

# **STATE OF THE CURE FOR TYPE 1 DIABETES**

**2017**

# **State of the Cure**

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## **Table of Contents**

<u>Chapter Title</u>	<u>Page</u>
<b>Introduction</b>	<b>01</b>
<b>Donor Priorities</b>	<b>03</b>
<b>Practical Cure Definition</b>	<b>04</b>
<b>Practical Cure Pathways</b>	<b>06</b>
<b>Practical Cure Projects in Human Trials</b>	<b>07</b>
<b>Cure Research Spending</b>	<b>10</b>
<b>Fundraising for T1D</b>	<b>15</b>
<b>Donating with Impact</b>	<b>16</b>

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## 01. Introduction

The 2017 State of the Cure for type 1 diabetes is the sixth annual edition of this report. Like all prior State of the Cure reports, it summarizes progress made during 2017 toward a Practical Cure (PC) for type 1 diabetes.

Any review of progress to a Practical Cure must start with the sobering fact that we are not there yet, and the past twelve months have yielded only moderate progress. While there are some areas of notable development in 2017, the overall key finding is largely the same as prior years— there is still a long road ahead. The year ends with only nine potential Practical Cure projects in human trials, none of which have yet published conclusive results.

At the same time, research grant spending by the Juvenile Diabetes Research Foundation (JDRF) has remained at significantly lower levels for two consecutive years, as compared to the previous ten years (2006-2014) when the Juvenile Diabetes Cure Alliance (JDCA) began tracking JDRF financials. Research grants as a percentage of revenue, which is an indicator of the priority level of research grants versus other areas of spending, increased by one percent from last year. In addition, the American Diabetes Association (ADA) continues to use only three percent of its income to fund T1D research grants.

One notable development in T1D research during 2017 was the creation of the JDRF T1D Fund, a for-profit investment fund. The fund raises many open questions, including strategic direction, ethical conflicts of interest, legal SEC/regulatory requirements, and perception among donors. These issues must be publicly addressed by the JDRF before evaluating the T1D Fund as good or bad for the overall mission of finding a cure for T1D.

A second notable development was the significant upsurge in the amount of resources targeting the prevention and/or delay of T1D. Although this area of research is important, we remain concerned that this increase in emphasis draws focus away from cure and Practical Cure research progress, which saw little to no noteworthy advancement this year.

Consequently, it is time to adopt a Practical Cure initiative as a core focus area throughout the entire T1D ecosystem. The JDCA argues that it is in the interest of all those living with T1D that a large proportion of research funding is concentrated on cure and Practical Cure research. Adoption of a PC initiative is the only way that we can ensure promising projects move through the research pipeline to completion as fast as possible and in time to affect those currently living with T1D.

## **HOW DO T1D DONORS WANT THEIR MONEY USED?**

**25 MILLION PEOPLE**

have a family member  
or a close relative with T1D

Together they donate

**\$450 MILLION DOLLARS**

per year to TYPE 1 DIABETES

**96%**

Say they want their money  
to be used for cure research

## 02. Donor Priorities: Survey Results

Most of the donations that fuel the major type 1 diabetes charities come from those directly connected to T1D— people living with type 1 as well as parents, grandparents, children, and friends. The JDCA has been conducting surveys of the T1D donor community to gauge attitudes and intentions for the last five years and has heard from over 10,000 donors in 15 different surveys.

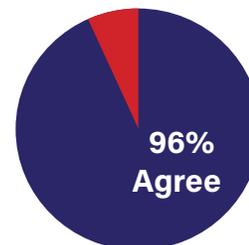
### Key Survey Findings:

**One key finding has been consistent over five years— the overwhelming majority of donors want their money to be used for research that seeks a cure for T1D.**

- **96%** of donors believe cure research should be the number one priority for charities, as shown in Chart 2a. This point is consistent with survey findings from prior years.
- **96%** of T1D donors state that they want the majority/most of the money raised from fundraising walks to be used to fund research.
- **79%** said **all** of the money raised at fundraising walks should be used for cure research.
- **90%** said the JDRF and ADA should seek direct donor input when making research funding decisions.
- **97%** of donors would donate to support Practical Cure research if that option were made easily available to them. The JDCA believes that if non-profits offered this option it would be a win-win and would ultimately increase overall donations. See Chart 2b.
- **67%** of respondents said "I will stop participating" or "I am less likely to participate" in future fundraising walks after learning how much of the ADA and JDRF income was actually used for research. See Chart 2c.

**Chart 2a:**

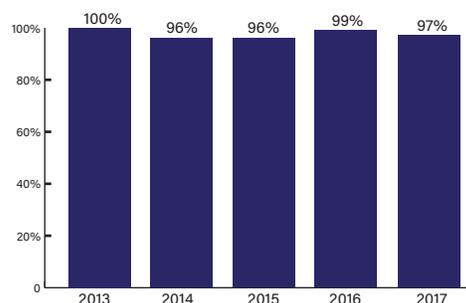
*Is cure research the primary reason you make a donation to a diabetes charity and/or participate in a fundraising activity? Answer is percent who agree.*



Source: JDCA Proprietary Survey of Donor Sentiment, November 2017

**Chart 2b:**

*Would you donate to practical Cure research projects if that option was made easily available to you? Answer is percent who agree.*

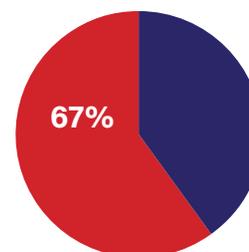


Source: JDCA Proprietary Survey of Donor Sentiment, November 2017

**Chart 2c:**

*Last year, JDRF used 38 percent of its income to fund research. The other 62 percent was used for non-research activities such as overhead, salaries, lobbying, and education.*

*How much does this impact your likelihood of participating in a fundraising walk in the future? Answer is percent who will stop/ are less likely to participate.*



Source: JDCA Proprietary Survey of Donor Sentiment, November 2017

### 03. Practical Cure Definition

The definition of a T1D Practical Cure reflects the wishes and desires of those currently living with type 1 diabetes. A Practical Cure is any solution which minimizes the disruptive aspects of T1D. Although it does not constitute a full reversal of the disease, it would deliver a dramatically improved and 'near-normal' quality of life.

A Practical Cure is different from a perfect or idealized cure in that it does not represent a reversal or complete elimination of the disease. With a Practical Cure, the disease may remain, but it is managed to achieve a near-normal lifestyle. This distinction is important. Scientists have been pursuing an idealized cure for almost 100 years, but are unlikely to deliver one in time to benefit those currently living with type 1. Alternatively, there are several projects in human trials that have the potential to become a Practical Cure, and there could be many more if resources and funding are allocated toward it.

#### **A PRACTICAL CURE IS OUTCOME FOCUSED**

The infographic on the following page shows the various outcome criteria that a Practical Cure must meet, including sleeping worry-free, no dietary restrictions, minimal monitoring, insignificant side effects, elimination of hypos, and HbA1C readings under seven percent with sustainability over time. There are also guidelines for the invasiveness of the type of solution, whether it be pharmacological or surgical. Any research approach, pathway, or philosophy that can deliver these outcome objectives is valued, desired, and merits pursuit.

#### **A PRACTICAL CURE IS TIME-BOUND**

Any Practical Cure solution must have a reasonable chance of being available within the next 15 years— in time to transform the lives of people who are currently living with the disease. Considering that, on average, it requires 10-15 years from the beginning of human trials to receive FDA pre-market approval, research projects that are currently in human clinical trials have the best chance of meeting the timetable. Projects which are not yet in human trials are much less likely to get through both animal and human trials in 15 years.

**Consequently, the JDCA focuses on projects in human trials.** A defined time objective prioritizes projects that have a reasonable chance of being in the market within the next 15 years. The JDCA argues that these projects should be fully-funded and fully-resourced, so they move through human trials as quickly as possible.

*A defined **time objective** prioritizes projects that have a reasonable chance of being in market within the next **15 years**— in time to transform the lives of people who are currently living with the disease.*

# A PRACTICAL CURE FOR T1D

**DEFINITION:** Any solution which delivers a near-normal lifestyle for people living with established type 1 diabetes.

**TIMING:** Available in the next 15 years.\*

## THE HIGHEST POTENTIAL RESEARCH PATHWAYS:

### Clinical Requirements Needed to be a Practical Cure for T1D

- ✓ HBA1C < 7%
- ✓ Minimal Monitoring
- ✓ Free Diet
- ✓ Eliminate Hypos
- ✓ Minimal Side Effects
- ✓ Less Than Ten Days in Hospital (if surgical)
- ✓ No More Than Five Pills Per Day (if pharmacological)



#### Cell Transplant

Implanting islet cells, stem cells, or precursor cells to achieve insulin independence. Cells are protected by an encapsulation device or immune system modification.



#### Immune System Modification

Therapy to stop the immune system from destroying beta cells, including modifying, blocking, and re-training.



#### Glucose Responsive Insulin

"Smart insulin" is injected and chemically activates only in response to changes in blood sugar.



#### Advanced Artificial Pancreas

A device that mimics the pancreas by monitoring changes in blood sugar and independently administers insulin without the patient's input.

\* Research project funding should be prioritized based on the potential of a project being completed in the next 15 years, in time to affect anyone currently living with T1D.

## 04. Practical Cure Pathways

There are four broad research pathways that have the potential to result in a Practical Cure within the next 15 years. Certain solutions may require a combination of the pathways while others may stand on their own. The four pathways are shown in the infographic on the previous page and discussed below.



### CELL TRANSPLANT

This pathway involves implanting islet cells, stem cells, or precursor cells into a person with type 1 diabetes to achieve insulin independence. The only proven source of islet cells is cadavers, which have very limited availability. Research into deriving a sustainable cell supply from human stem cells has seen promising advances and is currently being tested in humans. Islet cells require large supplies of oxygen and nutrients to survive. The current protocol is to transplant islet cells into the liver, but this approach yields a very limited cell survival rate. Other sites, including the stomach lining and omentum, are being tested as alternatives. There are currently three active trials in human testing.



### IMMUNE SYSTEM MODIFICATION / IMMUNOMODULATION

This pathway stops the body's immune system from attacking insulin-producing beta cells using drugs or stem cell therapy. Currently, immunology is being tested independently with hopes of regenerating beta cells still remaining at lower levels in the body long after diagnosis. If regeneration proves ineffective, immune system modification would need to be combined with islet cell transplantation. There are currently six active trials in human testing.



### GLUCOSE-RESPONSIVE INSULIN (GRI)

This pathway, also known as "smart insulin," (GRI) is chemically activated in response to changes in blood glucose. Once injected, smart insulin remains inactive until blood glucose rises above normal levels. At that point, the chemical component activates the insulin, and as blood glucose returns to normal, the insulin action ceases, avoiding low blood sugar. To qualify as a Practical Cure, smart insulin would have to last long enough to eliminate the need for multiple daily injections. *The only active GRI trial in 2016, Merck's MK-2640, failed.* There are no other active trials in human testing.



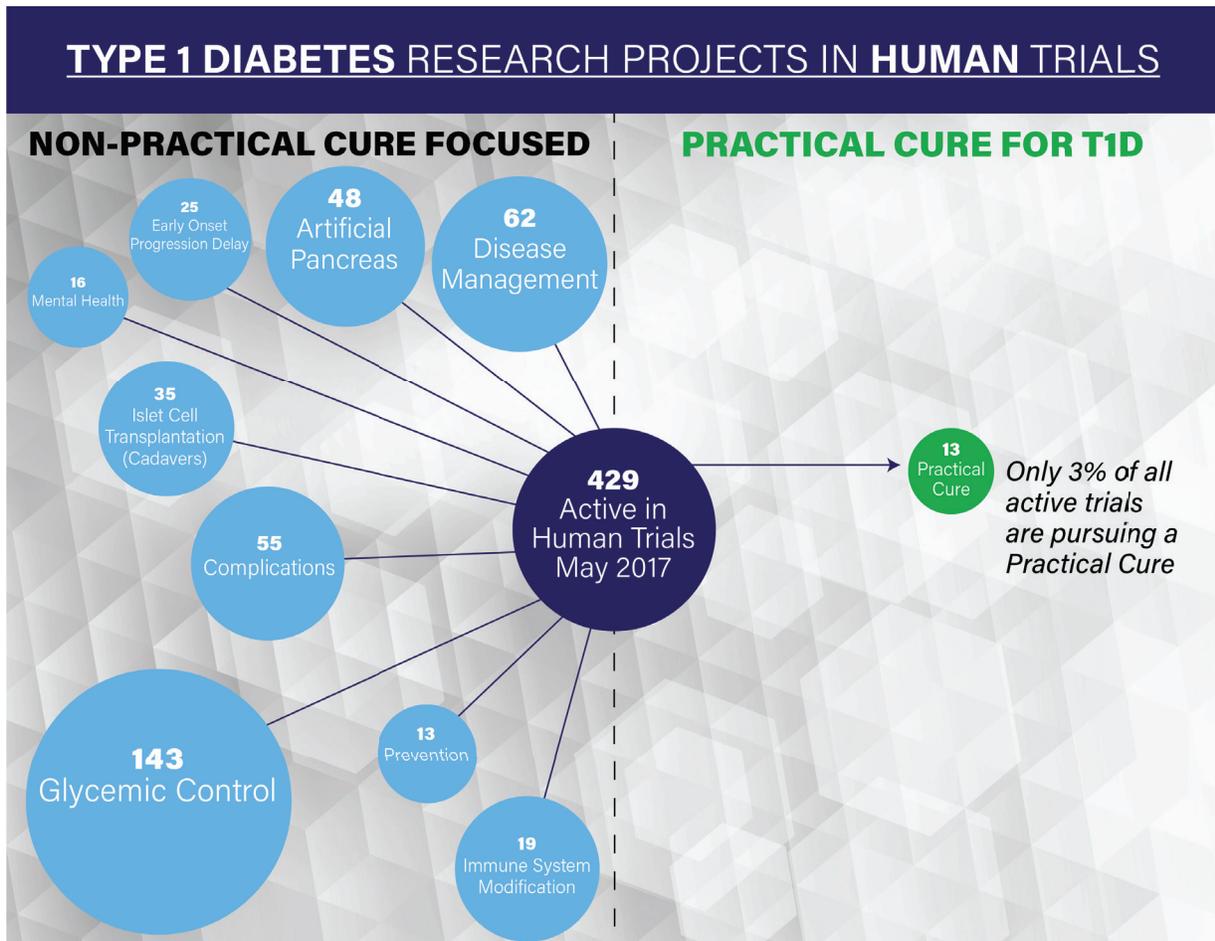
### ADVANCED ARTIFICIAL PANCREAS

This pathway is under development at several commercial and academic centers. The AP is designed to mimic the glucose-regulating functions of a healthy pancreas. It automatically works to control blood glucose levels and deliver insulin to prevent hyperglycemia and hypoglycemia. The JDCA recently completed a survey asking the T1D community to identify the requirements an artificial pancreas must meet to qualify as a Practical Cure. 88 percent of respondents said an *AP Device would be a Practical Cure if "it is small enough that you could generally forget that you are wearing it."* Although no current devices are small enough to meet the Practical Cure threshold as defined by people living with T1D, technology often progresses much faster than biological solutions.

## 05. Practical Cure Projects in Human Trials

As of May 2017, there were 427 active T1D research trials in FDA-approved human testing. These trials are researching a wide range of topics related to type 1 diabetes with the largest concentration working to improve glycemic control. Out of the 427 trials currently underway, 11 have the potential to be a Practical Cure. See Chart 5a.

Chart 5a:



Source: clinicaltrials.gov

Each Practical Cure project is summarized in the charts on the following pages and organized by pathway. Status, phase, and expected completion dates are also indicated. Please note that the JDCA presents these projects without any indication of preference or ranking.

Since last year, **three projects have been removed from the Practical Cure list**. Merck's smart insulin and ViaCyte's encapsulation projects have both failed. Diabecell's PC project has also been removed because it has not posted any research updates or results for more than three years.

**THERE ARE CURRENTLY NO ACTIVE GLUCOSE RESPONSIVE INSULIN OR ADVANCED ARTIFICIAL PANCREAS TRIALS IN HUMAN TESTING.**

## ACTIVE PRACTICAL CURE PROJECTS BY PATHWAY

### CELL TRANSPLANT



**Monolayer Cellular Service**  
Cliniques Universitaires-  
Saint-Luc-UCL,  
Brussels, Belgium

**Phase I**  
Completed: Results not yet posted

**Description**  
Islet cells are encapsulated in an alginate device (patch size of 1-3 cm) and transplanted subcutaneously. Phase 1a of testing is accompanied by immunosuppressive drugs. Phase 1b is free of immuno suppression.



**BAir Bio-Artificial Pancreas**  
Beta-O2 technologies Ltd.  
Tel Aviv, Israel

**Phase I/III**  
Ongoing, Not Recruiting  
Estimated Completion:  
March 2018

**Description**  
Islet cells are encapsulated in a device the size of a hockey puck, which is implanted in the abdomen. Requires daily oxygen injections.



**Autologous Stem Cells for T1D**  
Stem Cells Arabia  
Amman, Jordan

**Phase I**  
Recruiting  
Estimated Completion:  
January 2019

**Description**  
Treatment, Autologous stem cells are removed, purified, and returned with expectation that they will evolve into beta cells. White blood cells are removed and treated with mesenchymal stem cells and returned to the patient to stop the autoimmune attack.

### IMMUNE SYSTEM MODIFICATION / IMMUNOMODULATION



**University of Florida**  
Gainesville, FL

**Phase I/II**  
Estimated Completion:  
January 2018

**Description**  
ATG is aimed at stopping the autoimmune attack, and GCSF is intended to stimulate beta cell regrowth. Drug combination. Currently conducting two trials.



**Tianhe Stem Cell Biotech**  
Hackensack, NJ

**Phase I**  
Estimated Completion:  
Date January 2018

**Description**  
A patient's blood is passed through a machine which, through exposure to cord blood stem cells, re-trains the regular blood cells to cease the autoimmune attack.



**Massachusetts General Hospital**  
Hospital Boston, MA

**Phase II**  
Active, Not Recruiting  
Estimated Completion:  
January 2019

**Description**  
Tuberculosis vaccine repurposed to halt autoimmune attack and spur beta cell regeneration. Single drug.



**Jewish General Hospital**  
Montreal, Canada

**Phase I**  
Fully Enrolled  
Completed Results:  
Not Yet Posted

**Description**  
INGAP-P to induce beta cell regeneration combined with Ustekinumab for autoimmune modulation. Drug combination. Currently conducting two trials.



**Fondazione Italiana**  
Diabete Onlus

**Phase II**  
Estimated Completion:  
December 2018  
Recruiting

**Description**  
Rapamycin to modulate immune system by reducing IL2. Vildagliptin to promote beta cell regeneration. Drug combination.



**Caladrius Biosciences**  
Sanford Research

**Phase II**  
Estimated Completion:  
March 2020  
Recruiting

**Description**  
Use of Tregs to treat immune system imbalances. Endpoint increased pancreatic beta cell function as measured by C-peptide levels. Treatment.

## EMERGING PRACTICAL CURE PROJECTS

Emerging PC projects include projects which have the potential to begin human trials in the next two years. Although the JDCA does not actively study and track projects that are not in human trials, we do highlight high-profile projects, as shown below. This list is not comprehensive.

### CELL TRANSPLANT

- **PharmaCyte Biotech** has begun testing its Cell-in-a-Box microencapsulation technology. Its insulin-producing Melligen cells, derived from liver cells, are being tested in mice.
- **Orgenesis** has developed a process to convert a patient's liver cells into insulin-producing cells. Two clinical trials are scheduled to start in Germany and Belgium in 2018.
- **The DRI** has a long history of successful islet cell transplantation and is currently conducting multiple immunology studies. If combined and tested in established T1D, the approach would constitute a PC.
- **Sernova** is developing an encapsulation "pouch" the size of a credit card and containing donor islets. The company terminated a Phase I/II human trial earlier this year but plans to initiate a new trial in the near future.
- **Semma Therapeutics** is commercializing Doug Melton's work using stem cells to create beta cells. If successful, this work could be a key component of a Practical Cure.

### IMMUNE SYSTEM MODIFICATION

- **DiaVacs** is working on a reverse vaccine to stop the autoimmune attack. The company plans to initiate clinical studies in 2018.
- **Imcyse** is developing an immune system modification which employs modified peptides to alter T cell behavior. The company has started an 18 site trial testing in early-onset T1D patients; could be considered a PC if it addresses established T1Ds.
- **Anti IL-21 and Liraglutide** is testing a combo treatment. Anti IL-21 will address the autoimmune attack and Liraglutide will be used to stimulate beta cell growth. Currently testing in early-onset T1D patients; could be considered a PC if it addresses established T1Ds.

### GLUCOSE RESPONSIVE INSULIN

- **Sanofi** is working on smart insulin solutions in collaboration with MIT, UNC, and others.

## 06. Cure Research Spending

The three organizations that fund most of the type 1 diabetes research conducted in the United States are the ADA, JDRF, and NIH (National Institute for Health). The ADA and JDRF are non-profit organizations unaffiliated with the government, while the NIH is a US government agency.

In 2016, the ADA's annual income was \$171 million and the JDRF's annual income was \$197 million. The allocated funds by the NIH for T1D research totaled \$338 million in 2015, the most recent year this data was available. The following sections outline noteworthy developments of each organization over the last year.

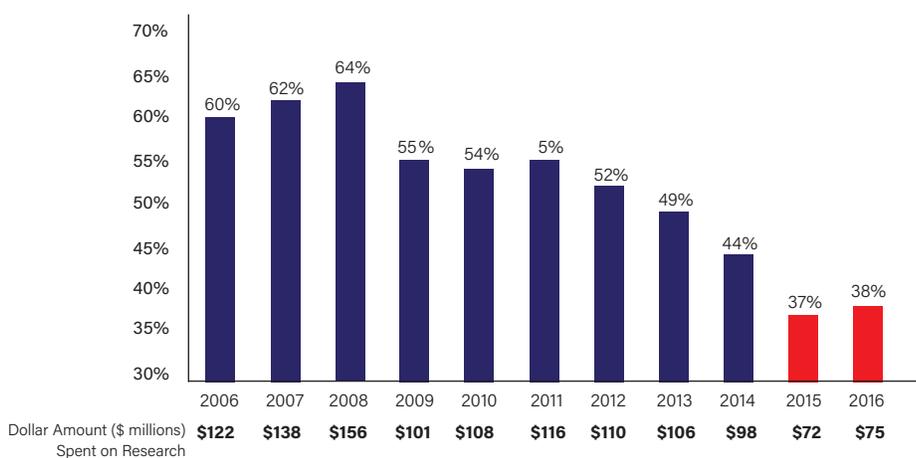
### JDRF:

Founded in 1970 with a mission of finding a cure for T1D, JDRF has grown to become the largest and most influential type 1 diabetes organization in existence. With chapters throughout the world and strong relationships with all the principle investigative research centers, JDRF is uniquely positioned to bring about a major breakthrough.

- Until 2008, expenditures were consistent with the organization's mission, with roughly 60 percent of all income used to fund research grants. After 2008, that percentage has steadily declined to 38 percent in 2016. See chart 6a:

**Chart 6a:**

JDRF Research Grants as a Percent of Annual Income



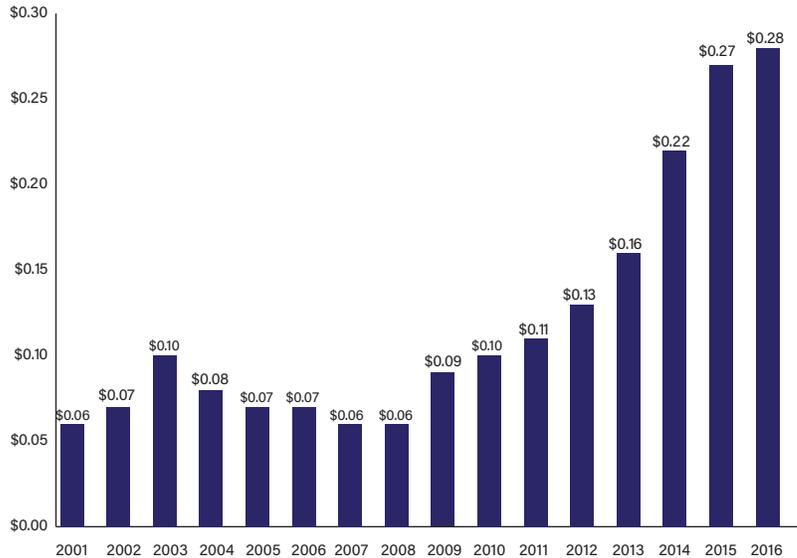
Source: JDRF Audited Financial Statements

- As research has dropped to a record low, spending on education has reached a record high. Education spending in 2016 was \$52 million, nearly 1/4 of annual income.

- Internal costs associated with giving research grants also reached a record high in 2016, rising dramatically from the early 2000s. In 2007, costs associated with administering research grants were six cents per grant dollar. As of 2016, it rose to 28 cents per research grant dollar. See Chart 6b.

**Chart 6b:**

JDRF Internal Cost for Each Dollar of Research Grants: A Rising Trend

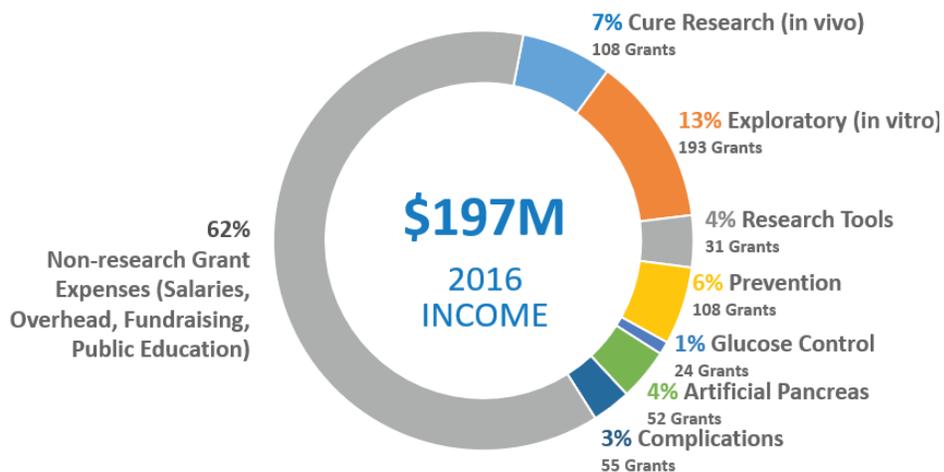


Source: JDRF Audited Financial Statements

- During 2016, JDRF posted an annual income of \$197 million. The 38 percent attributed to research addressed a range of topics including cure research, prevention, and complications. Prevention saw the biggest increase in funding, increasing from two percent of the annual budget in 2015 to four percent in 2016. See Chart 6c.

**Chart 6c:**

JDRF Utilization of 2016 Income by Research Grant Categories



Source: JDRF Audited Financial Statements and JDRF Grant Center

- JDRF funded 571 individual research projects in 2016, a 59 percent increase from the prior year (358 in 2015). The top five largest recipients collected 23.8 percent of total grant funding (\$17.5 million). Two of the top five recipients are for-profit. See sidebar.

Top Five JDRF Grant Recipients in 2016 (in millions)	
1.	University of Florida (\$4m)
2.	JDRF Canadian Clinical Trial Network (\$3.8m)
3.	University of California San Francisco (\$3.5m)
4.	Medtronic (\$3.2m)
5.	Novartis Institute for Functional Genomics, Inc. (\$3.0m)

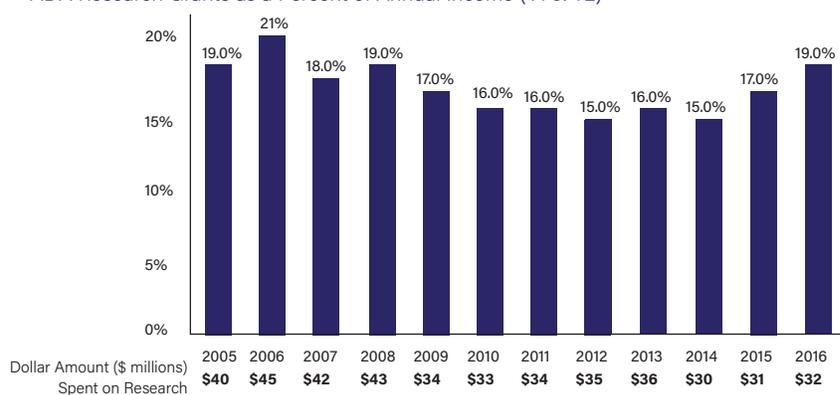
## The ADA:

The ADA was founded in 1940 with the mission of finding a cure for all types of diabetes. The ADA has evolved over time to become one of the largest diabetes organizations in the world.

- During the 12 years that the JDCA has been tracking the ADA, research spending is down compared to the early 2000s but is relatively constant in terms of the proportion of income. See Chart 6d.

**Chart 6d:**

ADA Research Grants as a Percent of Annual Income (T1 & T2)



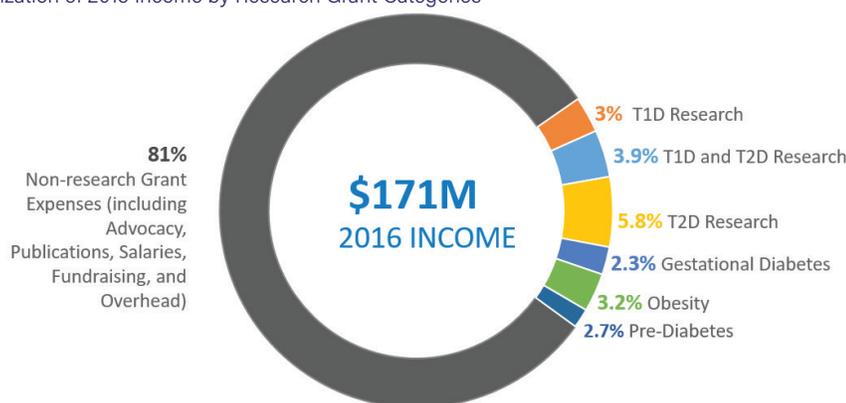
Source: ADA Audited Financial Statements

\*2006 was an 18 month fiscal year due to shift of fiscal year timing. The numbers for 2006 and 2007 have been adjusted for two twelve month periods and are, therefore, informed estimates.

- In 2016, the ADA posted revenue of \$171 million, down from \$182 million in 2015, raised primarily from donations and magazine proceeds. Just three percent of that income was allocated specifically to type 1 research. See Chart 6e.

**Chart 6e:**

ADA Utilization of 2015 Income by Research Grant Categories



Source: ADA Audited Financial Statements

If the ADA were to commit to a substantial investment and increase of focus on type 1 diabetes the impact would be monumental. The organization has an outstanding fundraising infrastructure, strong ties on Capitol Hill, and access to researchers throughout the world. A realignment to type 1 would undoubtedly help increase focus and could ultimately accelerate a cure.

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***If the ADA were to commit to a deeper focus on type 1 diabetes the impact could be monumental.***

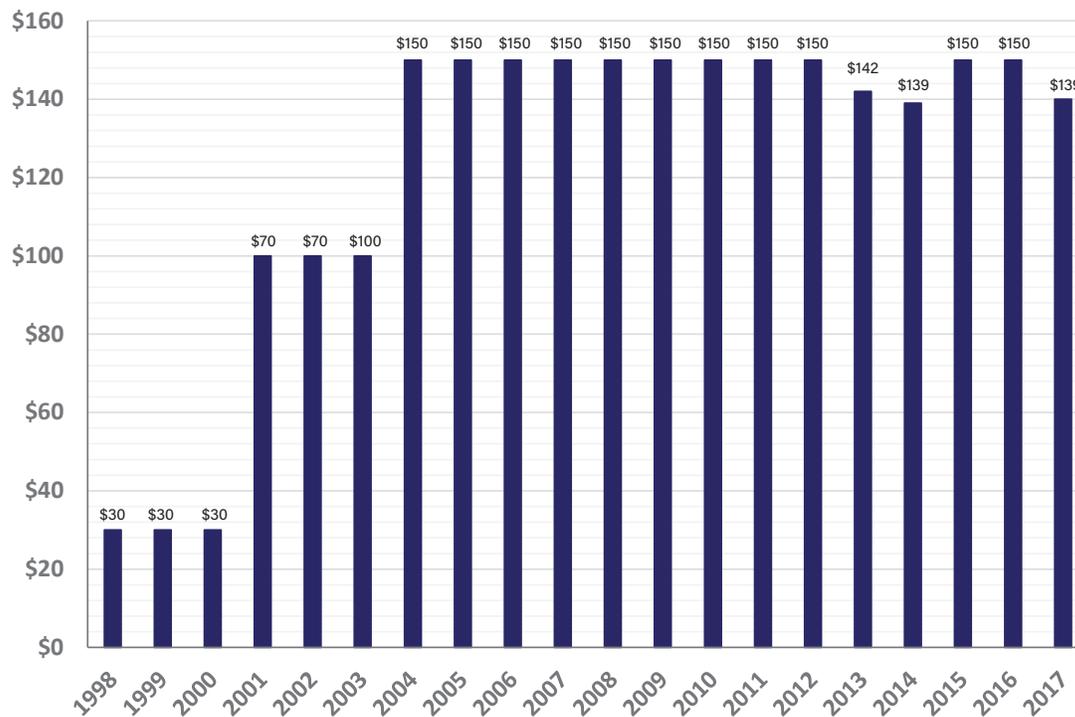
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## NIH:

Since 1998, in addition to already established research fundraising programs, the US government has set aside a special budget for type 1 diabetes research called the NIH Special Funding Program for Type 1 Diabetes. The program is managed by NIH in partnership with the Centers for Disease Control and Prevention (CDC) and the US Department of Health and Human Services.

**Chart 6f:**

NIH Special Diabetes Program Funding: (\$ millions)



Source: NIH Report of Special Diabetes Program Funding, June 2016

Throughout the past decade, almost 1/2 of the NIH budget has come from funding for the Special Diabetes Program, which has been set at roughly \$150 million annually. See Chart 6f. Over the summer, Congress was set to vote to decide whether to continue this worthy and important program into 2018. Funding has officially expired, although states do have enough funding to continue their programs for the remainder of 2017. Upon publication, the vote to renew had been delayed.

The program predominately funds large multi-center projects, studies, and networks. Major areas of progress to date include technology advances, such as the artificial pancreas and improved CGM devices, beta cell replacement, gene identification, and complications.

**It is important to note that very little of this investment has been used to advance a Practical Cure and there are no active human trials funded by the NIH which support a Practical Cure.**

## TOP T1D RESEARCH CENTERS BY BUDGET:

Every year, the JDCA provides an overview of the top 20 type 1 diabetes (T1D) research institutions with the largest allocated budgets. Our analysis includes three main budget sources, 1) The National Institute of Health research grants for T1D, 2) Juvenile Diabetes Research Foundation research grants, and 3) major donations or gifts from independent sources, including family foundations and 'captive' fundraising organizations.

The NIH, funded by tax dollars, is the single largest source of funds for T1D research and provides funding for over 150 organizations. Of the \$338 million in total NIH funding, the top five research centers received a total of \$88 million, as shown in Chart 6g.

**Chart 6g:**

The Top 20 T1D Research Centers by Annual Budget:

Recipient	T1D Total	NIH T1D\$	JDRF Grants	Major Gifts
USF	\$59,218,724	\$58,024,296	\$584,014	\$610,414
UCSF	\$21,856,418	\$7,086,992	\$4,261,000	\$10,508,427
University of Miami	\$15,556,039	\$3,046,286	\$1,684,753	\$10,825,000
Wake Forest University	\$14,739,955	\$14,739,955	\$0	\$0
City of Hope	\$13,811,410	\$5,248,351	\$153,559	\$8,409,500
University of Florida	\$12,749,396	\$7,150,600	\$5,505,577	\$93,219
Benaroya Research Institute	\$10,969,845	\$9,055,749	\$1,779,896	\$134,200
Vanderbilt University	\$10,164,236	\$9,217,218	\$947,018	\$0
University of Virginia	\$9,928,681	\$7,446,500	\$2,482,181	\$0
NIH	\$8,311,502	\$8,311,502	\$0	\$0
Joslin Diabetes University of Cambridge	\$7,953,725	\$3,664,543	\$2,689,182	\$1,600,000
University of Colorado Denver	\$7,761,365	\$6,360,942	\$1,400,423	\$0
University of Pennsylvania	\$7,137,221	\$5,863,944	\$1,273,277	\$0
University of Michigan	\$6,918,120	\$6,051,232	\$750,218	\$116,670
Yale University	\$6,762,079	\$4,514,165	\$2,247,914	\$0
Mayo Clinic Rochester	\$6,288,277	\$6,270,613	\$17,664	\$0
University of Minnesota	\$5,828,865	\$4,464,467	\$1,364,398	\$0
University of Emory	\$5,637,852	\$5,235,589	\$402,263	\$0
Emory University	\$5,560,407	\$5,089,693	\$336,248	\$134,466
University of Chicago	\$5,244,896	\$5,204,337	\$40,559	\$0
<b>Total</b>	<b>\$242,399,013</b>	<b>\$182,046,973</b>	<b>\$27,920,144</b>	<b>\$32,431,896</b>

## THE TOP FIVE T1D RESEARCH CENTERS



### University of South Florida

- USF had a total budget of \$59 million dollars in 2015.
- \$57m of USF's NIH budget comes from two large multi-million-dollar grants:
  - i. TrialNet (\$37m)
  - ii. The TEDDY Study (\$20m)



### University of California San Francisco

- UCSF had a total budget of \$22 million dollars.
- In 2015, UCSF received 25 NIH research grants and 22 JDRF research grants.



### University of Miami

- University of Miami had a total budget of \$15.5 million dollars.
- In 2015, UM received 15 NIH research grants and nine JDRF research grants.



### Wake Forest University

- Wake forest had a total budget of \$15 million dollars.
- \$14 million was awarded for the SEARCH for Diabetes in Youth Cohort Study.



### City of Hope

- COH had a total budget of \$14 million dollars.
- COH also received a \$50 million dollar gift, distributed over six years, to establish the Wanek Family Project to Cure T1D.

## 07. Fundraising for T1D

The ADA and JDRF are the two largest fundraisers for diabetes in the world. Each organization has built an extremely effective fundraising apparatus, combining professional staff with highly passionate volunteers. Both utilize campaigns that are directed nationally but executed on a local chapter level in cities throughout the United States.

Combined, the two organizations hosted 324 national fundraising events in 2017, including walks, rides, and galas, which generated over \$350 million in donations. These events are a prime source of funding for both organizations and deliver 3/4 of JDRF annual income and 1/3 of ADA annual income.

Most of these nationally-directed events either explicitly or implicitly communicate that the proceeds will be used for cure research. Many familiar event names feature a cure message, including *JDRF One Walk for a World Without Type 1 Diabetes*, *Ride to Cure Diabetes*, *Team JDRF to Cure Diabetes*, *Tour de Cure*, and *the Step Out Walk to Stop Diabetes*.

The JDCA has reviewed advertising messages used by the ADA and JDRF at national fundraising events for the last five years. In 2017, 98 percent of all JDRF national fundraising events featured a cure message, a number consistent with prior years. Yet, only seven percent of JDRF’s annual income was utilized for cure research. The ADA featured a cure message in 86 percent of its 2016 events, but only an estimated three percent of annual income was used for T1D research. See Chart 7a.

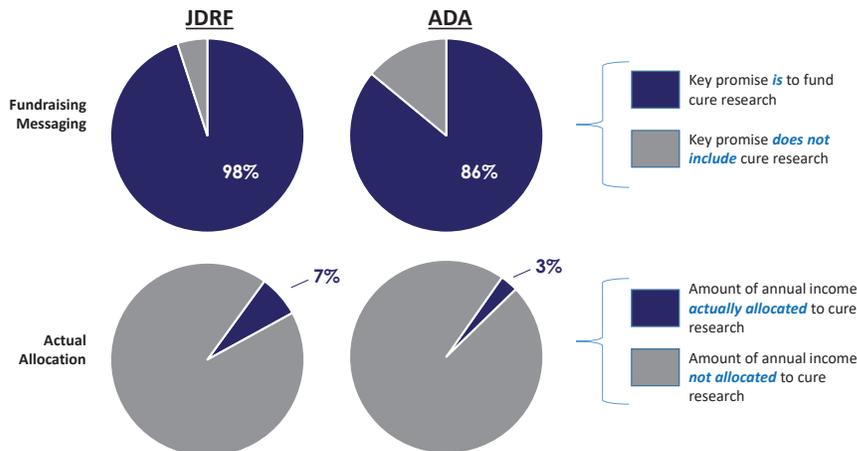
In summary, the fundraising promise remains unaligned with the way proceeds are used. As illustrated in Chapter 02 of this report, T1D donors clearly prioritize cure research, but only a small portion of donations are used to fund cure research.

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**98 percent of all JDRF national fundraising events featured a cure message. Only seven percent of JDRF’s annual income was utilized for cure research.**

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**Chart 7a:**  
2017 National Fundraising Messaging Compared to Actual Allocation

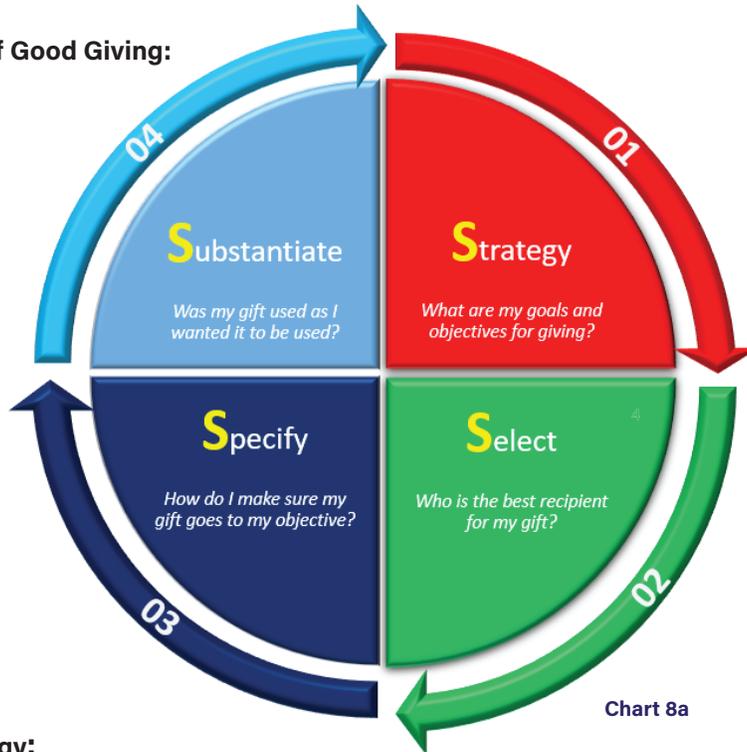


Source: JDRF and ADA Promotional Advertising

## 08. Donating with Impact

When making an individual donation, the 4S's of Good Giving provides a powerful, straightforward, and easy-to-implement approach that will help to ensure donor generosity is used the way it was intended. See Chart 8a.

### The 4S's of Good Giving:



### Strategy:

Within the T1D community, we know from ongoing market research that nine out of ten people want their gifts to be used to fund cure research. In this case, the objective is to give a gift that is actually used for cure research— any other application would be off strategy.

### Select:

There are many fantastic organizations within the T1D community. These can be broken down into three basic groups, 1) major charities such as the JDRF and ADA, 2) medical research centers (either with a national presence or in your local area), 3) specific research projects.

### Specify:

When giving to a charity, the only way to ensure your money is used the way you want it to be used is to specify the directive in writing.

Write a letter along with your gift specifically stating how the donation should be used. For example: 'This donation in the amount of \$XXX is to be fully used to fund cure research grants.' If the recipient is not willing or able to use the money to fund cure research they are obligated to return the money.

### Substantiate:

Every donor has the right to ask how a previous donation was used. This information can help you determine whether you want to reconsider your giving strategy. Asking how your gift is used also keeps the recipients on their toes and reminds them they are accountable and dependent upon you, the donor.



Juvenile Diabetes  
Cure Alliance  
*The Voice of the Donor For a Cure*