The Voice of the Donor for a Cure

Juvenile Diabetes Cure Alliance

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Type 1 Diabetes Research Funding Infrastructure in the United States

Conclusions:

→ The infrastructure that underlies type 1 research funding is multi-layered and complex.

→ This complexity creates roadblocks that inhibit the basic groups within the system from working together toward a common goal.

→ Donor philanthropy generates significant funds with which to pursue type 1 research. However, an extremely limited portion of those funds are allocated to projects that target a Practical Cure outcome.

→ Cure-minded donors have the ability to influence change in the system. They can collectively direct more funds to cure research projects by specifying how their donations will be used.

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.

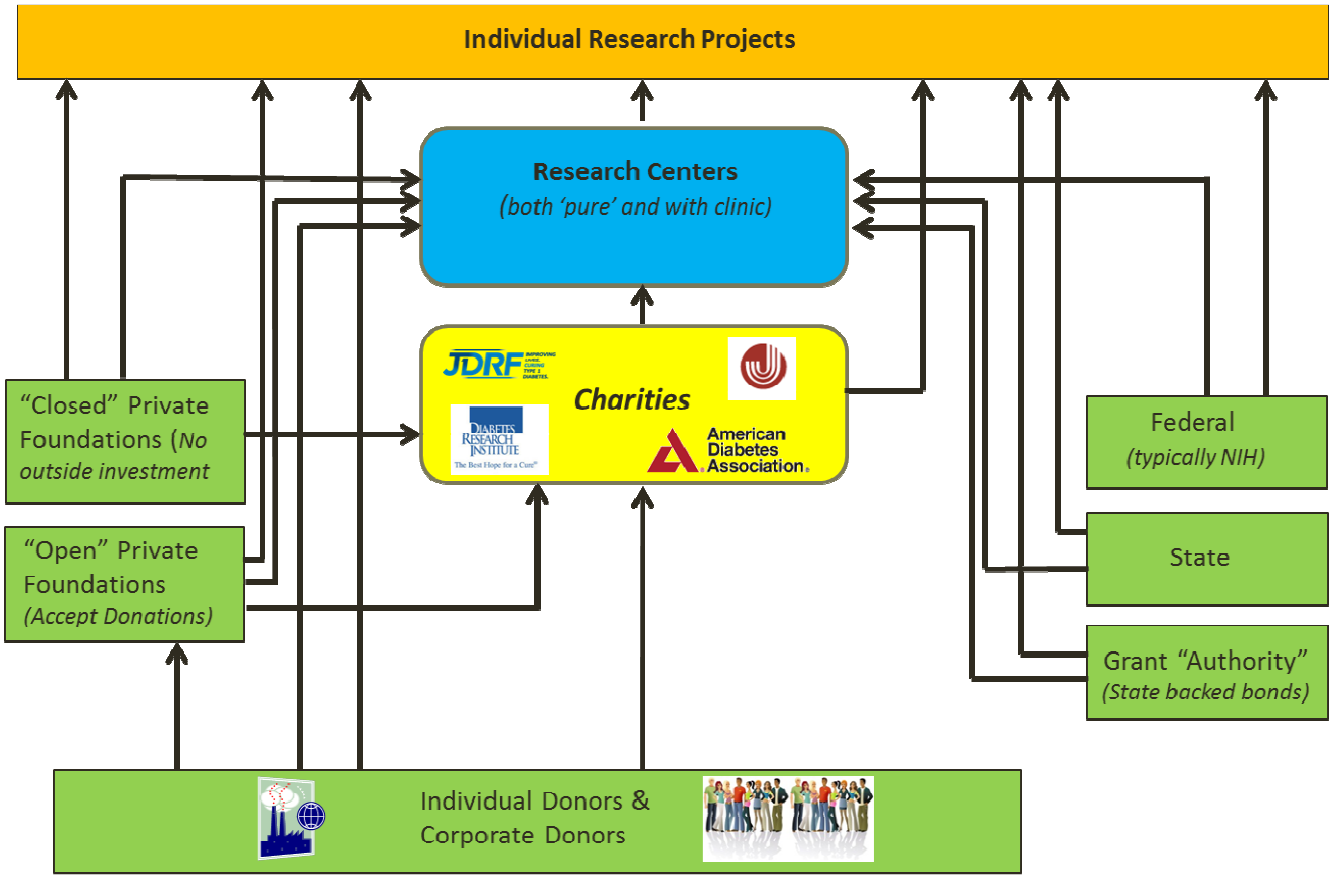
This report provides an introduction to the infrastructure that supports type 1 diabetes research in the United States. With the donors' interest in mind, we describe the type 1 diabetes research funding system by following the money trail from source to laboratory.

The trail will reveal that the research infrastructure is multi-layered and complex. Its labyrinthine structure inhibits focus, transparency, and constructive collaboration, which could significantly slow progress to a cure. However, donors can indeed improve the situation if we work in alliance to counteract the inherent obstacles within the infrastructure.
The report is written in three parts. The first gives a big-picture overview of the diabetes research universe. The second classifies major players in the universe as sources, bundlers, and spenders. The third discusses actions that donors can take to influence change.

I. Overview

The following chart provides a comprehensive and holistic view of the diabetes research system as it exists today. The chart visually depicts how funding for diabetes research advances from source to application. The money trail originates with the sources of funding, which appear in the green boxes and include private philanthropy and government grants. Yellow and blue boxes located in the center of the chart show the position of the charities and research centers as middlemen, or bundlers that raise funds and direct dollars to projects. The money trail ends at the top bar, entitled "Individual Research Projects," which reflects the thousands of research projects funded by the money sources.

Type 1 Research Infrastructure in the United States



II. Sources, Bundlers, and Spenders

In simplified terms, sources, bundlers, and spenders are the three basic groups that make up the type 1 diabetes research infrastructure. The sources provide the funds; the bundlers collect, package, and redirect the funds; and the spenders utilize the funds. Each group possesses its own unique complexities, as discussed below.

Sources

Donor philanthropy and government grants together deliver an estimated $700-800 million dollars per year to all types of activities related to type 1 diabetes.[1] These funds are used for research, education, fundraising, and lobbying, with the research dollars covering all major type 1 diabetes topics, including complications, treatment, prevention, and cure.[2] We estimate that philanthropy raises roughly 50% of the total dollars, while the other 50% derives from government grants.

Only a miniscule percentage of the total amount raised from philanthropy and government sources is allocated to Practical Cure research, i.e. research that would deliver a cure-like outcome for people who are now living with type 1 diabetes.

Bundlers

The major charities and regional research centers are the major bundlers of donated funds. The JDCA closely monitors the four main charities: JDRF, ADA, DRIF, and Joslin, all of whom are adept at raising funds. Additionally, we have examined roughly forty research centers that comprise the largest type 1 research programs throughout the United States. These organizations collect money any way they can – directly from donors, from grants by the big charities, and through government grants. All compete with one another for a finite pool of funds.

The bundlers have the responsibility and authority to allocate the funds as they see fit. Once the bundlers receive a dollar, it becomes very difficult to determine how the donated dollar is actually utilized, and nearly impossible to track the results, or lack thereof, that the donated dollar has driven.

Spenders

The scientists conducting research and performing clinical trials are the spenders in the infrastructure. There may be more than one thousand type 1 research projects underway in the United States. Most of these projects are in early stages of development and have yet to reach testing in humans. Of the projects that are currently in human clinical trials, only five have a shot at delivering a Practical Cure outcome or better in the near term. The system, as a whole, is not driving nearly enough high-quality projects into human clinical trials.

III. Implications for Action

The complexity of the type 1 research infrastructure inhibits rapid progress toward a cure. The current funding system fosters conflicts of interest that preclude a united focus on the most promising cure research. While there is clear merit in funding a wide range of research projects, it is imperative that cure projects with the greatest potential, i.e. with a reasonable chance of delivering a practical cure in the near future, are fully funded. To ensure that such projects receive the requisite funding, the community must unite with the common goal of ensuring that there is a consistent definition of “high potential projects.”

The competitive nature of the funding structure also creates a situation where the bundlers and research centers are incented to withhold information from their competitors. As a result, there is a distinct lack of transparency in

communicating details related to the progress of specific research projects. Improving transparency would result in donors having a better gauge on whether or not their dollars are being used effectively.

We believe strongly in the value of competition to spur individuals to excellence. But we also believe that an appropriate amount of collaboration, by which the best ideas can be shared constructively, is essential to accelerate collective progress towards a cure in the near future. As it stands, the structure clearly emphasizes competition to the detriment of collaboration.

If all players in the infrastructure were to establish a strategic priority to fund and support projects which have the best chance for success in the near-term, it would fundamentally improve the system. To do this, they would need to 1) adopt a baseline definition of a cure, which the JDCA suggests is a Practical Cure or better, and 2) introduce a clear timeline to achieve the cure outcome. Without implementing these changes, the infrastructure will continue to send researchers down numerous paths toward no particular goal and without a clear timetable.

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Endnotes

1. JDCA estimate arrived at by summing the NIH's $150 million Special Statutory Funding Program for Type 1 Diabetes Research, plus estimates of additional regular NIH appropriations for type 1, state grants, state agency funding, private foundation giving, type 1 giving to the ADA/DRIF/JDRF/Joslin, and type 1 diabetes philanthropy given directly to type 1 research centers by donors.
2. Philanthropy excludes type 1 donations made to diabetes clinics for patient care

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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