

# How the American Diabetes Association Can Restore the Loyalty of the Type One Diabetes Community

*...and benefit from it's fundraising engine*

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**All information and opinions in this paper are those of the JDCA.**

# INTRODUCTION

The American Diabetes Association is one of the most powerful and influential medical research organizations operating in the world today. Founded in 1939 by six physicians, it is the longest-running diabetes-focused non-profit in the world.

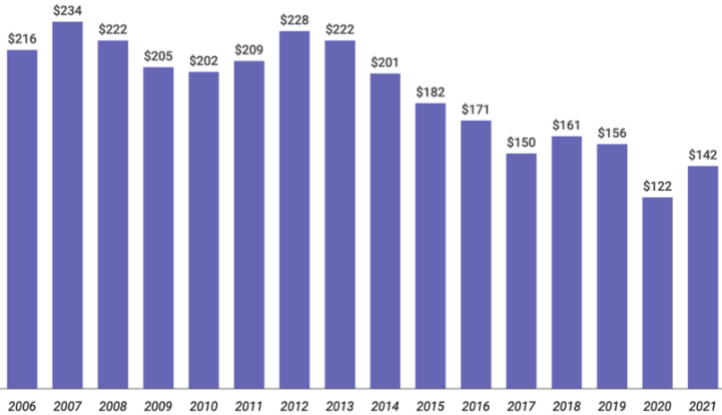
The American Diabetes Association claims to support all types of diabetes, including type 1, type 2, gestational, and pre-diabetes. The ADA’s vision is a “Life free of diabetes and all its burdens.” Their mission is “We lead the fight against deadly consequences of diabetes and fight for those affected by diabetes.” According to the website, the ADA delivers its mission and vision in four ways<sup>1</sup>:

- We fund research to prevent, cure, and manage diabetes.
- We deliver services to hundreds of communities.
- We provide objective and credible information.
- We give voice to those denied their rights because of diabetes.

The ADA's annual scientific sessions are one of the research community's most influential and essential yearly events. These multi-day meetings attract leading researchers and businesspeople worldwide and provide a unique opportunity to showcase and discuss the latest advances in diabetes care and research.

However, the ADA's business model has rapidly changed over the past several decades and is at a crossroads. Significant fundraising declines over the same time frame underscore this change. See Chart A. Such junctions require reflection and provide an opportunity for reinvention and revisiting mission and purpose.

Chart A: ADA Annual Revenue (\$ Millions)<sup>2</sup>



**Now is such junction.** The question to address is not what we are today but what will we be in twenty years? Will the ADA be more focused or less focused, bigger, or smaller, and what will be the new impact areas? In short, what is the unique value proposition from now on? These are the questions the national board must address quickly, or the organization will remain adrift, which no one wants. A strong ADA means better for more people.

## ALL DIABETES OR TYPE 2 ONLY?

One significant change to address is the degree to which the ADA covers all types of diabetes. It is evident in the leadership and deployment of resources that over the past decades, type 2 diabetes has taken an increasing focus and resources. While thirty years ago, the organization split its focus into both primary types of diabetes, today, it focuses primarily on type 2. This is evident in the amount of money allocated to T2D research, which was 4x more than for T1D in 2020<sup>3</sup>, and this was underscored, qualitatively, by the prior CEO's self-chosen Twitter handle: "Type 2 CEO". It is also worth noting that the ADA declined to share the 2021 research grant split between T1D and T2D for the first time in the past 15 years.

The shift in focus to T2D is logical. Nine out of ten people with diabetes are Type 2 and the incidence of diagnosis is rising both in developed and developing markets. Type 2 diabetes costs the United States about \$450 billion per year in direct medical and lost productivity costs. The NIH estimates that throughout the world 462 million people have type 2 diabetes with the incidence rising annually, particularly in the most developed countries<sup>4</sup>. The numbers provide a compelling case to not just keep the focus on Type 2 but make it the sole focus of the ADA.

Type 2 is a very different disease than type 1. Where type 2 is a decay in the insulin regulation system, exacerbated by lifestyle choices, T1D is an auto-immune disease whose onset is genetic and otherwise random. Where the severity of T2D is manageable by oral pharmaceuticals combined with lifestyle changes, the progression of T1D will not stop. It can only be treated by taking external insulin, without which the T1D person will die.

As of today, the ADA's mission encompasses all types of diabetes. One question ADA executives and board members must face is whether it is time to evolve the mission to focus on type 2 or reinvigorate investment in type 1.

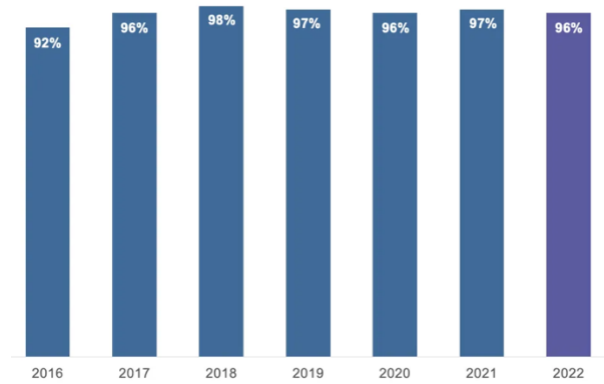
A strong case must be made for maintaining the T1D community. First is good for the community. The second is fundraising power, whose door is starting to close. The T1D community today is choosing to give its money to other entities. Yet the reputation of the ADA within the community remains strong and respected. If the board decides to win back this community, now is the time.

## HOW MIGHT THE ADA RE-COMMIT TO THE T1D COMMUNITY?

The answer is quite simple: nothing is more critical to the T1D community than to fund research that leads to a cure. By recommitting to a cure for T1D as one of the ADA's primary initiatives, the T1D community will respond enthusiastically.

In the ten years that JDCA has been fielding surveys to track the values and priorities of the T1D community in the United States, finding a cure for T1D has been the number one priority. Each year we have fielded the survey, the percentage of respondents who say that cure is job #1 has been consistently over 90%. See Chart B.

Chart B: Do you believe funding cure research should be the top priority for diabetes charities? (% Yes) <sup>5</sup>



Over the years, the JDCA has asked this question with many different derivatives. The answer is always the same: the number one reason T1D people give is to support cure research. This is a crucial insight. It reveals the primary hope of the community, which is easy to dismiss as wishful and impractical. It also points to the highest yield fundraising promise. In comparison, it is immediately practical and actionable. Restoring the fundraising engagement of the T1D community is a powerful method to rebuild the ADA's income engine.

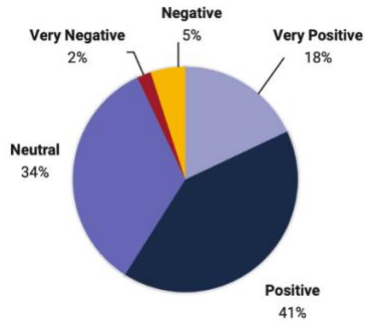
## THERE IS A TIGHT WINDOW TO REGAIN THE T1D COMMUNITY

The T1D community still holds a positive or neutral perception of the ADA. However, this perception is shifting negatively as the ADA pulls further away from addressing the top concerns of the type 1 community. This shift is achievable if the ADA acts now. A comprehensive survey of the T1D community held in the Spring of 2021 found that if the ADA revitalized funding cure research for T1D, the interest in supporting the organization would increase dramatically – a true win-win.

**Key highlights of the survey:**

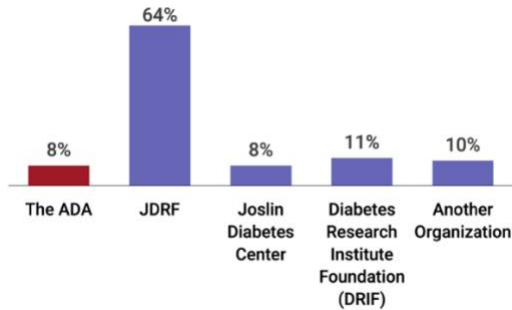
- **Today, the ADA still has a solid reputation** within the T1D community. 59% have a positive general opinion of the ADA, and 34% have a neutral sentiment. See Chart C.

Chart C: How would you describe your general opinion of the American Diabetes Association? <sup>6</sup>



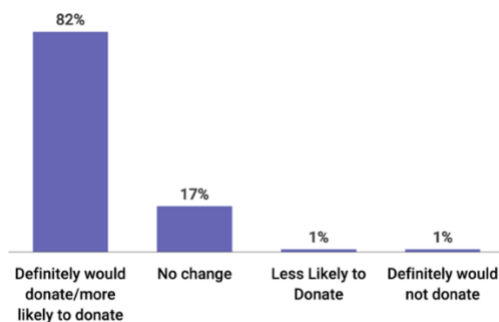
- **Yet, most T1D donors choose to give to other organizations**, not the ADA. Only 8% said they would choose the ADA when making a T1D donation decision. See Chart D.

Chart D: If you had some spare cash that you wanted to donate to a diabetes organization next year, who would you choose? <sup>7</sup>



- If priorities at the ADA shifted, **82% of T1D people said they would contribute to the ADA if a functional cure for T1D took top priority**. See chart E.

Chart E: If the ADA made finding a functional/practical cure for T1D a top priority, how likely would you be to donate to the ADA? <sup>8</sup>



# WHAT WOULD A T1D CURE PROGRAM LOOK LIKE?

A T1D cure program starts with a clear objective, strategies, and a related set of performance metrics. Easy to say, harder to do, but essential for delivering results. Once established, the program can be widely communicated internally and externally with researchers and laypeople. If done well, it will inspire many.

An example program structure might look something like the example below. We present this as a recommendation and a platform to discuss, debate and envision how the ADA may restore a commitment to a T1D cure.

## **Objective:**

- Establish and resource a 5-year plan to advance a T1D functional cure.

## **Strategies:**

- Double each year our level of grant funding for T1D cure research.
- Carve out a dedicated T1D cure accelerator program.
- Initiate a T1D-specific cure venture philanthropy initiative.

## **Metrics of success (for consideration):**

- \$10 Million per year deployed to T1D cure research grants by 2026
- A dedicated team established to identify, fund, and advise T1D cure research projects put in place by the end of 2023 (at the start of the accelerator program).
- T1D cure venture philanthropy fund launched by Dec 2023, and potential investors contacted.
- Direct participation in a significant research breakthrough/milestone achievement within the next five years.

# CONCLUSION

The ADA sits at a crux in its evolution as an organization. COVID has ended but has left the ADA weakened. Type 2 diabetes has become the ADA's focus (at least by default, if not strategic). Fundraising is down to decade-low levels. The T1D community is choosing other organizations to give money to.

The T1D community would welcome the return of the ADA to its cause and will give money in support if the proper steps are taken. The reputation of the ADA within the community remains solid, a good base from which to launch a reinvigorated initiative.

What will the ADA be as it goes forward? The board of directors must decide if the focus will be type 2, which the population numbers support, even if the fundraising numbers do not. **If this is the direction, we argue that the board has a moral imperative to communicate this directly and neither solicit nor accept money from T1D people who want to see their donations used for a T1D cure.**

Alternatively, the board may decide to recommit to T1D. An initial outline for action is above. From the viewpoint of the T1D community, this would be a welcome win-win.

The option that is not sufficient is to do nothing. Nothing is nothing, and such wishy-washy ambiguity does not make for a precise, robust, and future-focused organization.

**Now is the time.**

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End Notes:

1. <https://diabetes.org/about-us>.
2. ADA audited consolidated financial statements 2006-2021; JDCA “American Diabetes Association Financial Deep-Dive” (July 16, 2022). <https://www.thejdca.org/publications/report-library/archived-reports/2022-reports/american-diabetes-association-financial-deep-dive.html>.
3. ADA audited consolidated financial statement 2020. <https://diabetes.org/about-us/reports>.
4. NIH, National Library of Medicine “Epidemiology of Type 2 Diabetes – Global Burden of Disease and Forecasted Trends (March 2020). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7310804/>.
5. JDCA annual “T1D Donor Sentiment Survey” from 2016-2022; JDCA “T1D Donor Sentiment Survey” (June 2, 2022). <https://www.thejdca.org/publications/report-library/archived-reports/2022-reports/t1d-donor-sentiment-survey-analysis.html>.
6. JDCA “What the ADA’s Leadership Overhaul Means for T1D Cure Research” (March 17, 2022). <https://www.thejdca.org/publications/report-library/archived-reports/2022-reports/what-the-adas-leadership-overhaul-means-for-t1d-cure-research.html>.
7. Ibid.
8. Ibid.