50 year Lilly for Life anniversary is coming, thanks to the DCCT/EDIC. My goal is to walk a 10-K with the 'David Nathan fan club' wearing a Lilly for Life sweat suit, EDIC glow in the dark green shoes – you will spot us from the moon! Avon, Ohio

DCCT/EDIC were a lifesaver to me. Having type 1 diabetes, I can still do anything. I just need to plan ahead, be organized and take care of myself. Columbia, MO

THANK YOU ALL! You have probably kept me alive much longer than I should be. Iowa

My participation in the DCCT/EDIC has not only benefited me personally but has allowed me to give back to the whole diabetes community. I cherish the knowledge that I have gained and the relationships formed with the medical professionals who have made this research such a brilliant success. Plano, TX





PARTICIPANT REFLECTIONS

DCCT/EDIC has meant the world to me. The care from all the nurses and doctors has been amazing. I look forward to my visits when I meet everyone every year. From my first visit with an EKG with suction cup leads to being able to see the future of diabetes care firsthand has been an extraordinary ride. Thank you! Lynden, WA

It has been my pleasure to be associated with the top tier diabetes doctors and clinical nurse wizards in the whole of diabetes data collection and treatment. THANK YOU for teaching me how I can live strong and long through education and attention to my treatment. Granbury, TX

It's hard to believe 38 years have passed. I contribute my good health to being part of the project. The research team has always been there to answer questions, give advice, help with medical supplies and the annual gifts are not bad either. Borrego Springs, CA

Being in the DCCT/EDIC has empowered me to be part of the solution, not just the problem. Through my continued participation, I derive hope for the future and daily strength to keep up my efforts, founded on unwavering DCCT/EDIC team support of my diabetes care. Courtice, ONT, CAN

Through our collective efforts, we have shown the world that diabetes is something we can die with, not die of. It's entirely up to us. Cleveland, OH

Having type 1 is challenging. My pregnancies were difficult, but we did have a little girl named Emily. She is nearly 30. During that time, the DCCT staff would call me every day to get my sugars, tweak my insulin dosages and were a great support. All of the staff have been wonderful. I truly appreciate this study and what I have learned from it. Bentleyville, PA

Together the doctors, nurses and participants, we are changing the way our future generations will deal with this disease. My thanks go out to everyone who participates. Happy 40th! Lakeland, FL

One of my life achievements has been helping people with the same disease that I have through this study. I am very proud to have been chosen to participate. I am grateful for the study staff that has helped me control this horrible disease. Charleston, SC



PARTICIPANT REFLECTIONS

Being part of the study has been great! The commitment of the staff and participants all working towards the goal of helping those affected by T1D live as full a life as possible has been so appreciated. Seattle, WA

What a wonderful experience! Everyone's goal was to make me a healthier person. The team was always kind, thoughtful, knowledgeable and compassionate. It is an honor to participate in this groundbreaking study that has played an extremely important role in the education and treatment of diabetes . . . and it continues to be a large part of my support system. I am grateful and proud to be a part of this monumental study. I hope the study receives funding for many more years. Long Island, NY

My 38 years in the study has given me insight into the importance of glucose control. I have met a lot of great people and been able to help others. Dade City, FL

I joined the DCCT study 40 years ago and I'm proud that my small contribution has helped countless thousands of others. Congratulations to the world-class researchers on this historic anniversary. Boston, MA



*“We do not learn from experience . . .
we learn from reflecting on our experience.”*

– John Dewey

The NIDDK, DCCT/EDIC researchers and the entire diabetes community are indebted to the DCCT/EDIC participants for their enduring research partnership that continues to improve the lives and care of all people with type 1 diabetes.

Thank You

ACKNOWLEDGEMENTS



National Institute of
Diabetes and Digestive
and Kidney Diseases

The DCCT/EDIC has been supported by U01 Cooperative Agreement grants and contracts with the Division of Diabetes Endocrinology and Metabolic Diseases of the National Institute of Diabetes and Digestive and Kidney Diseases, and through support by the National Eye Institute, the National Institute of Neurologic Disorders and Stroke, the General Clinical Research Centers Program (1993- 2007), and the Clinical and Translational Science Center Program (2006-present), Bethesda, Maryland, USA. Trial Registration: www.clinicaltrials.gov; identifiers NCT00360815 and NCT00360893.

Supporting Contributors Over Time: The DCCT/EDIC study has been supported by several commercial entities that have provided free or discounted supplies or equipment for participant use. These include: Abbott Diabetes Care - Alameda, CA; Animas® Corporation - Westchester, PA; Bayer HealthCare LLC Diabetes Care, North America Headquarters - Tarrytown; NY Becton Dickinson and Company - Franklin Lakes, NJ; Dex4® (formerly CanAm) - Atlanta, GA; Eli Lilly and Company - Indianapolis, IN; Genentech - San Francisco, CA; Lifescan - Milpitas, CA; Medtronic MiniMed, Inc. - Minneapolis, MI; Omron Corporation - Shelton, CT; OmniPod® Insulin Management System - Bedford, MA; Roche Diabetes Care - Indianapolis, IN; Sanofi-Aventis U.S. LLC - Bridgewater, NJ. These commercial entities were not involved in the design or conduct of the DCCT/EDIC.

