



# The Diabetes Story: A Call to Action

## 2018 Presidential Address

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### A CALL TO ACTION

A presidential address of the American Diabetes Association (ADA) provides an opportunity to have a voice, the stage, and the pulpit, so to speak. For what purpose? To increase awareness and urgency around the crisis that diabetes poses to the individual and to the world. Each official outreach to the diabetes community as President of Medicine & Science presents an opportunity to tell an important story: the story of the magnitude of the diabetes crisis. In this address, I will provide the reader with important facts about the diabetes epidemic in hopes that you, each of you, will tell the story of diabetes early and often. I believe that tangible awareness of this crisis can change this story for the lives of people with diabetes and impact the global health and financial burden of diabetes.

### WHY STORYTELLING IS A TOOL TO AUGMENT DIABETES AWARENESS

Storytelling is a potent strategy for conveying both information and inspiration about a topic. By weaving together the individual reality and the global health burden of the inadequately addressed diabetes epidemic, we can frame the urgent and misunderstood diabetes epidemic as a story: a story that will create the impetus for action. In the next few sections, I will highlight the key elements of the 24/7/365 burden of diabetes on an individual and the unaddressed issues for people living with diabetes. Next, I will present the facts regarding the U.S. and global epidemic including the life span—and health span—shortening complications of diabetes. I will emphasize the unsustainable economic implications of 30 million in the U.S. and 425 million globally living with diabetes (1,2). Next, I will discuss the urgent need of a health care delivery system to address the life-threatening reality of lack of accessible health care and medications and the unaddressed reality of the psychosocial impact and stigma and consequences of diabetes on the individual and family. Further, I will outline the foundational role of research, from fundamental biology to effective implementation of all aspects of diabetes care, to meaningfully address the global diabetes crisis. I will close with a request that all of us in the field of diabetes know the numbers, tell the story, and inspire action to prevent and cure diabetes and to improve the lives of people affected by diabetes—each of us in our own way.

### THE INDIVIDUAL BURDEN OF DIABETES

One of the first steps in telling any good story is to get the audience's attention. What better way than the story of Annie, a young child living with type 1 diabetes. Annie's story is the story of the 24 h a day/7 days a week/365 days a year individual burden of diabetes. Annie's story is the story of loss of freedom of childhood and the need for determination and empowerment. Diagnosed at a young age, diabetes took over the lives of Annie and her family. She no longer had the freedom to simply play without concern about what her activity would do to her blood glucose. Some of the joys of childhood, such as playdates or sleepovers, caused trepidation and needed scrutiny, education, and planning. Annie's parents worked actively with her school to make sure that she could be safe. It is critical that each school provide a mechanism for any child with diabetes to be able to test blood glucose and eat as needed to maintain safe blood glucose levels. Children living with diabetes across our country have routinely been turned away from schools because their school or school system did not have the resources to provide a school nurse, for example. Over the past decades, the ADA has been fighting this battle for safety at school and advocating on behalf of children like

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Annie and their families to get access to expert medical care. One might expect in the wealthiest nation in the world that this kind of basic request would not be difficult to achieve, but that isn't the story—for Annie or for any child trying to manage diabetes while in school. It took determination for Annie to gain access to optimal care and a safe school setting. Still, for her lifetime, she will need to meet the financial challenge of supporting all aspects of her diabetes care.

We have not yet won this battle for people living with diabetes, but many advances are improving lives. One of the most encouraging aspects of Annie's story is that through access to expert health care and resources like ADA Diabetes Camps, she gained both empowerment and a sense of community—that she was not alone. At camp, she learned effective self-management (a skill for a lifetime) and, just as important, she met and supported others living with diabetes and got their support in return. Recently, Annie and her family have been offered further empowerment through technology with the use of continuous glucose monitoring. Now both Annie and her parents can be assured that her blood glucose is in a safe range. Annie is currently participating in a clinical research trial to see if the hybrid closed-loop insulin pump system is safe and effective for children. This is an exciting step forward, yet it is not a cure. Annie is facing another 70–80 years with diabetes and all the uncertainty that holds. We need a cure.

### THE REALITY OF DAILY LIFE WITH DIABETES

Once you, the storyteller, have your audience's attention, make it real. Every day, each choice related to food and physical activity can affect the blood glucose of people living with diabetes. For the majority of the 30 million people in the U.S., managing diabetes will last their entire lifetime. Every day. Every choice. What about the role of health care providers? If an individual with diabetes sees a health care provider for 1 h four times each year (which exceeds access provided in most health care systems), they would have spent 0.046% (4 h of 8,760 h per year) of their lives getting advice on diabetes management. The responsibility for managing

diabetes rests on the shoulders of the person with diabetes and their family. The reality is that the person living with diabetes struggles with daily decisions that will affect their blood glucose: when to test, when to eat, how much to eat, when to correct, whether it is safe to exercise, and even whether it is safe to go to sleep. These are just the immediate questions. There is an additional layer of responsibility that burdens the individual. What will happen if I don't control my blood glucose? Will I have a heart attack or stroke? Will I lose my eyesight or be on dialysis? What happens if I lose my insurance? What happens if I want to change my job? What will happen to my family? How do I cope with an incurable disease? Can't I just take a vacation from diabetes? Diabetes is all day, every day, for a lifetime.

### THE NUMBERS

Diabetes affects 1 in 11 people in the U.S., so most people will have some connection with diabetes (1,2). Individuals born in the U.S. in the year 2000 have a 1 in 3 chance of developing diabetes (3). Most diabetes in the U.S. and worldwide is type 2 diabetes. It is possible to delay or prevent type 2 diabetes—to decrease the burden of diabetes. Type 2 diabetes is very personal to me. My paternal grandfather died of diabetes before I was born. I had a child's vague idea that diabetes was serious, but I did not think about diabetes again until my father became ill with what turned out to be diabetes. In 1975, when my father was diagnosed, he was admitted to the hospital for a week of education with the whole family involved, which confirmed my impression that yes, diabetes is serious. In 2018, the diagnosis of diabetes is often made with little fanfare in the clinic setting and there is an appalling underutilization of education. To empower a lifetime with diabetes, affected individuals need a lifetime of support with education on diet, physical activity, medications, mental health, and prevention of complications. Diabetes is an expensive unpaid job without administrative support. The ADA and partner organizations can help people and their providers to find this support. Our failure in education and prevention is evident. According to Centers for Disease Control and Prevention statistics, in 1975, 4.79 million people in the U.S. had diabetes—a little over 2% of

the entire U.S. population (4). The increase from 2% to 9% in less than 50 years is unacceptable and represents a failure to focus on wellness and prevention.

There are deadly consequences to the diabetes epidemic. In 2003, my father suffered a major stroke, leaving him with a dense right hemiparesis; his life and the life of my mother were changed forever. Like Annie, he and my mother lived independently and courageously, continuing to engage most aspects of life: travel, family, and painting. Seven years later diabetes took my father's life with a second stroke. Diabetes is deadly. For this call to action, the take-home points from his story are that diabetes is a leading cause of death and a serious, costly, life-altering disability. The impact of a stroke, heart attack, amputation, heart failure, blindness, or kidney failure on everyday life is overwhelming. In the U.S. alone, there are 30 million diabetes stories.

### THE FINANCIAL IMPACT OF DIABETES

A total of 30.3 million people in the U.S. and ~425 million people globally live with diabetes (2). In the U.S., diabetes costs \$327 billion dollars: \$237 billion in direct health care costs and \$90 billion in loss of productivity (5) (Fig. 1). Put another way, 1 in 4 health care dollars is related to diabetes. No other disease with statistics and costs like these would be ignored. Considering these facts, it is reasonable to question why diabetes is not at the center of our health care agenda. For this segment of the



**Know the story -- tell the story  
WE CANNOT IGNORE THIS EPIDEMIC**

**Figure 1**—Talking points regarding the diabetes epidemic: 30.3 million people in the U.S. live with diabetes at an expense of 1 in 4 U.S. health care dollars, \$327 billion (\$237 billion direct and \$90 billion lost productivity) (4). For the 30.3 million people with diabetes, diabetes management is a full-time (24/7/365) burden for a lifetime (1,2).

discussion, I will focus on type 2 diabetes. Using just my own life timeline as an example, from 1975 when my father was diagnosed until today in 2018, the number of people with diabetes in the U.S. has increased from 4.79 million to 30.3 million (4).

This seemingly inexorable increase in diabetes was foreshadowed or at least accompanied by an increase in obesity and sedentary lifestyle. Diet and physical activity are modifiable risk factors for both the development of and the prevention of type 2 diabetes. The public perception of type 2 diabetes (even in the medical and political sectors) is that people with diabetes have caused their disease. The relationship between diet and physical activity and diabetes contributes to a stigma around diabetes. It is critical that we, as members of the diabetes workforce (army), be aware of this stigma when you tell the diabetes story—not just what diabetes is, but why it matters and the urgency of care.

### **MOVING FROM DIABETES STIGMA TO INSIGHT**

As a storyteller, two points can help your audience move from judgment to insight. First, the genetic predisposition to type 2 diabetes is robust and can lead to diabetes for people of all body types. Second, stigma and marginalization are barriers to effective prevention and care for anyone who has or is at risk for diabetes. For this second point, it is reasonable to raise the following question: “If your sibling informed you that they had an incurable disease that would shorten their life expectancy and possibly cause a heart attack, stroke, blindness, kidney failure, or amputation, would you chastise them or support them?” We, the dedicated workforce of the ADA, need to ask this question and start this discussion.

### **UNSUSTAINABLE HEALTH CARE BURDEN OF DIABETES**

The financial burden of diabetes is not only overwhelming for people living with diabetes, it is an unsustainable burden on the health care system nationally and globally. In addition, despite the investment of 1 in 4 health care dollars on diabetes in the U.S., we are not effectively treating or preventing this disease. Every 5 years, the ADA conducts a health care expenditure analysis for diabetes. Between the years of 2012 and 2017,

health care expenditures in the U.S. increased from \$245 billion to \$327 billion dollars (5). Diabetes is a public health crisis. It is fiscally irresponsible that diabetes and its delay or prevention is not at the center of the health care and research agenda. In addition, the increase in the number of people living with diabetes increases the number of people with complications of diabetes, which are both expensive and disabling. Graphs will show that we are decreasing the number of complications per 10,000 individuals living with diabetes. This is good news. However, because the number of people with diabetes is increasing so significantly, the total number of people with diabetes-related heart attack, stroke, blindness, kidney failure, depression, or heart failure continues to increase, nationally and globally. Frankly, these complications are expensive and not a good investment of health care dollars.

Educators have taught us that as storytellers our critical point should be introduced, expanded upon, and repeated. There are 30.3 million people with diabetes in the U.S. costing \$327 billion—that is 1 in 4 health care dollars (4,5)—and we are neither effectively preventing nor treating diabetes. We do not currently have a cure for diabetes or effective nationwide implementation of evidence-based interventions to prevent or delay diabetes.

### **IT STARTS WITH AWARENESS**

An epidemic of this proportion should not be able to sneak up on us, yet, quietly and exceeding all expectations, the number of people with diabetes has outstripped every prediction across the world. Greater than 30 million people in the U.S. live with diabetes, with another 84 million with prediabetes. Many are unaware of their risk or diagnosis. The ADA, in collaboration with many partners, is working on campaigns to increase recognition of the disease and its risk factors. Specifically, the ADA has a risk test available online (6). In addition to raising awareness of risk, the ADA is working with partners to increase the awareness of psychosocial barriers that disproportionately affect people with diabetes, limiting their ability to care for themselves and productively function in society. Further, advocacy efforts on behalf of people with and at risk for

diabetes highlight the need for access to care, affordable medications, and diabetes research. Awareness of the scope of the epidemic, financial and individual consequences, and the need for innovative solutions is a story worth telling. In your community and on Capitol Hill, we need to get the word out. Diabetes needs to be addressed with rigor similar to our nation’s approach to the opioid epidemic.

### **NEED TO DISCUSS DIABETES RESEARCH WITH THE PUBLIC**

Every year, the ADA publishes the “Standards of Medical Care in Diabetes.” The ADA Standards of Care, now a living document, informs people with diabetes, their providers, and health care systems of the optimal evidence-based strategies for the management and prevention of diabetes and its complications. These recommendations are based on research. We need effective, accessible ways to discuss research with the public at large without deafening the listener. Research seeks to understand the answers to important and unanswered questions. Here again storytelling is a useful strategy. The favorite story in diabetes research is the story of the discovery of insulin and its transformative impact. Why this story? It is simply a great story. Moving from the knowledge that there was a “factor” that lowered blood glucose to the discovery and extraction of insulin and its use in people in an incredibly short time frame is accessible science. Something was missing, it was identified, and it was replaced. To even the most uninterested listener, the discovery of insulin is understandable and transformative. As the ADA workforce invests in changing the diabetes landscape, we need to be comfortable with storytelling about research.

### **DIABETES RESEARCH INFORMS THE NEXT STEPS**

Research increases understanding of current unknowns. It builds upon fundamental knowledge garnered from previous research. What are the critical unknowns in diabetes? Unfortunately, the unanswered research questions in the field of diabetes are legion, as outlined in my adaptation of Maslow’s pyramid of self-actualization, known as Maslow’s Hierarchy of Needs (7) (Fig. 2). Maslow’s pyramid was designed to demonstrate

the critical components needed for psychological self-actualization, i.e., a fulfilling and satisfying life. It is my belief that the ultimate goal for the person living with diabetes is optimal diabetes self-management and excellent outcomes (until there is a cure). Achieving this goal for millions of people can only be addressed by research that addresses each of the current barriers to achieve this outcome. We have major gaps in fundamental and clinical knowledge and implementation strategies to reverse the diabetes epidemic. I use a modified version of Maslow's pyramid to illustrate urgent research questions that demand attention.

### LOOMING UNANSWERED QUESTIONS IN DIABETES RESEARCH

Our fundamental understanding of the pathophysiology of diabetes is incomplete. At this moment, we do not know precisely what causes type 1 diabetes or type 2 diabetes or whether these designations are even correct and useful. We do not know why diabetes leads to complications in some individuals and not in others. More fundamentally, we do not understand common and/or unique genetics, cell biology, and integrative physiology that contribute to diabetes risk and progression. Because of these unknowns, we do not know precisely who should get what intervention or medication for optimal benefit. Basic

diabetes research is imperative to fill these knowledge gaps.

### KNOWING VERSUS DOING RESEARCH GAPS

Huge and unappreciated is the gap between what we know and how we use that knowledge to improve the lives of people with diabetes (implementation science). A few examples:

- Once we have established an evidence-based treatment, we do not know the best strategy to implement that treatment or the optimal health care system for its implementation. This is true for specific medication decisions and across the health care system and the communities in which people with diabetes live.
- We do not understand optimal health care system design for access and affordability of chronic disease management that requires intensive self-management.
- We do not have the appropriate research base to understand how to effectively and efficiently support safety at school, in the workplace, or in prison.
- We do not have evidence to support interventions to effectively erase the social stigma associated with diabetes.
- We have strategies to address the mental health issues for people with diabetes. We now require evidence

that demonstrates the impact and cost-effectiveness of these interventions.

- We do not have strategies to implement established resources that can enhance both provider and person with diabetes self-efficacy.

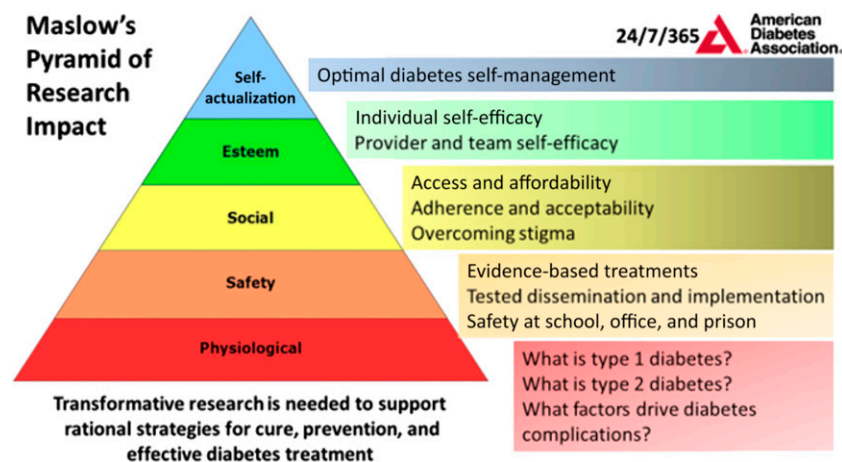
We need research to understand what the health care system would need to provide established efficacious interventions and innovative strategies to touch the daily lives of people living with diabetes. We need data that will enable us to move beyond health care systems and into the community. Investment is needed to address these important, urgent, and costly diabetes research questions (basic science to implementation).

### TRANSFORMATIONAL INVESTMENT LEADS TO TRANSFORMATIVE DISCOVERY

The relationship between research and the impact of research on individuals is difficult to communicate. Two stories come to mind. The first is Soviet cosmonaut Yuri Gagarin's trip into space. In the time of the Cold War, it was devastating to the U.S. not to achieve the first manned spaceflight. The Defense Advanced Research Projects Agency (DARPA) was created to make pivotal investments in breakthrough technologies for national security. DARPA explicitly reaches for transformational change instead of incremental advances (8). In addition to military advances and our space program, transformative research investment through DARPA led to the Internet and a multitude of other transformative technologies including biomedical research. The second tangible story of research to clinical impact is HIV-AIDS. Major investments in HIV-AIDS research led to transformative discoveries in fundamental science and to clinical interventions that have changed HIV-AIDS from a death sentence to a chronic disease. It is crucial to invest in transformative diabetes research to successfully stem this epidemic.

### THE INVESTMENT IN DIABETES RESEARCH NEEDS TO MATCH THE MAGNITUDE OF THE PROBLEM

The diabetes epidemic warrants transformative investment nationally and globally. In the U.S., the largest funding agency for biomedical research is the National Institutes of Health (NIH). Recently, a financial breakdown of the



**Figure 2**—Maslow's Pyramid of Research Impact. To illustrate the breadth of research gaps in diabetes and highlight the ultimate impact of effective research, a modified version of Maslow's Hierarchy of Needs is employed (7). Reaching the pinnacle of optimal diabetes prevention and treatment will require research from fundamental discovery to clinical implementation and population and community health. We currently have glaring knowledge gaps from the foundation to the peak of the hierarchy of needs. Major investments in transformative diabetes research are needed to close this gap and change the future.

NIH expenditure per disease indicated that NIH was investigating \$2,727 per individual affected by HIV-AIDS and \$38.60 per individual living with diabetes.

The discussion of the urgency of the need for transformative research in diabetes needs to be reframed. Once again, an effective storyteller will rely on the same facts: we are currently spending 1 in 4 health care dollars on the 30 million people in the U.S. with diabetes. Diabetes is an incurable disease that lasts a lifetime, with many disabling and life-shortening complications. It is critical to increase the investment by NIH in diabetes research and build the diabetes research workforce. To accomplish this objective, it is critical to mobilize a global innovative workforce to focus on the unanswered questions highlighted above. In the U.S. alone, \$90 billion annually is lost in productivity to the workforce. This unproductive spending warrants additional research investment beyond traditional research funding agencies. Transformative research funding is needed, both from NIH and from other public and private partners. Investment in research is the only strategy to prevent diabetes, treat diabetes effectively, and ultimately cure diabetes.

### A CALL TO ACTION

The mission of the ADA is to prevent and cure diabetes and improve the lives of all people affected by diabetes. Our vision is a life free of diabetes and all its burdens. We are fighting the good fight, and we are not there yet. We are the mission workforce that needs to be engaged to achieve this vision. What can you do? Know the facts. Tell the story. Change the world for people with and at risk for diabetes.

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