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

THE JUVENILE DIABETES CURE ALLIANCE RESEARCH

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The goal of the JDCA is to provide the T1D donor community with an independent analysis of the latest research and fundraising trends.

What Must Change to Achieve a Practical Cure?

A Practical Cure for T1D is any solution that can be widely available in the near future and enables people with established T1D to lead a near-normal lifestyle free from daily disease management routines. The value of a Practical Cure is intuitive to anyone who has lived with the burden of 24-hour glucose management, the cost of diabetes devices, supplies, and drugs, and the fear of the potentially fatal complications of the disease.

Every November for World Diabetes Month the entire diabetes community comes together to raise money in the hope that they can improve the quality of life of people living with diabetes. Our aim in publishing this report is to raise awareness, spur discussion, and ultimately drive systemic change towards the T1D donor's number one priority: achieving a Practical Cure. This report will address the key changes that must take place to make a Practical Cure a reality in the near future. While there are a handful of projects researching Practical Cure solutions, it has not yet been accepted as a priority for the research community and remains a distant fantasy.

This report will look beyond COVID-19 while also acknowledging its current impact on T1D research. Fundraising is down in 2020 and many researchers are pivoting to the global pandemic, putting T1D Practical Cure research at risk. Now more than ever, the community of donors, researchers, and research funders should come together to ensure that the T1D donor's hope is not forgotten.

What Will it Take to Achieve a Practical Cure in 15 Years?

- T1D nonprofits need to standardize and adopt a uniform Practical Cure definition.
- T1D researchers and nonprofit executives need to be incentivized to achieve a Practical Cure in 15 years.
- JDRF and the ADA need to restore T1D cure-focused funding.
- Donors need to advocate for Practical Cure research funding.

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What is a Practical Cure?

A Practical Cure will revolutionize the quality of life for those living with type 1 diabetes, but it does not need to be a perfect solution. A Practical Cure is much wider in scope than a so-called "idealized" cure because it is not predicated on biologically eliminating the disease from the body. Instead, the definition of a Practical Cure is determined by the outcomes that patients want. Any research project that can deliver the outcomes defined in *Figure 1* qualifies as a Practical Cure.

Figure 1.

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.*

Clinical Requirements Needed to be a Practical Cure for T1D

- ☑ **HBA1C <7% and/or >75% Time in Range (70-180 mg/dl)**
- ☑ **Minimal monitoring**
- ☑ **Free diet**
- ☑ **Eliminate hypos**
- ☑ **Only mild and temporary side effects (no long-term side effects)**
- ☑ **Less than 5 days in hospital (if surgical)**

* The amount of time it takes most projects to get through the FDA clinical trial process.

The Highest Potential Research Pathways

Immune System Modification

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

Encapsulation

Involves the development of an encapsulation device to protect the cells from the body's immune response.

Advanced Artificial Pancreas

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

Glucose-Responsive Insulin

"Smart Insulin" can be delivered through a pill, patch, gel or injection and chemically activates in response to changes in blood sugar.

Cell Regeneration

This approach involves regenerating residual beta cell mass that persists in the body even after many years of living with T1D.

Cell Transplantation

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

Gene Editing Cell Therapy

This approach involves editing cells, using gene therapy, so that they are not recognized by the T1D autoimmune attack.

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Pathway to a Practical Cure

The four recommendations below provide a blueprint for researchers, fundraisers, and donors to align with the goal of achieving a Practical Cure for T1D in the next 15 years.

1. T1D nonprofits need to standardize and adopt a uniform Practical Cure definition.

By standardizing a single Practical Cure definition and adopting it as their goal, T1D nonprofits like JDRF and the ADA can leverage their position as grant-giving entities to deliver this outcome on behalf their donors.

To date, neither organization has adopted a defined Practical Cure initiative with a 15-year timetable as one of the main parts of its research portfolio. However, if adopted, we have no doubt they have the ability, experience, and resources to make progress quickly towards delivering a Practical Cure. In our assessment, no other organizations are as well-positioned to make great strides towards a Practical Cure as the ADA and JDRF.

2. T1D researchers need to be incentivized to achieve a Practical Cure in 15 years.

Once a Practical Cure definition with a 15-year timetable has been accepted and adopted, all funders of T1D research need to become more proactive in soliciting Practical Cure projects. T1D researchers and funders should be incentivized to design and pursue Practical Cure projects. In order to achieve this goal, salary incentives must be used to encourage nonprofit leaders and research investigators to pursue a Practical Cure vigorously. Nonprofit CEOs, principal investigators, and the staff within these organizations should see their workflow, performance expectations, and incentives aligned with finding a Practical Cure in the next 15 years.

In 2019, ADA and JDRF executives were paid nearly all of their compensation regardless of whether they made progress toward a cure for T1D. This differs from the dominant model which guides for-profit companies' executive salaries as well as that of a handful of successful nonprofits, where executives earn more when they meet performance objectives. The American Heart Association (AHA), for instance, uses metrics and goals related to both fundraising and mission goal progress to incentivize executives. In 2018, 46% of the AHA's CEO compensation was tied to performance.

3. JDRF and the ADA need to restore cure-focused funding.

In 2019, JDRF used only 38 cents of every dollar raised from donors to fund research, almost 50 percent less than their rate ten years ago. Of that, only eight cents were used to specifically fund cure research. Meanwhile, the ADA spent only $3.7 million (out of $156 million raised) specifically on T1D research in 2018, a 10-year low. This decline must be stopped if there is to be a real chance for a Practical Cure in the next 15 years.

4. Donors need to advocate for Practical Cure research funding.

As the primary source of income for the main diabetes charities, donors play a key role in ensuring that a Practical Cure research platform is a top priority. Eight years of surveys show that donors overwhelmingly support the concept of a Practical Cure. Ongoing pressure from donors to adopt, institutionalize, fund, and fully resource Practical Cure research is critical to the development of a Practical Cure in the next 15 years.