

Diabetes Advocacy Orgs: 2016 Milestones & 2017 Goals!

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HAPPY NEW YEAR 2017!

As there seems to be consensus that 2016 sucked in many ways, we're especially glad to greet a new year.

It's a tradition here at the 'Mine to essentially call the country's [top diabetes advocacy organizations](#) to the mat at the end of each year to explain what they've accomplished, and what they're aiming for in the new year ahead.

*So as always, we asked the pointed questions to **a dozen leading U.S. diabetes non-profits**: What did these groups actually achieve in 2016? And what do they plan to make happen in 2017?*

*Below are the answers we received from their various leaders and spokes-folks (in alphabetical order). Once again, there's a ton of **great info here about what's happening in the Diabetes World**, so we invite you to settle in with a cup of coffee for extended reading...*

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American Association of Diabetes Educators (AADE)

2016:

In 2016, we kicked off the first year of AADE's [2016-2018 Strategic Plan](#), which puts people with, at risk for and affected by diabetes at the center of all our work. Everything we've done and will continue to do is reflected in these strategies, from access to diabetes education initiatives to our work in diabetes prevention and new models of care.



Technology was a huge emphasis in 2016. To show our commitment to staying ahead of the curve, we hired AADE's first [Chief Technology and Innovation Officer](#), Crystal Broj. She has worked with AADE's Technology Workgroup – a mix of members and other experts from the Diabetes Online Community (DOC), related diabetes organizations and other stakeholders – to define the current state of technology from a diabetes education vantage point. Over the last year, and into the future, the group will provide technical assistance and input to identify technology trends, knowledge gaps and external healthcare forces relevant to diabetes education.

Preventing type 2 diabetes was also a big focus. We were thrilled in November when the Centers for Medicare and Medicaid Services (CMS) announced via the [2016 Physician Fee Schedule](#), that diabetes prevention education will become a reimbursable Medicare benefit in January 2018. We worked closely with our members to draft comments to CMS, advocating for evidence-based prevention services. The [AADE Diabetes Prevention Program \(DPP\)](#) has been [shown to be an effective tool](#) to stop or delay the onset of type 2 diabetes when administered through diabetes self-management education and support (DSMES) programs. Currently, more than 45 AADE DPP sites operate across the country, and we are working with diabetes educators and others to scale the program nationwide.

To continue to amplify the message that DSMES works, AADE, in coordination with the *American Journal of Managed Care*, published a [joint issue of Evidence-Based Diabetes Management](#), highlighting [DSMES as an effective self-management tool](#) that [saves health systems money](#).

To serve both diabetes educators and people affected by diabetes, we developed several new tip sheets in both [Spanish](#) and [English](#), focusing on [cardiovascular disease and diabetes, its related targets of care, how to prevent cardiovascular issues](#) and [questions people with diabetes can ask their diabetes care team](#); mental health issues like [diabetes distress, depression, stress](#) and [anger](#); and [glucose monitoring resources](#), from [insider tips](#) to [expert recommendations](#).

In August, we held the largest gathering of diabetes educators in the country at AADE16 in San Diego. Technology again played a major role, with many sessions focused on breaking developments like the Artificial Pancreas, digital health and the role social media plays in diabetes education. The DOC was integral to the success of the conference, including a special live broadcast of DSMA Live with Cherise Shockley.

On the advocacy side, 2016 saw unprecedented participation from AADE members and related healthcare organizations in trying to pass the [Access to Quality Diabetes Education Act H.R. 1726/S 1345](#). As we go into 2017, we are well positioned to move the bill through the next Congress.

2017:

Technology will remain at the forefront of AADE initiatives. The roadmap created by the AADE Technology Workgroup will continue to be developed, to apply clinical and consumer technologies within the [AADE Technology-Enabled Framework](#).

Speaking of roadmaps, stay tuned in 2017 for new diabetes language guidance for educators and other healthcare professionals.

The advocacy momentum we built in 2016 will continue in to the new year with an emphasis on Diabetes Action Plans (DAPs), biannual reports that provide a narrowly focused look highlighting the problems and costs associated with diabetes. For AADE members, these DAPs often represent the most comprehensive picture of diabetes in a particular state, and provide a two-year blueprint for states to define the scope of and treatment for diabetes. AADE continues to work with members to develop and expand state plans.

Building on the success of the 2016 AADE Annual Conference in San Diego, we will host more than 3,000 diabetes educators and related healthcare professionals in Indianapolis, IN, at [AADE17](#) – Friday, Aug. 4 to Monday, Aug. 7. Together we will work to drive change and innovation, with focuses on type 1 diabetes, new and developing technologies, prediabetes and diabetes prevention, and new models of care delivery and population health.

American Diabetes Association (ADA)

2016:

During its 76th year, the American Diabetes Association continued its commitment to its mission – to prevent and cure diabetes and to improve the lives of all people affected by

diabetes. We recognize the impact of diabetes on so many Americans and the increased need to support innovation and research advances that can lead to improved health outcomes and quality of life. 2016 highlights included:

- **Research Advances:**
 - The Association funded 31 post-doctoral fellowships and 57 research and development grants through our core research program, an overall funding success rate of 12.6 percent—the highest since 2012.
 - Association-supported researchers contributed to improved understanding of how diabetes develops and progresses, and helped identify new prospects for combating the disease and its complications.



- **Pathway to Stop Diabetes Research program:** We received more than 100 nominations for our fourth [Pathway to Stop Diabetes](#) awards program, which encourages promising young scientists to dedicate themselves to diabetes research. Up to six more awardees will be selected and named in January 2017 to join the 17 Pathway researchers currently being supported by multi-year grants.
- **76th Scientific Sessions:**
 - Our [Focus on Fellows program](#), held for early-career endocrinologists in conjunction with the 76th Scientific Sessions, increased in scope by 33% to 200 attendees. This program encourages top talent to focus on the clinical care of people with diabetes.
 - The [Diabetes is Primary](#) live presentation included 159 attendees and the resulting webcasts were viewed by more than 10,000 medical professionals around the world.
- **Insulin Affordability:** Our actions on insulin affordability, which included [a petition](#) that has garnered more than 150,000 signatures since Nov. 17, drew significant attention and will remain a priority into 2017. Through this patient advocacy initiative, the Association calls on all entities in the insulin supply chain to increase transparency and make insulin affordable for all who need it. We also ask Congress to hold hearings with all entities in the supply chain in order to shine light on the reason/s for the drastic increase in costs and to take action on behalf of people who need affordable access to this life-saving medication.
- **#ThisIsDiabetes:** Our annual American Diabetes Month engagement and awareness campaign launched with a new social media-based initiative, [This Is Diabetes](#), which ran throughout the entire month of November. It sought to showcase the scope and seriousness of diabetes through authentic personal stories, images and videos from people affected by the disease—which we augmented with professional videos, educational infographics and Facebook Live broadcasts featuring experts in health disparities, research and lifestyle management.
- **Prediabetes Awareness PSA Campaign with the Ad Council:** This first-of-its-kind campaign is a collaboration among the Association, the Centers for Disease Control and Prevention (CDC) and the American Medical Association (AMA). Targeted at the 86 million Americans with prediabetes, the PSAs were launched in January and began airing across the country in April. Through December 31, the campaign garnered more than \$30 million in donated media, and more than 318,000 risk tests have been completed on its website, [doihaveprediabetes.org](#)—helping our audience learn their risk for type 2 diabetes and take steps to prevent or delay it.
- **Medical Innovation Partnerships:** IBM/Watson Health—The Association began a long-term [partnership with IBM Watson Health](#), combining the clinical and research data of the Association with the powerful computing power of Watson to create a first-of-its-kind diabetes advisor to facilitate access to information for everyone in the diabetes community. The partnership will continue to seek ways to bring together the capacity of Watson, and the resources and experience of the Association.
- **Diabetes Dance Dare:** This social media-driven awareness campaign included notable celebrities Shaquille O’Neal, Usher, Kelly Clarkson, Lance Bass, Camila Cabello and Mark Cuban in the [#DiabetesDanceDare](#). The campaign generated more than 54,000 social media posts and more than 300 million social media impressions.
- **Capitol Hill Advocacy Day 2016/Team Tackle Launch:** 34 professional football players joined more than 75 diabetes advocates in Washington and held more than 125 meetings with members of Congress and their staff. Advocates urged members of Congress to continue to

fund diabetes research and programs, and the professional football players announced the new [Team Tackle](#) awareness initiative for diabetes and prediabetes.

2017:

In 2017, we will continue our dedication to research, support and education for all people with and affected by diabetes and the health professionals who help them manage their care. As the leading source of information about diabetes care and management, ADA is committed to ensuring that advances in care are available to people with diabetes and their health care providers.

The Association's Chief Scientific & Medical Officer Robert E. Ratner, MD, retired at the end of 2016 after nearly five years of stellar service, and we are proud to [welcome William T. Cefalu, MD](#), as his successor. Dr. Cefalu joins the Association on Feb. 20, 2017, from LSU's Pennington Biomedical Research Center in Baton Rouge with more than 30 years of work in diabetes research and care. We look forward to leveraging his expertise and perspective to help us strengthen and enhance the ADA's diverse programs and services for diabetes health care providers and people with diabetes.

ADA is also poised to fight for the advancements made by the Affordable Care Act, urging leaders to immediately follow any [repeal of the ACA](#) with a replacement that ensures vital health care coverage for people with diabetes, especially critical protections for pre-existing conditions, and affordable access to insulin and other diabetes medications.

CWD (Children with Diabetes)

2016:

During 2016, Children with Diabetes focused on delivering three conferences:



[Friends for Life Falls Church](#), with its proximity to Washington, DC, focused on advocacy. We partnered with the [Diabetes Patient Advocacy Coalition](#) and learned about how new devices reach patients from Stayce Beck, PhD, MPH, Branch Chief at the Diabetes Diagnostic Devices Branch at FDA; about the impact of competitive bidding on morbidity and mortality among people with diabetes by Gary Puckrein, PhD, president and CEO of the [National Minority Quality Forum](#); and heard from an esteemed panel about research and development in artificial pancreas technology.

[Friends for Life Orlando](#) hosted thousands for an incredible week that included concerts by country music stars [Eric Paslay](#), [Raelynn](#), and [George Canyon](#), all of whom live with type 1 diabetes; continued partnership with the [American Association of Diabetes Educators](#) to recognize FFL staff who have earned their CDE credentials; the first ever CWD Fellows Program, in partnership with AADE and AACE, to share "type 1 in the wild" with young health care professionals (MD, PhD, and BSN/RN) as they embark upon their careers; and the first ever Spanish Track, which offered Spanish-language programming for adults whose native language is Spanish -- in addition to our usual incredible faculty who deliver world-class education and support to our families. Through our partnerships with the American Diabetes Association, the DRIF, the JDRF, the College Diabetes Network, Beyond Type 1, and the Diabetes Hands Foundation, FFL families enjoyed one of the most amazing conferences we've ever held.

[Friends for Life Anaheim](#) drew hundreds to the Disneyland Hotel and included the team from Diabetes Patient Advocacy Coalition to deliver advocacy education and training, including a session on access to care and products. A team from Nightscout once again shared their technology with families who embrace their #WeAreNotWaiting philosophy. We also enjoyed the support of the [PADRE Foundation](#), which helps families in the local area.

In 2016, CWD continued its sponsorship of ISPAD's [Lestradet Award](#), given to Dr. Lynda Fisher, who has cared for children with type 1 diabetes and their families in the Los Angeles area for many, many years.

2017:

For 2017, we will host three conferences in the United States:

[Friends for Life Anaheim 2017](#), from May 5-7, will return to the Disneyland Hotel and will focus on advanced diabetes care technology and the psychosocial impact of that technology on people living with diabetes, as well as their caregivers and families.

[Friends for Life Orlando 2017](#), from July 4-9, is shaping up to be our largest FFL Orlando ever. Returning to Disney's Coronado Springs, sessions will include topics on advocacy, advanced technology, biological research, care, and support. We'll have content for kids of all ages, including grown ups. The CWD Fellows Program will bring our second group of young health care professionals to learn about real-life with type 1 diabetes. Our Spanish Track returns, offering sessions in Spanish by native speakers for adults whose primary language is Spanish.

[Friends for Life Falls Church 2017](#), from October 6-8, will again focus on policy and advocacy, given its proximity to Washington, DC.

In addition to our conferences, we are working to rebuild our online presence for 2017, bringing it up to current standards.

With the help of our [generous sponsors](#) who make FFL possible, our amazing faculty and staff, and in partnership with many other organizations, we look forward to continuing to make a difference for families living with type 1 diabetes in 2017.

College Diabetes Network (CDN)

2016:

CDN continues to grow its Chapter network and programs to further our mission to connect and empower students and young professionals living with diabetes:



CDN Chapters – To date, CDN has over 105 affiliated Chapters at colleges and universities across the U.S., with 30 Chapters in the process of becoming formally affiliated. CDN updated the Chapter Activity Guide for 2016, to include new events and programs that Chapters across the country can hold on campus and in their community. CDN student members continue to have access to information on jobs, internships, and research opportunities.

Off to College Program – This past year, we released our Off to College booklets, utilizing information from the popular Off to College event guide. These free booklets, one for parents and one for students, provide advice and wisdom on everything from what to pack for that first semester to how to find a new endo. These booklets are available for digital download for families, and in hard copy for clinics and providers. Click here for a preview of the [Student Booklet](#) and the [Parent Booklet](#). You can also request your own copies [here](#).

Student-Led Initiatives – A record number of CDN Chapters, alumni, and supporters across the U.S. participated in the third annual [College Diabetes Week \(November 14-18\)](#). Over 80 Chapters across the country hosted awareness events on campus and in their communities. Chapter members' blogged, posted, and tweeted about life with T1D as a young adult. CDN hosted their first ever Twitter chat (transcript available [here](#)).

Chapter Stipends and Activity Grants – In 2016, CDN distributed 118 stipends of \$50 to Chapters. These stipends allowed Chapters to provide food to members at meetings, host events on campus, and travel to local events. CDN also granted 22 Chapters Grants, ranging from \$100 to \$500. Chapters used these grants to fund advocacy and educational events on their campus, mentorship programs for teens with diabetes, and more!

Newly Diagnosed – In the summer, CDN staff and a student intern interviewed 25 individuals who were diagnosed with T1D as young adults (ages 17-25). These interviews were compiled and analyzed to better determine the gaps faced by young adults diagnosed with diabetes, and to understand what type of resources would be most helpful. CDN will use this research to guide the development of specific programming for newly diagnosed young adults, launching in 2017 (see below).

Campus Advisory Committee – In July, CDN convened the first-ever summit meeting of the Campus Advisory Committee (CAC), a group of 11 campus professionals and organizational partners established to identify and address the gaps faced by young adults with diabetes on college campuses across the United States. In their meeting, the group discussed challenges faced by students with diabetes on campus, and developed a roadmap for new programming working directly with campuses to address these needs.

More Effective Clinical Care – CDN hosted its third annual Clinical Advisory Committee (CLAC) meeting at the 2016 ADA Scientific Sessions. CDN staff and students met with clinical providers and discussed important issues regarding diabetes care.

2017:

Annual Retreat 2017 – For the fourth year in a row, CDN will bring 25 student leaders from different Chapters together for a week of leadership training, networking, and planning for the upcoming school year.

Chapter Stipends and Activity Grants – In 2017, CDN plans on continuing to provide Chapter Stipends and Grants to Chapters across the country. CDN anticipates distributing more than 300 \$50 stipends to Chapters, along with 20 Chapter grants of up to \$500. This funding will allow CDN Chapters to continue to make significant impact in their local communities.

Mental Health – CDN knows that diabetes can drastically affect the mental health of patients, especially those undergoing the stress and challenges of young adulthood. Identified by CDN students as a top priority for 2017, CDN will be developing and launching resources for young adults with diabetes to help address the challenges of the intersections of diabetes, mental health and body image.

Resources for the Newly Diagnosed – Continuing on discussions held at the 2016 and 2017 Annual Retreat, CDN will be holding a focus group of those diagnosed with T1D as young adults. Following this focus group, CDN will launch a Newly Diagnosed Young Adult Guide and video series.

- CDN plans to hire several new staff this year to better support the exciting new programs and initiatives they will be undertaking in 2017. CDN will also be updating their website to better integrate with their Providing a public statement on the effectiveness of Diabetes Prevention Programs at the Institute for Clinical and Economic Review (ICER).
- Attending a roundtable to weigh in on PWDs’ roadblocks to taking insulin as prescribed (“adherence”) with the Pharmacy Quality Alliance (PQA).
- Providing a public statement supporting CGM data use to FDA, which helped result in [expanded guidelines for Dexcom G5 users](#).
- Attending meetings related to access and choice after the United HealthCare decisions.
- Participating as an advisory board member and reviewing educational materials before distribution for the U.S. Department of Health and Human Services Agency for Healthcare Research and Quality (AHRQ).
- Attending the FDA workshop to discuss outcome measurements beyond A1C.
- Participating in Diabetes Self-Management Education and Support (DSME/S) meetings as a member of the Diabetes Advocates Alliance (DAA).
- Recruiting for the Patient Out of Pocket Experience Advisory Board.
- Attending the Type 2 “Diabetes Linkup” event to discuss ways to amplify the type 2 voice to ensure more even represented in advocacy discussions.
- Attending the National Diabetes Volunteer Leadership Council’s [Access to Insulin Roundtable](#), to weigh in Salesforce database, and make our tools and resources more accessible.

Diabetes Hands Foundation (DHF)



2016:

Our year began with new CEO Gene Kunde at the helm, working to recruit [a strong team](#) and strategically plan for the future. A decision to renew and strengthen the Diabetes Advocates program led to adding a full-time Director of Advocacy in August, to focus on building out more advocacy programming and offerings:

[TuDiabetes](#) and [EsTuDiabetes](#), two social support networks offered by DHF, had over 1.2 million user sessions each. TuDiabetes re-launched weekly live interviews (25 episodes aired) and our new EsTuDiabetes Facebook page gained over 150,000 followers while providing shareable, educational content.

The [Big Blue Test](#) encouraged 53,000 people to log their blood glucose level before and after physical activity (8,000 more entries than 2015). Three non-profit organizations received \$5,000 Big Blue Test grants to continue their work supporting undeserved communities of people with diabetes: Diabetes Sisters, We Are Diabetes, and the Riverside Community Health Foundation.

Our annual [MasterLab conference](#) welcomed over 115 attendees from more than 28 states and 8 countries, with 50 advocates attending on scholarship thanks to Lilly Diabetes. This year, attendees completed personal advocacy plans as they learned from engaging speakers and sharpened their advocacy toolkits.

Advocacy and access discussions - in 2016, DHF participated in over 20 public hearings, document review committees, and working groups related to advocacy. Some of those highlights included:

- Providing a public statement on the effectiveness of Diabetes Prevention Programs at the Institute for Clinical and Economic Review (ICER).
- Attending a roundtable to weigh in on PWDs' roadblocks to taking insulin as prescribed ("adherence") with the Pharmacy Quality Alliance (PQA).
- Providing a public statement supporting CGM data use to FDA, which helped result in [expanded guidelines for Dexcom G5 users](#).
- Attending meetings related to access and choice after the United HealthCare decisions.
- Participating as an advisory board member and reviewing educational materials before distribution for the U.S. Department of Health and Human Services Agency for Healthcare Research and Quality (AHRQ).
- Attending the FDA workshop to discuss outcome measurements beyond A1C.
- Participating in Diabetes Self-Management Education and Support (DSME/S) meetings as a member of the Diabetes Advocates Alliance (DAA).
- Recruiting for the Patient Out of Pocket Experience Advisory Board.

- Attending the Type 2 “Diabetes Linkup” event to discuss ways to amplify the type 2 voice to ensure more even represented in advocacy discussions.
- Attending the National Diabetes Volunteer Leadership Council’s [Access to Insulin Roundtable](#), to weigh in on the cost of and access to insulin, and its effect on our community.

Branding and resources - we updated our visual branding for Diabetes Advocates with a new logo showing a fingerprint, as we are very aware of the role that hands play in the life of people with diabetes. We also re-invigorated [DiabetesAdvocates.org](#) and created a [Resource Library for advocates](#), which is beginning to offer robust education tools, policy news, and resources for new learners looking to get started as well as experienced advocates ready to lead a larger initiative.

2017:

In 2017, we will be supercharging our Diabetes Advocates program to deliver more tools, workshops and opportunities for our community to do its best work, together! We aim to:

- Increase the accessibility of advocacy by broadening the definition of that work, and providing resources for beginners and seasoned advocates alike. Advocates can be empowered patients advocating for their health care, lobbyists, legal gurus fighting to ensure fair accommodations, social entrepreneurs, bloggers changing social perceptions, community leaders, policy influencers on a committee, or a health care provider – we want to support and connect those working to improve life with diabetes.
- Provide resources free of charge for advocates at a central place to virtually learn, connect, and get involved in changing the status quo. We will continue to build out [DiabetesAdvocates.org](#) through our [newsletter](#), and our stream of updates on [Twitter](#), helping to build a larger, more diverse network of informed advocates, especially type 2 advocates.
- Pilot two Regional Mini Advocacy Sessions for under-supported communities, to reach a diverse group of individuals (including underserved populations and the T2 market) and provide them with the tools, resources, and support they need to understand their role in healthcare decisions and self-advocate for their best care.
- Launch a new intensive weekend MasterLab Leadership Institute, featuring expert mentorship and strategic workshops to advance social impact leaders and their visions to improve life with diabetes.
- Promote roundtables and partnerships, creating liaisons among leading non-profits and governmental agencies to build advocacy conversations nationally.

Diabetes Political Advocacy Coalition (DPAC)

2016:

As the first and only 501(c)(4) non-partisan non-profit organization devoted to the patient voice in federal and state diabetes policy advocacy, DPAC is proud to provide easy ways for people to learn and speak out on issues of safety, quality, and access.

Over 26,000 direct advocacy actions were taken using DPAC's online platform in 2016, giving [DPAC Insiders advocates](#) direct access to policy makers, health insurance providers, and federal agencies. DPAC presented actionable advocacy sessions at five patient-centric conferences, offered expert views on important topics such as commercial health insurance and Artificial Pancreas pathways, and represented the diabetes patient voice on the Hill, at FDA meetings, and in the media. It's been an outstanding second year for the Diabetes Patient Advocacy Coalition!

Safety: DPAC spearheaded the [#SuspendBidding campaign](#), asking Congress to review the data showing harm from the restriction of access through Medicare's Competitive Bidding Program for diabetes testing supplies. Our [DPAC's Ask An Expert \(AAE\) presentation](#) series brought Dr. Gary Puckrein to explain the complex data to our advocates and ways to prevent this from continuing. DPAC delegates spoke on panels at a Congressional Hill meeting in June and the Diabetes Technology Society in November, sharing the patient voice and perspective.

Our community came together through DPAC, signing a petition to FDA in support of a labeling change for the Dexcom G5. Over 6,100 signatures were collected in under two weeks. This lightning-quick mobilization, in conjunction with other organizations' efforts, helped to share the patient's voice regarding risks and benefits of continuous glucose monitors (CGM). The FDA's final recommendation was a positive outcome and will help in the effort to garner coverage for Medicare beneficiaries. DPAC represented the patient voice on this topic at the AACE CGM Consensus Meeting in February.

Quality: DPAC hosted Dr. George Grunberger, 2016 President of AACE, as a [guest on AAE to discuss the importance of the National Diabetes Clinical Care Commission Act](#) and worked with AACE to carry the bill through the House. While this bill did not pass, the passion of our advocates shone through with emails to Congress asking for this important federal diabetes commission.

DPAC also participated in a [panel discussion about Beyond A1C measures](#) for diabetes medications, sharing patient insights on quality of life and risk/benefits at FDA in August alongside prominent advocacy leaders and medical professionals.

Access: DPAC gave the [#DiabetesAccessMatters](#) campaign a digital home for action, helping advocates share their thoughts to health insurance executives about the restriction of access to the devices, medications, and services medical professionals prescribe. Thousands of emails were sent through DPAC's easy-to-use website and the ability to share our community's stories helped to raise awareness about the importance of "one size does not fit all."



Access to affordable insulin was highlighted this year, with DPAC representation at the NDVLC Insulin Roundtable meeting in November, where several solutions were presented from the advocacy groups at the meeting.

2017:

With a new Congress and administrations on federal and state levels, our focus will be on ensuring that access to safe medications, devices, and services are protected. [We seek to grow our DPAC Insiders advocate community, which is free to join.](#) After all, 29 million people with diabetes and their families working together to raise a collective voice on diabetes policy is a powerful community. Our 2017 plans include:

- Focus through the DPAC Ask An Expert series, which brings a deeper look to issues impacting people with diabetes, on the re-introduction of bills, the dismantling of ACA, and ways to effectively advocate for better policy.
- Interactive actionable policy advocacy sessions at The Diabetes UnConference and all Children With Diabetes Friends for Life conferences.
- Expansion of our DPAC District Days program, providing step-by-step assistance to those wishing to bring diabetes policy issues to their Congressional representative.
- New and innovative ways to advocate with even easier ways to interact with policy makers.
- Hosting a Community Policy Advocacy Summit, bringing large diabetes non-profit organization leaders together to discuss how we can all work collaboratively for more effective campaigns.
- Affordable access and healthcare policy campaigns for all Americans with diabetes for the devices and medications they need to stay healthy.

Diabetes Research Institute (DRI)

2016:

At the DRI, which is solely focused on finding a biological cure for diabetes, we made significant progress in the three major research areas required for achieving that goal, with an emphasis on the sustainability, or immunology-related, pillar which is key to attacking type 1 diabetes:

- **Site:** After the DRI's first successful transplant in August 2015 in Miami, a patient in the [BioHub Trial was successfully transplanted](#) in May 2016 in Milan, Italy. This was the first successful transplant performed with this technique in Europe. The recipient has been free from insulin therapy and with excellent islet function and glucose control since the second month post-transplant. Results at international centers have been mixed, and we are trying to perfect and standardize the technique across centers of excellence.
- **Sustainability:** To prolong islet survival and function after transplantation, and in preparation for clinical translation, we have been optimizing the [new conformal coating \(CC\) technology](#)



developed by Dr. Alice Tomei, and identified three different coating formulations that can be used in the clinic. Pre-clinical testing continued in transplantation and autoimmune models using encapsulated islets transplanted into a biological scaffold similar to that used in the BioHub trial.

We developed a method for selectively targeting and imaging insulin-producing cells which could have a highly positive impact in defining T1D occurrence and progression. The use of [aptamers](#) that bind to beta cells may provide the opportunity for real-time beta cell imaging. It may also enable researchers to target and deliver protective immunomodulatory agents to delay and/or prevent T1D and its recurrence.

- Regulatory T Cells (T regs) were used in pre-clinical models to promote immune tolerance and to control autoimmunity. This population of immune cells was shown to inhibit immune responses, making the use of these cells an attractive approach for cell-based therapies. In pre-clinical testing, infusion of islet-specific T regs resulted in 100% remission of autoimmunity and diabetes, even following a strong immune challenge.
- Functional subsets of Natural Killer (NK) immune cells were identified in a pre-clinical model of T1D, and these NK subsets resemble those found in humans. Importantly, one of the NK subsets expresses a unique gene signature that includes up to 10 genes that have been previously found to be associated with T1D risk.
- **Supply:** Our discovery that the human pancreas harbors stem-like cells with the ability to transform into insulin-producing cells when exposed to a single molecule, [BMP-7](#), enabled us to pinpoint their location and explore their potential to generate new beta cells. Our preliminary data using this clinically approved agent may open the door to developing regenerative strategies for clinical testing.

2017:

Progress in these areas has enabled us to advance this research into clinical trials, while also furthering research in the sustainability area:

Clinical Trials:

- Continuation of BioHub Trial to transplant islets in the omentum and expansion of the clinical trials to international DRI Federation Centers.
- We have received FDA approval to begin a trial using [low doses of IL-2 after diabetes onset](#). Follow up of the patients will enable us to understand the potential impact of IL-2 administration in promoting islet cell survival by restoring immune system balance and thereby preventing beta cell destruction and loss.
- In a first step toward reversing autoimmunity in T1D with a combination therapy, patients with recent diagnosis will be included in a [clinical trial \(DIPIT\)](#) using five immunomodulatory drugs (ATG, Exenatide, Filgrastim, IL-2 and Etanercept), which will be tested for safety and efficacy. The agents are given for varying durations throughout the trial.
- A clinical protocol is in the final stages of development and will address the role of combination therapy with high-dose omega 3 fatty acids and vitamin D on the progression of disease in patients with new onset (≤ 6 months) or established (> 6 months) T1D. Inflammation has been demonstrated to play a significant role in T1D pathogenesis and “safe” anti-inflammatory strategies initiated either early at onset or later in the disease process may have a positive impact.

Sustainability:

- We will further evaluate different formulations for conformal coating for clinical translation and the selective site targeting of cells and/or immunomodulatory drugs to avoid systemic immunosuppression. We will also evaluate conformal coatings of stem cell-derived insulin-secreting cells in collaboration with [Semma Therapeutics](#).
- We will focus on combining mesenchymal stem cells (MSC) subpopulations with human islets in a biological scaffold to test their function and survival in inflammatory/immune conditions (such as the ones in T1D), first *in vitro* and then *in vivo* (NOD mice) during islet transplantation.
- Building upon our islet-specific T reg research, future experiments will examine how these cells change the immune environment to promote the resetting of the immune response against the insulin-producing cells, and how the environment affects the survival and function of these T regs.

diaTribe Foundation

2016:

This was another big year for The diaTribe Foundation! Thanks to the support of our generous funders, we were able to make considerable strides in our mission to improve the lives of people with diabetes and prediabetes and advocate for action. Highlights include:



FDA Advocacy – We continued our work in patient advocacy at the FDA through a series of meetings in Spring and Summer 2016. Most notably, we co-organized an FDA public workshop entitled [Diabetes Outcome Measures Beyond Hemoglobin A1c \(HbA1c\)](#), that gathered patients, advocates, healthcare providers, scientists, manufacturers, and policymakers to discuss the value of additional outcomes in diabetes therapy regulation. During the meeting, The diaTribe Foundation’s Founder and Chair Kelly Close and dQ&A CEO Richard Wood presented findings from a survey on patient priorities for diabetes therapies, bringing thousands of patient perspectives to the conversation. We also organized advocacy efforts at several FDA Advisory Committee hearings, where we discussed patient perspectives on basal insulin/GLP-1 combinations and on using the [Dexcom G5 for insulin dosing](#).

d16 – In January 2016, we hosted our inaugural [d16: Executive Innovation Lab](#) on Diabetes and Obesity in Palo Alto, CA. d16 engaged leaders across diverse sectors to produce innovative, systems-level solutions to reduce the societal burden of diabetes, heighten the urgency and need for action around the epidemic, and bring a new way of thinking into the diabetes ecosystem. For more on d16 and the ideas generated at the event, please view our [Consensus of Ideas](#).

Diabetes Prevention – The discussions spawned at d16 inspired us to focus on diabetes prevention in two key ways. First, we participated in the San Francisco and Oakland soda tax campaigns through delivering testimonies at several town hall meetings, phone banking for the San Francisco campaign, talking to voters on election day, and following the campaigns’ progress through [our blog](#). This November, we were thrilled to see soda taxes pass in San Francisco, Oakland, Albany, Boulder, and Cook County, a testament to the growing public interest in tackling the toxic food environment and protecting the health of future generations. Second, we have spent the past six months conducting a series of

interviews and research efforts on programs that have demonstrated success in preventing type 2 diabetes. We are currently compiling our findings into a collection called the “*Anthology of Bright Spots*,” which will be published online as a free resource in 2017.

diaTribe.org – In 2016, *diaTribe*, our online publication offering actionable updates and advice for people with diabetes and their loved ones, reached over 1.6 million unique visitors from over 225 countries and territories around the world, and our subscriber list grew by over 72%.

Outreach – In early 2016, The diaTribe Foundation launched Kelly Close’s [blog](#), which features her ideas and opinions on a range of public health topics, from soda taxes to drug development to the social determinants of health. In addition, Kelly delivered and led over 20 speeches and panel discussions at prominent conferences throughout the year, including at the American Diabetes Association (ADA) 76th Scientific Sessions, the American Association of Diabetes Educators (AADE) annual conference, QualComm Life Connect 2016, SXSW, TEDx at Eli Lilly, and the Milken Institute’s Partnering for Cures conference.

Staffing and TdF Board – In 2016, we were pleased to add four new associates to The diaTribe Foundation, who will continue driving forward our mission in 2017. We were also thrilled to welcome IDEO’s Dennis Boyle to the Foundation’s board of directors earlier this year.

2017:

We look forward to continuing momentum on several key fronts:

Launch of Advocacy site – In early 2017, we will launch our first-ever home page dedicated to diabetes advocacy updates and opportunities to get involved in the latest efforts.

d17 – In September 2017, we will host our second executive innovation lab on diabetes and obesity. At d17, we will continue the conversations started at d16 to drive greater innovation, collaboration, and impact in diabetes and obesity.

Anthology of Bright Spots publication – We look forward to publishing the Anthology online, that will offer insights on the programs and initiatives that have been most successful in preventing diabetes.

Continued FDA Advocacy – In 2017, we plan to continue our work in regulatory advocacy through additional efforts at FDA Advisory Committee hearings. We also hope to build upon momentum from the August workshop on diabetes outcomes beyond A1c through another gathering focused on changing FDA guidance to reflect patient priorities.

International Diabetes Federation (IDF)

2016:

Education has been the cornerstone of our work over the past year. We were able to secure funding for and launch the [IDF School of Diabetes](#), a flagship initiative aimed at empowering health professionals and people with diabetes so that they are best equipped to tackle all aspects of diabetes management, prevention and treatment.

2016 also saw continued and strengthened collaboration with partners and aligned organizations, resulting in the development of a number of valuable resources to improve the management and treatment of diabetes and its complications. IDF notably launched guidelines on [managing diabetes during Ramadan](#) and released a new report on [diabetes and cardiovascular disease](#), presenting a clear summary of the problem of measuring heart disease in PWDs, as well as real-world solutions to facilitate evidenced-based decision making and encourage collaboration between different sectors.

[World Diabetes Day](#) – Nov. 14 once again provided an inspiring display of unity and commitment as the global diabetes community rallied around IDF's call to promote early diagnosis and treatment of diabetes and its complications. Close to 1,300 activities were organized in 160 countries, primarily focused on screening for type 2 diabetes and eye complications. IDF developed an [online risk assessment tool](#) (adapted from the Finnish FINDRISK) and encouraged its members and wider network to screen individuals at risk and report their totals. Over 700,000 people were screened around the world during the month of November 2016.

2017:

IDF is the global voice of people with diabetes. To add legitimacy to this claim, one of the flagship activities of IDF in 2017 will be the launch and development of the Blue Circle Voices, a global network that will draw upon the experiences of people living with or affected by diabetes from all countries represented by IDF to inform our activities so that they best reflect the needs of the diabetes community. IDF looks forward to the added value that the Blue Circle Voices will bring to its work.

One of the highlights of 2017 will be the launch of the 8th edition of [IDF's Diabetes Atlas](#), the authoritative resource on the global burden of diabetes, containing data on diabetes cases, prevalence, mortality and expenditure on the global, regional and national level. The new data and other findings will serve to inform policy development and lead to initiatives and solutions that will improve the lives of all people living with diabetes and the many at risk.

The year will end with IDF's biennial congress, [IDF 2017](#), held in Abu Dhabi, United Arab Emirates. This marks a welcome return to the country following the very successful event held in Dubai in 2011. With the number of people with diabetes in the region expected to more than double within the next 20 years, Abu Dhabi is the perfect location to bring together the extensive global network of physicians, scientists, nurses, educators, other healthcare professionals, government officials, policy makers and diabetes associations that IDF represents. The IDF Congress will continue to provide a unique forum for knowledge exchange and sharing of best practice in diabetes prevention, education and treatment, helping to foster the collaborations, connections and political breakthroughs that are required to improve the lives of PWDs, help protect those at risk and reduce the impact of diabetes on our societies.



JDRF



2016:

- Researchers demonstrated a link between one's [gut bacteria](#) and the risk of developing T1D. In countries where the standards of living are higher, there was a prevalence of microbes that are associated with immune dysregulation and alter the pathways involved in autoimmunity.
- The first results were published for the [Fr1da study](#), which is screening three- and four-year old children for beta cell autoantibodies during routine pediatrician visits. So far, 144 children were found to have two or more autoantibodies—an indicator of incipient T1D—while they were still asymptomatic, and thanks to follow-up counseling, none of those children who proceeded to symptomatic disease experienced an episode of diabetic ketoacidosis, a potentially deadly acute complication of T1D.
- JDRF announced the launch of the [Clinical Trials Connection](#) tool to help increase participation in clinical trials. The widget asks people to answer a few questions about themselves to quickly and easily match them to nearby trials for which they are eligible.
- After more than a decade of JDRF leadership to catalyze the development and regulatory pathway of Artificial Pancreas systems, the FDA [approved](#) Medtronic's MiniMed 670G hybrid closed-loop system, the first-ever approved to automate insulin dosing to reduce high blood sugar levels. The system can help people with T1D stay within their desired blood sugar range, especially at night, the most dangerous time for blood sugar lows.
- Two JDRF-funded researchers found chemical triggers that can convert pancreatic alpha cells to beta-like cells that produce insulin, which people with T1D are no longer able to produce. The trigger compounds included [GABA](#), a common dietary supplement, and an FDA-approved anti-malarial drug called [artemisinins](#).

2017:

- **Advocacy:** JDRF will advocate for renewal in 2017 of the Special Diabetes Program, which funds \$150 million a year in T1D research, and advocate for greater health care access for diabetes therapies including Medicare coverage of CGM, health plan policies that provide robust coverage for diabetes therapies, and health care policies that protect those with preexisting conditions.
- **Artificial Pancreas Systems:** Hybrid Closed-loop AP systems will begin to become commercially available starting in 2017, and JDRF will continue to support the development and improvement of these systems, other AP technologies, as well as advocate for insurance/Medicare/Medicaid access to these therapies as they come to market. JDRF also plans to fund research into next-generation systems.
- **Beta Cell Replacement:** JDRF will be supporting research on state-of-the-art gene modification techniques to develop and test improved beta/islet cell preparations, with a pathway toward therapeutic use in beta cell replacement for T1D patients. JDRF also plans to support projects that define encapsulation systems and advance preclinical or clinical proof of concept studies aimed at validating beta cell replacement approaches for individuals living with T1D. In addition,

JDRF plans to expand the efforts on novel encapsulation approaches within its annual Encapsulation Consortium.

- **Glucose Control:** JDRF anticipates funding new studies to preserve or restore hypoglycemia awareness and/or the counter-regulatory response in T1D. We are soliciting letters of intent for research with the potential to translate novel therapeutic strategies that will significantly reduce the incidence of hypoglycemia by maintaining or restoring awareness of potentially life-saving hypoglycemia warning symptoms in individuals with T1D.
 - JDRF will be officially rolling out its T1D Performance in Exercise and Knowledge (PEAK) program nationwide in 2017, designed to provide education and support to those with T1D who would like to engage in exercise, safely.
- **Prevention:** A number of beta cell neoepitopes, modified forms of native antigen, have been described and implicated in T1D pathogenesis. However, to date, the utility of T1D neoepitopes either as biomarkers for improved disease staging/prognostication or as therapeutic intervention points has not been determined. JDRF intends to support research projects that address these questions in both a prevention and therapeutic approach.
 - The Fr1da study in Bavaria will be expanding in 2017 to screen more children for markers of T1D before the onset of symptoms. The testing will move to a wider area of Germany, and a demonstration project testing in the U.S has begun and results should be accumulating.
 - JDRF is also expanding its effort into improved autoantibody assays for predicting the risk for T1D. We are currently soliciting applications for research on optimizing and validating existing technologies for predictive screening and autoimmunity, which can be applied for wide-spread use in population-based screening efforts.
- **Restoration:** We may see the beginning of new clinical trials on the effect of repurposed drugs that are approved for other indications – similar to the clinical trials focused on the common blood pressure drug verapamil, which have shown promise in saving beta cells in experimental systems. The initial results of the verapamil randomized controlled trial in humans should begin to emerge in 2017. We expect to see research projects lead to new understanding of the human immune response that occurs in T1D and how to control it.

T1D Exchange

2016:

T1D Exchange was founded on the belief that people affected by type 1 diabetes need better solutions faster. We take an innovative approach that puts the community of people touched by type 1 diabetes at the center of

research that will meaningfully impact their lives. In 2016, we had a productive and busy year, including:

Going Beyond A1c: T1D Exchange has been collecting evidence since we launched in 2010 showing that most people with type 1 diabetes are not reaching the recommended A1c targets.



T1D Exchange

New data shows approximately 75% of people in the [T1D Exchange Clinic Registry](#) are not achieving optimal A1c levels. This data is transformative in that previously, there was no data based on a representative population nationally. It indicates that patients are not necessarily “noncompliant,” but that better solutions are required for people with T1D.

As part of the joint [Health Policy collaboration](#) with Helmsley Charitable Trust and JDRF announced in 2016, T1D Exchange seeks to evaluate and define measures other than A1c that are important in measuring improved T1D clinical outcomes, such as hypoglycemia and time in range. This initiative will include input from individuals living with T1D and their caregivers as well as clinicians and research experts. The aim is to expand clinical, patient-reported, and economic outcomes used to evaluate and compare potential therapies in the research, regulatory, and healthcare settings.

Adoption of Technology: Our data also shows that people have better A1cs when they use an insulin pump, and/or a CGM (CGM improves A1c regardless of the way you deliver insulin). Yet there are still many people who have not adopted insulin pumps or CGMs.

T1D Exchange is currently conducting research with 100,000 healthcare professionals to understand barriers to prescribing devices, and we are also developing research to understand what effects patient adoption of devices.

Our goal is to generate actionable data that will help increase device use in patients who can benefit (better, more affordable access) and pave the way for optimal use of today’s (and future) technologies—such as automated insulin delivery.

Automated Insulin Delivery (AID): In Summer 2016, we polled our online [Glu community](#) about which therapeutic solution on the horizon they find most promising. More than half of our 653 respondents chose a closed loop system, because it has the potential to improve outcomes and reduced the burden of living with T1D.

In September, our community celebrated when [Medtronic announced it won FDA approval for its 630G](#), the first hybrid closed loop system, which will soon be commercially available.

To support continued innovation on this front, [T1D Exchange recently announced a multi-million dollar investment](#) aimed at significantly advancing components of AID and accelerating differentiated system approaches. It’s our first investment initiative where we seek to support game-changing innovations and approaches in insulin delivery that deliver better outcomes and quality of life.

Diabetes Innovation Challenge: In 2016, we also held our first [Diabetes Innovation Challenge](#) – sort of a Shark Tank program for new and novel ideas in diabetes. Our aim is to help find these innovation organizations, raise their visibility and allow them to make connections that can ultimately lead to them securing the necessary support to move them to the next stage of development. This program offered the opportunity for 30 semi-final innovators that chance to present their work to a network of funders, investors, and partners from academia and industry. There were many great innovations presented this year at the finalists’ event, supported by lead sponsors American Diabetes Association (ADA) and JDRF. Awards totaled \$150,000 cash or in-kind services to 8 innovative companies.

The [winners included](#) companies developing everything from an implantable, wireless CGM platform to an auto-injector to administer glucagon to an ultrasensitive non-radioactive autoantibody test that can be readily used to detect type 1 diabetes far sooner than today’s methods.

In 2016, we also provided a series of educational events on the basics of insulin, conducted a large and important study on the misdiagnosis of T1D, and produced a learning series called [You Told Glu](#) that includes popular content around tips for eating pizza and getting more sleep!

2017:

We expect 2017 to be another important year in driving new insights and discoveries in type 1 diabetes, as we continue to work on our:

- [Biobank](#) offering – where patients can proactively donate biological samples when they are needed in research.
- Quality Improvement program – an ambitious initiative to help improve the standard of care in a clinic setting for T1D. This will take a few years to build, but much like the original moonshot, we won't ever know what we can achieve without trying.
- Patient-Centered program Glu – an easy way to connect with the type 1 community, also available via our [new myGlu app](#) (sorry! only for iPhones and iPads for now).

Taking Control of Your Diabetes (TCOYD)

2016:

For 22 years, [TCOYD](#) has been transforming the way people live with diabetes by encouraging them to take a more active roll in their condition through education, motivation, empowerment and humor. 2016 was a year of transition and growth for TCOYD; we reached every corner of the county this year, from Alaska to Florida, and from Hawaii to Washington DC by bringing our flagship educational diabetes conferences to the doorstep of so many great American cities.



Throughout the course of the year, TCOYD hosted nine national patient conferences, nine national continuing medical education (CME) conferences, a five-part mini-series and 13 CME dinner series events. At the close of 2016, TCOYD had hosted a total of 426 programs and events since 1995 and there is absolutely no sign of slowing down.

As the year comes to a close, Sandra Bourdette, executive director, takes a step toward retirement and will be succeeded by one of the TCOYD dream team members, [Jennifer Braidwood](#). Sandra's tenure as the Co-Founder and executive director has carried TCOYD from a small grass roots organization out of a house in Del Mar, CA, to a nationally leading diabetes not-for-profit.

2017:

With new leadership comes the potential for great change and that is exactly what is on the horizon for TCOYD in 2017. While continuing to deliver national patient and healthcare provider conferences, TCOYD will add a digital platform to our offerings in the first half of the year with the launch of a new website in Q1.

This will create a one-of-a-kind experience that combines live in-person events with a one-stop resource center focused on digital relationships and information. This pairing will offer anyone affected by

diabetes the resources and motivation, both in person and at their fingertips, plus the information and inspiration to live the absolutely best life they can. With the launch of the new website comes a new look and branding feel as well.

Our logo and color pallet will be updated to reflect the evolving landscape and to showcase the new resources that TCOYD will be providing to the diabetes world. As the logo becomes cleaner and crisper, so do the offerings and experience TCOYD brings at every engagement. TCOYD will continue to fully embrace what has always set us apart... humor.

From the very beginning, founder Dr. Steven Edelman has made sure to keep it light and entertaining in order to make a difficult subject palatable. His borderline crass humor has always defined the TCOYD experience and this will be showcased in every interaction with the organization.



We can only hope that 2017 turns out to be a landmark year on many D-fronts.

We hope you will join us in saying: cheers to that!

- The DiabetesMine Team

www.healthline.com/diabetesmine