

Juvenile Diabetes Cure Alliance

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What Can Donors Do Today to Drive Practical Cure Development?

Conclusions:

- Donors can significantly influence the prospects of cure development by specifying that their donations be used to fund Practical Cure research
- The major type 1 non-profits can be excellent choices for donors to direct their support for Practical Cure research
- An alliance of donors acting in unison can elevate Practical Cure research to a top priority

Organizations of Focus:

American Diabetes Association (ADA)

Diabetes Research Institute Foundation (DRIF)

JDRF

Joslin Diabetes Center (Joslin)

Our Mission:

To direct donor contributions to the charitable organizations that most effectively fund research with the goal of delivering a type 1 Practical Cure by 2025.

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This report discusses the actions that donors can take to increase funding for Practical Cure research. **This area of research receives extremely little attention from the major diabetes non-profits; only three cents of every cure research dollar are applied to Practical Cure research.** A Practical Cure would provide people with type 1 diabetes with a lifestyle that is not markedly different from individuals without type 1. Directing greater financial support to Practical Cure development increases the likelihood of achieving this objective in the next fifteen years. **The most powerful thing that donors can do to increase the prospects of cure development is to stipulate how their donations should be used.**

Currently, none of the four major charities prioritize Practical Cure research. Their cure development efforts focus on an idealized cure rather than a practical one. A Practical Cure is an outcome-based objective that would free patients from the worries and daily routines associated with managing type 1 even though they would still have the disease. An idealized cure, in contrast, would restore a person to the state they were in prior to being diagnosed with type 1. Developing an idealized cure will likely require many generations at a minimum, in our view, whereas a Practical Cure can potentially be developed much earlier.

Practical Cure Definition



Minimal Monitoring

- ✓ Does not require blood glucose monitoring beyond once a week
- ✓ Keeps A1C levels between 5 and 7



Sleep Worry Free

- ✓ Allows patients to sleep care free



Free Diet

- ✓ Does not restrict a patient's diet
- ✓ Does not require carb counting



- ✓ Best case: Zero side effects
- ✓ Acceptable: Insignificant side effects



Reasonable Meds

- ✓ If pharmacological, an easily managed regime



Fast Recovery

- ✓ If surgical, less than 72 hours recovery

The JDCA advocates that the non-profits focus their cure efforts on strategies with the potential to deliver meaningful results in a relevant timeframe. The major type 1 charities have the capability to spearhead a significantly more effective Practical Cure initiative. Due to their comprehensive resources, the non-profits are uniquely suited to drive Practical Cure research. The non-profits possess a combination of strengths that include:

- Broad and deep scientific expertise
- The capacity to identify projects that target a potential Practical Cure
- Credibility with the scientific community
- The administrative infrastructure necessary to fund and monitor many research projects
- The ability to attract substantial donations on a recurring basis from a broad donor base
- Independence from the influence of revenues and profits that encumber commercial enterprises

These strengths make the major charities excellent choices for donors seeking to fund cure development. However, the charities are not currently applying a high enough proportion of their resources to Practical Cure research, even though this type of research has the most potential to deliver a cure in a timeframe donors would expect. Fortunately, **donors can take action to elevate Practical Cure research to a top priority at the diabetes non-profits.**

Donors have a very powerful voice if they act in unison. Donors leverage their intentions when they focus their collective resources toward the common goal of a Practical Cure. By acting together donors can significantly increase the resources directed to these projects and create greater urgency for curing type 1 as soon as possible. A significant increase in funding for Practical Cure research would ensure that the most promising projects are fully funded.

Actions that donors can take to ensure that their donations support Practical Cure research include the following:

- Stipulate that the donation be used only for research that targets a Practical Cure. Please see the JDCA stipulation letter in Appendix A as an example of how easily this can be done.
- Call the JDCA at (212) 308-7433 for additional assistance regarding how to ensure that your donation is directed to Practical Cure work.
- Refer to the JDCA's Giving Guide as a useful tool for major gifts that are structured to take effect over multiple years. The Giving Guide can be viewed or downloaded from the donor tools on our website.
- Join the Alliance. Your voice will be amplified by uniting with like-minded donors. Alliance members also receive the latest JDCA publications via e-mail. Joining the Alliance is easy. You can sign up at the JDCA's homepage: www.thejdca.org. There are no obligations and your privacy will be respected.
- Stay informed on Practical Cure progress by reading the JDCA's reports.

The most powerful thing we can do is to specify how we want our donations to be used. A stipulated, or restricted, donation requires the charity to use the donation only for the purpose that the donor specifies. When donors give money without a written stipulation, the charity can choose to spend the money in ways that may not coincide with the donors' intentions or expectations. The most effective method to ensure that the non-profits make Practical Cure research a priority is to stipulate that your donation be used to fund research projects that target a Practical Cure.

Stipulating that a donation be used for a specific purpose is as easy as attaching a letter to the donation. Donors can write their own letters, or you can use the JDCA's prepared stipulation letter, which can be downloaded from the JDCA website at www.thejdca.org/donor-action. An example letter can also be seen in Appendix A.

All four of the major diabetes non-profits accept restricted donations. If you do stipulate that your contribution be directed to Practical Cure research, please let the JDCA know. Appendix B lists the four non-profits and their mailing addresses. Additionally, donors may have a favorite type 1 diabetes research center that is not on the list. If you donate for Practical Cure research at those centers, please let us know so that we can stay abreast of their Practical Cure work.

Summary

The major type 1 non-profits have numerous strengths that equip them to support cure development. However, Practical Cure research receives very little funding from the four major non-profits: **just three cents of every cure research dollar**. The good news, however, is that donors can take action today to ensure that the non-profits direct significant resources to projects that can potentially deliver a cure in time to benefit those now living with type 1.

The most effective way we can impact the pace of cure development is to stipulate in a letter attached to our donation that the money must be used specifically for Practical Cure research. Donors united by a common goal of achieving a Practical Cure within fifteen years can significantly increase the funding and prioritization of research that targets this outcome.

Appendix A: JDCA Stipulation Letter

Stipulation Letter

{Month, Day, Year}

{Name of RECIPIENT Organization}

{Street Address line 1}

{Street Address line 2}

{City, State ZIP}

Re: Attached Donation

Dear Sir/Madam:

I would like to take this opportunity to thank you for all the effort your organization has put towards type 1 diabetes initiatives. Without your work over the years there would be far fewer advances in the pursuit of a cure. You have always offered people like me hope that a cure is on the horizon.

In particular, I have a strong and urgent desire to see a Practical Cure for type 1 diabetes delivered as quickly as possible. As a result, I specifically request that the enclosed donation only be used to support research that meets the definition of a Practical Cure (below) and has the potential to be ready for use by the year 2025. For a more detailed description of a Practical Cure, please refer to the JDCA website (www.thejdca.org) or call 212-308-7433.

Sincerely,

Donation Amount _____

Print Name

Sign Name

Date

JDCA Practical Cure Definition:

- i. Minimal side effects
- ii. Not require blood glucose monitoring beyond once a week
- iii. Not require carb counting
- iv. Not restrict patients' diet
- v. Allow patients to sleep care free
- vi. Keep A1C levels between 5-7
- vii. If surgical, requires full recovery of less than 72 hours
- viii. If pharmacological, requires no more than a reasonable pill and/or injection regimen

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New York, NY 10022

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www.thejdca.org

Appendix B: Non-Profits' Mailing Addresses

American Diabetes Association

P.O. Box 7023
Merrifield, VA 22116

Diabetes Research Institute Foundation

200 S. Park Road
Suite 100
Hollywood, FL 33021

JDRF

26 Broadway
14th Floor
New York, NY 10004

Joslin Diabetes Center

One Joslin Place
Boston, MA 02215

Analyst Certification

The JDCA analyst responsible for the content of this report certifies that with respect to each organization covered in this report: 1) the views expressed accurately reflect his own personal views about the organizations; and 2) no part of his compensation was, is, or will be, directly or indirectly, related to the specific views expressed in this research report.

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