

# **Working Together**

to Cure T1D and Improve Lives



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# In Celebration of Our Type 1 Diabetes Champions

This year we celebrated Type 1 Diabetes (T1D) Champions, recognizing everyone whose big and small achievements showcase the spirit, determination and strength of rising above a disease that challenges each of us, every day.

In the following pages, we will highlight a few of the champion moments we've had at JDRF this year across Research, Advocacy and Community Engagement. None of our successes would have happened without your unwavering support as we work together to create a world without T1D.

# T1D Champions. All Day. Every Day.

In Research, several key breakthroughs are bringing us closer to cures, including advances in both beta cell and immune therapy research. Also, key technology advances improved the lives of those living with T1D today in real and meaningful ways.

Our Advocacy efforts — made more impactful through so many voices joining ours — helped raise critical awareness of the need for access, affordability and choice. We also built strong bipartisan support for federal funding for T1D research through the Special Diabetes Program. And we continued to work closely with regulatory officials to move advances from the lab and into the lives of people with T1D.

Through Community Engagement, we continued to support and engage members of our community at all ages and all stages of their lives, ensuring that those impacted by T1D know they are not alone. One parent recently told us: "Your outreach in our darkest time was a lifeline to our family. Your ongoing support has made JDRF part of our family."

We are at the cusp of enormous opportunities to find cures for T1D and transform the lives of those affected by it. To accelerate progress, we need all of you — our T1D Champions — urgently working alongside us, every day. We need you to engage more people, raise more funds and leverage more dollars. Together, we will make it easier to live with T1D — and finally bring to our loved ones the cures they so need and hope for.



**Aaron J. Kowalski, Ph.D.** President and CEO, JDRF



**Ellen Leake, Chair**JDRF International Board of Directors

# **Celebrating Our T1D Champions**

This year we celebrated T1D Champions, recognizing everyone whose big and small achievements showcase the spirit, determination and strength in rising above the disease that challenges each of us everyday.



#### **Niketa Calame**

Niketa Calame of California was diagnosed her freshman year of college. At first, she struggled, not realizing the chronic nature of the disease and the impact of not managing it effectively. "This is an every day, every hour, every minute disease," Niketa says. "It's important to remember we're warriors making life or death decisions every single day!" Niketa, now 38, has a Master of Fine Arts degree from the Actors Studio Drama School in New York. She has been a T1D advocate since her first visit to Washington, D.C., for JDRF Government Day.



### John "Jack" Hughes

Jack Hughes is 92 and still bikes at least 100 miles a week. But even more, this year he joined the JDRF Ride in Death Valley. The Cincinnati great-grandfather who was diagnosed at 41, is a long-time cyclist who has 60,000 lifetime miles, more than 2,000 miles this year and several JDRF rides. He joined the Death Valley ride to show his gratitude for the developments that have improved his life — nearly all driven by JDRF. Jack's family cheered him on as he trekked through the desert mountain terrain. "I enjoy the cycling," he said, "but, to me, it's all about contributing to the T1D community."



#### **Sahil Mehta**

Sahil hasn't let diabetes slow him down — in any way. The 27-year-old Michigan resident, diagnosed at 7, has an engineering degree and is an active dancer and DJ. He admits that no day is the same, with some tougher than others. He faces lows during sports, exams, dance competitions and other focus-driven and physically demanding activities. "You push through and take it one day at a time." Sahil says living with T1D has made him stronger and helped him better control his health.



#### **Grant Leonard**

Five-year-old Grant Leonard of Arizona tells people "my pancreas is broken" when he tries to engage their support for everyone living with T1D. This summer, he attended JDRF's Children's Congress, urging the renewal of the Special Diabetes Program to continue funding for T1D research. He also urged Congress to make insulin available to everyone who needs it. When he's not advocating for others, Grant says he enjoys being a preschooler because he loves to learn. When he grows up, he plans to be a firefighter because: "I'm so brave and want to help people."



### **Clayton and Ellie Ketchum**

At 16, Ellie and her dad, Clayton, decided to brave all challenges — including Ellie's T1D — to hike Vermont's Long Trail. The Connecticut teen wanted to push beyond her comfort level. Her dad wanted to create memories. They did both. While they cut the trip short due to blistered feet and a few T1D challenges, it still was a success. "It was never about how far we could hike," Clayton said. "It was about being together. It was about showing Ellie that nothing can stop her if she puts her mind to it."

This is an every day, every hour, every minute disease. It's important to remember we're warriors making life or death decisions every single day!



# Research Advances

## JDRF funding is accelerating research in two key areas: Curing T1D and Improving Lives.

Since two moms founded JDRF seeking a better tomorrow for their families, we have played a leadership role in every major advance, improvement and breakthrough delivered for the T1D community.

Today, we feel we are at a true tipping point as research is advancing at unprecedented rates of speed. This year alone, scientists have unlocked several key puzzles giving us new confidence that it's not a matter of whether we'll cure this disease, but when.

# **Curing T1D**

The keys to curing T1D lie in **Beta Cell Therapies** and **Immune Therapies**. Leading scientists are making tremendous advances in both areas. JDRF and the JDRF T1D Fund are right beside them, making their work possible through funding, connecting them to other scientists and bringing new experts into the field.



## **What are Beta Cell Therapies?**

This is a complex area of research with scientists simultaneously focused on seeking to transplant insulin-producing beta cells from outside sources into the pancreas without the need for chronic immune suppressing drugs. They also are seeking ways to internally regenerate and protect existing beta cells.

#### This year, we saw several advances getting us a step closer to curing T1D:

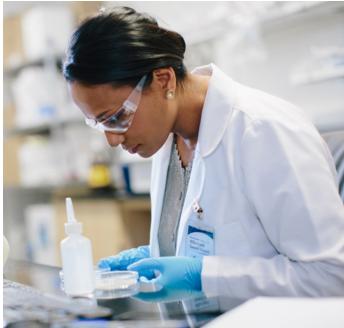
Researchers created a better beta cell by making mature, insulin-producing beta cells from stem cells. They respond to blood sugar more like human beta cells, reacting to glucose in a matter of days, not weeks, after transplantation.

<u>Scientists put beta cells back in the body</u>, without rejection. By loading a drug into the device that encapsulates the beta cell, they were able to suppress the body's negative reaction to the new cells.

<u>Scientists identified chemicals</u> that can help beta cells multiply and reproduce in the lab. They now are working on making drugs that can be tested in clinical trials.

Companies now are focusing on beta cells thanks to investment by the T1D Fund







### What are Immune Therapies?

While T1D remains one of the only major autoimmune diseases without a modifying drug therapy, we are getting close. Immune Therapies focus on ways to keep the immune system from attacking and destroying beta cells, and to prevent the onset and advancement of T1D.

#### This year we saw the following key advances in this area of complex research:

**The drug Teplizumab** showed that it could delay, for an average of two years, the onset of T1D in adults and children who are almost certain to develop the disease. The drug could become the first immune therapy approved for T1D. JDRF supported early clinical trials and now a company that is part of the T1D Fund portfolio is taking it through a phase III trial.

<u>A remarkable breakthrough</u> may explain how people develop T1D. JDRF partnered with the Parker Institute for Cancer Immunotherapy and the Helmsley Charitable Trust to learn why a key cancer treatment leads to the development of T1D. This may lead to interventions to prevent or treat T1D.

Work to prevent T1D was advanced thanks to JDRF-funded testing of two anti-viral drugs. In the first of its kind clinical trial, Pleconaril and Ribavirin are being tested to see if they can stop or delay the destruction of beta cells and maintain insulin production.

# **Research Advances**

# **Improving Lives**

Because we are part of the T1D Community, we understand the everyday struggles and stresses that come with this disease. That's why we fight every day to advance research and technology that can reduce the burden of living with T1D and keep people as healthy as possible until we find cures for the disease.

We are striving to improve lives by driving research and work in **Glucose Control Therapies** and **Complications Therapies**, which includes psychosocial well-being.



#### **What are Glucose Control Therapies?**

Fewer than 30% of people with T1D in the United States consistently maintain target blood-glucose levels. That means that more than 70% are at risk of serious health issues.

Glucose Control Therapies focus on helping people improve glucose control and overall metabolic balance, including improving artificial pancreas technology, developing next-generation insulins and developing new drugs to control glucose.

#### Here are just a few of the advances from this year:

Two drugs — Zynquista™ and Forxiga® — were approved by the European Commission for adults with T1D as an adjunct to insulin to help diminish the risk of blood-sugar swings. Work continues to secure similar support with the U.S. Food and Drug Administration. JDRF was critical in fostering the drug development process for Zynquista and was one of the first to support a clinical trial to see if it helps in T1D.

A new artificial pancreas system helps maintain consistent glucose levels. The t:slim X2™ insulin pump with Control-IQ™ advanced hybrid closed-loop technology by Tandem® Diabetes Care resulted in more time in range — less highs, fewer lows — with no severe hypoglycemic events. (In December 2019, the FDA approved the algorithm that enables the system.)

Our Open Protocol Initiative, which allows people to connect to preferred devices even if made by different manufacturers, has been widely embraced by the sector. The FDA also authorized the first interoperable insulin pump, or alternate controller enabled (ACE) pump, that can digitally interact with devices made by other manufacturers.



### (A) What are Complications Therapies?

We know that 40 - 60% of people with T1D experience eye disease and 25 - 40% experience kidney disease, and that psychosocial issues are higher among young adults with T1D.

Through our Complications Therapies, we are accelerating therapies to prevent and treat kidney and eye disease and improve psychosocial well-being.

#### Here are a few advances from this year:

<u>Seventeen proteins in the blood</u> were associated with end-stage kidney disease (ESRD) — a true breakthrough in predicting who with T1D may develop ESRD. Further testing may offer hope that they may thwart the potentially life-threatening complication altogether.

<u>Two therapies are entering clinical trials</u> to see if they can prevent eye disease completely. JDRF supported both drugs.

We expanded our focus on psychosocial well-being, aiming to support and lessen the short-term and long-term psychological burdens that come from living day to day with T1D.





# **Advocacy**

# JDRF champions every member of the T1D community. Sometimes we work behind the scenes, sometimes publicly, but always passionately.

We work with Congress, the Food and Drug Administration, other federal agencies, pharmaceutical and device manufacturers, insurance companies and organizations to secure critical funding, drive innovation forward and advocate for coverage, affordability and choice. Our work is strengthened and bolstered by a robust grassroots volunteer network and hundreds of thousands of advocates who support and amplify our calls to action.

- Coverage: JDRF is committed to everyone in the T1D community having the medical coverage needed to manage their disease and lead healthy lives. We are driving private plans and Medicare to cover all diabetes devices, including those newly approved by the FDA. This year, we saw expanded coverage of the implantable CGM, Eversense®. We are also fighting to ensure that people with pre-existing conditions like T1D have access to comprehensive health insurance and at competitive rates.
- Affordability: Insulin prices tripled from 2002-2013. Today, one in four people with diabetes is rationing insulin. We continued pushing drug companies, health plans, employers, pharmacy benefit managers and the Federal Government to reverse this trend. JDRF testified before Congress, met with public and private-sector decision-makers, participated in media interviews, spoke out on social media, and made insulin costs a focus of JDRF Government Day and Children's Congress.
- Choice: JDRF mobilized the T1D community when the largest national health insurance provider, UnitedHealthcare, announced it would limit pump choices. The T1D Community sent nearly 165,000 emails to UnitedHealthcare and spoke on social media about the need to choose your own device.





**Regulatory Approval:** JDRF partners with the FDA and other regulatory agencies to ensure new therapies are available as quickly as possible to meet the unmet needs of our community.

The FDA advanced JDRF's call for an open protocol environment, which will allow for more options in artificial pancreas devices and thus improved outcomes. The FDA created the "ACE" pump designation and cleared the Tandem® t:slim X2™ insulin pump as the first in the category. The FDA also granted "Breakthrough Therapy Designation" to Teplizumab, a drug being developed for the prevention or delay of T1D. JDRF funded one of the first clinical trials of this drug.



**Federal Funding:** JDRF advocates built strong bipartisan support for the Special Diabetes Program, which provides \$150 million in T1D research. With the leadership of Sen. Susan Collins, Sen. Jeanne Shaheen, Rep. Diana DeGette, and Rep. Tom Reed, we had 68 members of the U.S. Senate and 378 members of the U.S. House of Representatives sign onto letters of support for the program, laying the groundwork for a renewal in FY20.



# Children's Congress Empowers Youth, Inspires Leaders

It was personal, powerful and impactful. More than 165 children from all around the world converged on Capitol Hill to educate Members of Congress about life with T1D, and why it is so critical to fund research until cures are found.

Every two years, JDRF Children's Congress brings youth Delegates, ages 4 - 17, to Washington, D.C., to advocate for their needs and those of everyone living with T1D. The Delegates come from all 50 states, the District of Columbia and each of JDRF's five Affiliate countries.

This year, as always, the event touched everyone who participated.

#### "Thank you so much for coming. Your passion and hope for a cure are contagious."

That is what Congressional leadership said to the youth delegates during the U.S. Senate Special Committee on Aging, hosted by Senator Susan Collins (R-ME) and Senator Bob Casey (D-PA).

Children's Congress has been critical in securing continued federal funding of T1D research through the Special Diabetes Program.

It also has become a life-changing event for the youth attending. Delegates form life-long friendships, meet T1D celebrity role models, develop leadership skills and leave empowered to improve their lives and the lives of all people affected by T1D.





We need more research to find a cure. We need even better devices. And we need to figure out what causes TID so we can stop it. All of the kids here at JDRF's Children's Congress need you to continue to support us.



















# Supporting, Engaging Our T1D Community

To cure T1D, and help people stay healthy until that day, we need not only research and advocacy – we need to engage, support and connect the T1D community.

The work we do through Community Engagement is both broad and deep. It includes holding events that foster connection and networking, support of our advocacy efforts, educating healthcare professionals and raising critically-needed funds to drive research forward.

# Our education materials reached more than 200,000 families:





Bags of Hope for the newly diagnosed

**Back to School materials** 

What You Need to Know videos for teachers, coaches and friends

Pregnancy with T1D video series



# Our personal connection programs supported more than 30,000 families:

T1D Connections pairs volunteers with the newly diagnosed so no one living with T1D feels alone. The Online Diabetes Support Team (ODST) gives on-line support, advice and resource connections. Our TypeOneNation Forum fosters an on-line, connected community.

Communities, corporate partners, volunteers and more than 1 million families united around spectacular events that helped raise more than \$232 million:





**TypeOneNation Summits**, a day of education, networking and connection, held in 53 U.S. cities

Young Adult Conferences, uniting those 18-30 for networking, education

**Young Leadership Committees** advocate, learn and fund raise



**81 Galas** united 45,000+ people, raising **\$77 million** 

**166 Walks** raised **\$62.5+ million** 

**5 Rides** with 2,440 riders, raised **\$10+ million** 

33 Golf events = \$6+ million

34 other events = \$4+ million





# Healthcare professional trainings reached more than 54,000 members of the medical community:

Healthcare professionals play a critical role in supporting the well-being of the T1D community. JDRF supports them in improving their quality of care by sharing emerging data, research, resources and best practices.

# Finding "Her Voice" through JDRF

Like so many others, Elizabeth Link's first experience with T1D was a hospital visit. She was 12.

A JDRF Bag of Hope and a snuggly Rufus told her she was not alone, and offered her parents a link to support. Still, Elizabeth felt frightened and isolated. None of her friends had this odd disease. And suddenly, she was managing so much, all the time.

During her first year, Elizabeth's parents, Gregg and Deb Link, received emails of support from JDRF and connections to materials on the JDRF website. Among those materials was a back-to-school kit that helped the family transition into the new norm of T1D and helped support the hectic pace of a student athlete.

Then came information about a summer camp for kids with T1D. Intrigued, Elizabeth attended. Suddenly, she was surrounded by others just like her. She saw that managing could become thriving. And she saw that she really was not alone.

After that, Elizabeth became increasingly involved with JDRF. She served as a JDRF Youth Ambassador for two years with the Minnesota chapter. Her family joined walks, attended TypeOneNation Summits and participated in clinical trials.





At 16, Elizabeth was selected to represent Minnesota as a 2019 Children's Congress Delegate, where she spoke to her representative and senators about T1D issues and also met with the FDA.

"JDRF has helped Elizabeth realize she is not alone in living with T1D," her mother said. "Meeting children as well as adults who are doing more than just managing their own disease and are actively advocating for others affected by T1D has been incredibly empowering for Elizabeth. Through the opportunities afforded her by JDRF, she has found her voice to speak up on issues that matter to her and has been inspired to join the work of advocacy."

At school, Elizabeth plays in the marching band and competes in track, diving and volleyball.







This year, she won a state-wide essay contest writing about her experience with T1D and her participation in Children's Congress.

Her essay opened with actor Victor Garber's testimony that: "No mother in the U.S. should lose her son due to insulin rationing, and no father should have to rely on buying insulin from Canada to keep his child alive." She concluded with: "As I think back to my experiences as a delegate to the JDRF Children's Congress — as one of 160 children living with type 1 diabetes from all across the country — I realize that we, too, raised our voices together to influence change. We are the future. We will build on the foundation which our forefathers have established for us, and we will strive to keep America great."

She received a standing ovation.

# **Making It All Possible**

# Our global supporters make our work to cure T1D and improve lives possible.

We have Chapters located in and supporting every major region of the United States.

# 60+ Chapters

Together, supporting more than **1 million people** 

hosting more than **450** events

and helping raise more than

**\$232** million

We also have 5 international affiliates giving us a global footprint in:











## Our Chapters and Affiliates play a critical role in raising the funds needed to advance research. But they do not work alone.

JDRF donors alone could never fund all of the critical scientific research needed to cure this disease and help those living with it today. That is why JDRF works on many fronts to raise additional dollars, drive strategic investments and secure funding from other organizations.

#### **Corporate Partners**

Hundreds of corporate partners support JDRF through direct giving, sponsorships and employee events. Many have been supporting our mission for decades, driving millions of dollars into T1D research. (Our leading partners are highlighted on page 24.)



Raising millions through company support and individual giving.

#### **Industry Partners, Governments, Organizations**

Our advocacy, leadership and expertise in emerging research influences and attracts still more funding for cures research and advances to improve lives. This includes funding from the U.S. government and international governments. Other non-profit organizations and philanthropy foundations also either partner with us to invest funding or do so on their own based on our leadership work. We collaborate with hundreds of industry partners — including pharmaceutical and technology companies — that also invest in T1D research. **Together, we have become a strong network, funding and supporting T1D advances.** 



For every \$1 from JDRF, nearly \$2.50 additional was invested in T1D research this year.

This year, we saw an additional:

**\$31M** 

from non-government organizations and charities

\$80M

from industry partnerships

\$182M

in U.S. funding (including SDP) and international government funding

# **Making It All Possible**

# **DRF**T1D Fund

The only of its kind in the world, the JDRF T1D Fund was started to catalyze investment in T1D. We saw small companies doing potentially breakthrough work that were either stalled or dying due to a lack of investment, with very few financial investors focused on the disease. The Fund could fill that void by both making its own investments and bringing in more financial backers.

Just three years later, the Fund is being heralded and winning media headlines for its creative blend of philanthropy and big business strategy. It is making T1D an area that others want to invest in.

By the end of FY 2019, the Fund had invested \$26 million in 15 companies – 11 focused on cures – and attracted more than \$100 million in private capital to T1D.

Its portfolio includes companies reproducing Beta Cell Therapies, Immune Therapies and a few companies focused on underfunded transformational approaches to improve lives.

"Our aim is to find and help support companies with the potential to bring breakthrough solutions to the market faster for the T1D Community," said Sean Doherty, Fund Executive Chairman.





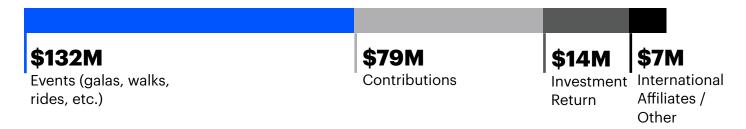


**\$26** M invested in **15 companies** since 2016.

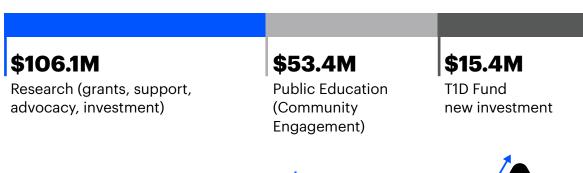
# **JDRF by the Numbers**

With millions of supporters, we are driving forward our mission of improving lives today and tomorrow by accelerating life-changing breakthroughs to cure, prevent and treat T1D and its complications. This year, we saw:

## \$232M in revenue

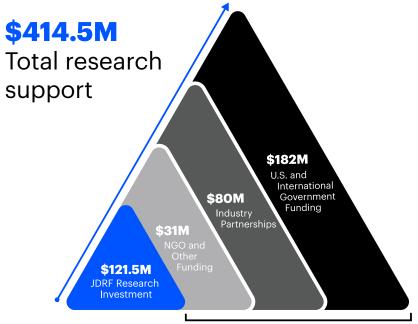


## **\$175M** advancing our mission





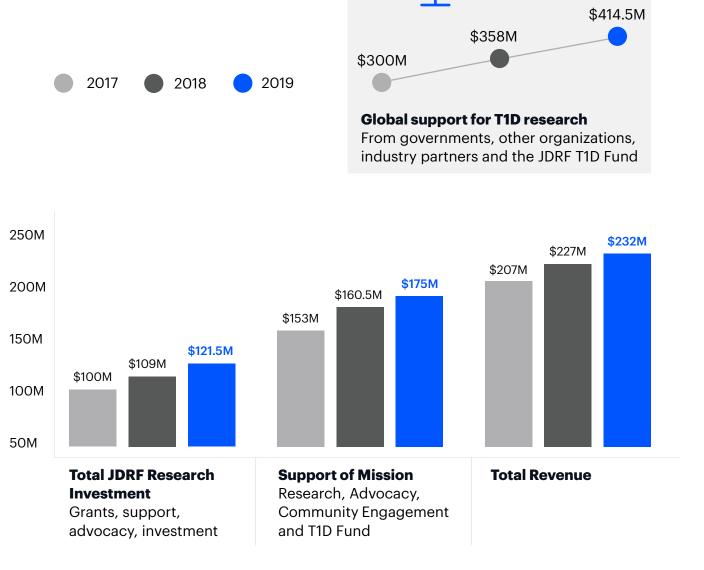
Our advocacy, leadership and expertise in emerging research both influences and attracts still more funding for cures research and advances to improve lives.



JDRF attracted \$293M in additional investments for T1D research

# **JDRF by the Numbers**

By diversifying and innovating our fundraising model, we have increased year-on-year investment in T1D research. Through innovative programming and partnerships, we are expanding support of our T1D community. In the last three years, we have seen:



# **JDRF by the Numbers**

JDRF researchers work with the world's leading scientists and institutions to advance the most promising T1D innovations. In the last year, we have seen:

\$121.5M Research, grants, support, advocacy, investment

**21** Countries

**400** Researchers **23** 

Early career scientists

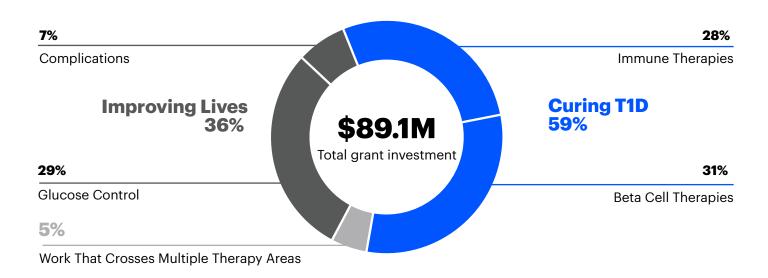
**\$89.1M**To grants

**+180**Research grants

**+70**Clinical trials

**\$16M**To clinical trials

## **Investing in Curing T1D and Improving Lives**



# **Corporate Partners**and Leadership Giving

Hundreds of corporate partners support JDRF nationally and locally through direct giving, sponsorships, portion-of-proceeds campaigns, fundraising teams, employee events and more. Several companies have been working with us for decades, driving millions of dollars into T1D research. They are joined by hundreds of individual donors who, through Leadership Giving contributions, drive our mission forward with deliberate and focused speed.

### **Elite Partners**

Contributing more than \$2,000,000 annually





# **Principal Partners**

Contributing between \$1,000,000 and \$1,999,999 annually









# **Champion Partners**

Contributing between \$500,000 and \$999,999 annually









# **Major Partners**

Contributing between \$250,000 and \$499,999 annually

Abbott Advance Auto Parts Bluegreen Vacations Dexcom Floyd's 99 Barbershop Insulet

**Pharmaceuticals** 

## **Supporting Partners**

Contributing between \$100,000 and \$249,999 annually

Amazon Smile	Acensia Diabetes Care	Cars	CVS Health	Delta Tau Delta	Discover
Lexicon	Livongo	MilliporeSigma	Sanofi	Talking Rain	Tommy Hilfiger
Walgreens	Whitlock	Xeris			

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# Thank you, for being OUR Champions. All Day. Every Day.

From all over the world, you share your stories, your voices. You inspire us, each other and motivate others to join our mission. You ignite our walks, runs and galas while raising funds needed to drive Research, Advocacy and Community Engagement. You speak up and out for everyone in the T1D community, helping to educate, empower and change the future. We are here because of you. We are here for you. We champion you, but you are OUR champions.



























Every gift takes us one step closer to a cure for T1D. Find out how you can support JDRF and make a difference in the lives of people with T1D by visiting **jdrf.org/donate**.

#### jdrf.org

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