

Juvenile Diabetes Cure Alliance

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Will JDRF's New T1D Voices Council Influence Cure Development?

Conclusions:

- JDRF has a long and pioneering history of involving donors and volunteers in the process of reviewing and funding research grants
- A new volunteer advisory group, the T1D Voices Council, was created in 2012 to bring a patient perspective to help inform JDRF's research priorities
- While the formation of the Council appears to be a move in the right direction, we would like to see greater organizational change that aligns with the donors' expectations in a rapid and practical manner

Organizations of Focus:

American Diabetes
Association (ADA)

Diabetes Research
Institute Foundation
(DRIF)

JDRF

Joslin Diabetes Center
(Joslin)

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The JDCA has been receiving inquiries from Alliance members regarding the significance of JDRF's new T1D Voices Council ("Council"), and its role in comparison to the disbanded Lay Review Committee. In response, this report will describe the Council, its purpose, and the important role it could play in shaping JDRF's cure development efforts.

Background

JDRF has been a pioneer in involving donors and volunteers in its research funding decisions. With the creation of the Lay Review Committee (LRC) in 1974, JDRF became the first disease-related non-profit where lay volunteers participated in selecting which research grant proposals the organization would fund. The LRC's role evolved with the growth of JDRF's research program from \$410,000 in 1974 to over \$110 million in 2012.

David P. Stenger's article on *The role of Lay Review Committees in diabetes research* describes the evolution.¹ Initially, lay reviewers evaluated research proposals and took scientists' ratings into account to create a list of projects that was submitted to the Board of Directors for approval. Beginning in 1990, lay reviewers also sat in on the scientific advisors' deliberations, which made the scientists more aware of the type 1 community's concerns. However, the scientists continued to focus on basic and exploratory research, and the review process became cumbersome as the research budget grew.

In 2012 the LRC was disbanded and the T1D Voices Council was created. The Council is not intended to replace the LRC. The LRC had significant say in funding decisions at the individual grant level, whereas the Council provides input into research priorities, but does not make funding decisions. The Council's broad focus is "to help guide the organization's activities and ensure that its efforts remain aligned with the needs of people with the disease."² JDRF now has scientists on staff to evaluate and oversee the allocation of research resources. Volunteers who serve on the Research Committee, a sub-group of JDRF's International Board of Directors, also provide input into the research funding process.

What is the T1D Voices Council?

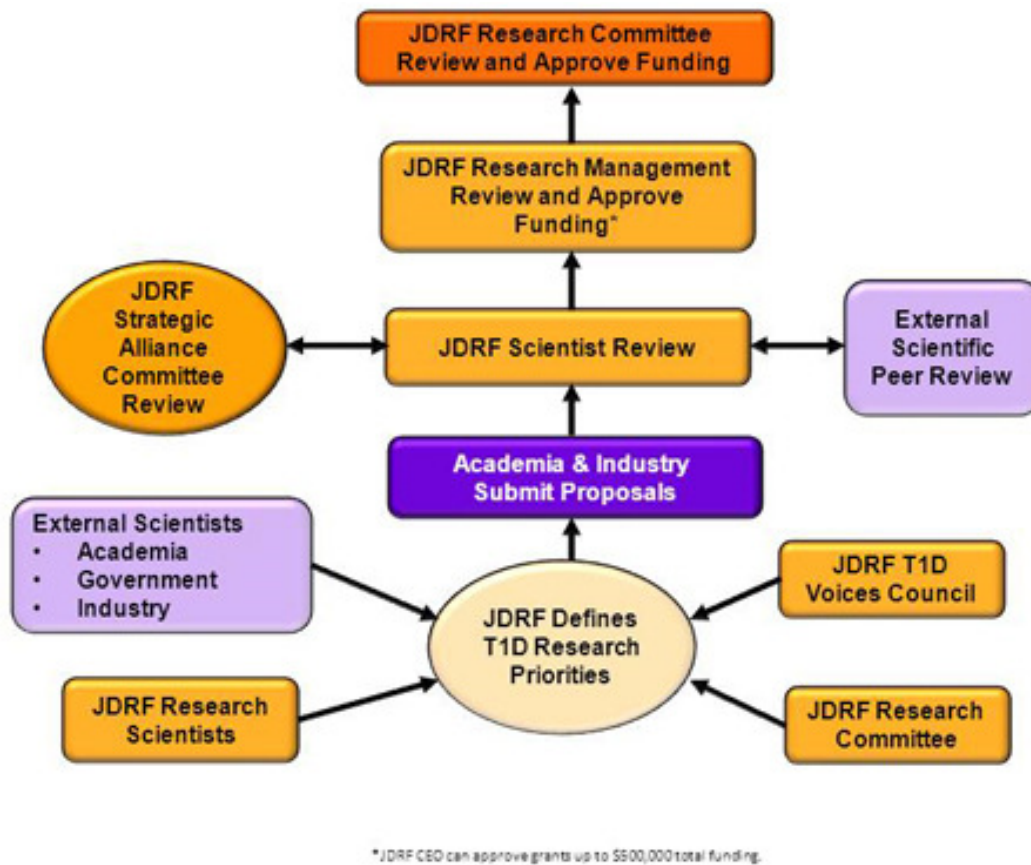
The Council was established as a "patient advisory group" and is "designed to represent the broader T1D community" by offering patient input on JDRF's activities and priorities.³ **The Council will "provide a patient perspective" on a wide range of issues including**⁴:

- how JDRF should define a cure
- what JDRF's research priorities should be
- how JDRF's resources should be split among its priority areas
- what guidelines and expectations should be set for clinical trials

The Council is currently comprised of 17 members intended to represent the diverse population affected by type 1 diabetes. The Council has two co-Chairs, one of whom is JDRF's Chief Scientific Officer. All other members are volunteers. Council members are selected from local JDRF chapters and international affiliates to serve staggered two-year terms. JDRF has not made the membership selection process entirely transparent. Council meetings are scheduled to take place 2-3 times per year.

The Council is one of many groups that participates in JDRF's research funding process. The following chart, obtained from JDRF's website, illustrates the position of the Council in the oversight of JDRF's research funding.

JDRF Research Funding Oversight



Source: JDRF website

As can be seen in the chart, there are several groups that inform JDRF’s research priorities including many constituencies other than the donor. The Council’s position on the hierarchy of influence is unclear, as are specific interactions among the groups represented in the chart. **At this time it is also not apparent exactly what impact the Council’s recommendations will have in shaping or guiding cure research priorities.** Nonetheless, the creation of the Council is an innovative approach in seeking input from the T1 community and we view it as another example of volunteer involvement that has long been a JDRF hallmark.

Summary and Conclusions

JDRF has utilized input from donors and volunteers since its inception and has been a pioneer in volunteer involvement among non-profit organizations. The recent formation of the T1D Voices Council appears to be an innovative way of incorporating the type 1 community’s voice into defining JDRF’s research priorities.

The Council recently held its first meeting. Therefore, it is too early to determine what impact it may have on cure development. There are limitations related to its ultimate effectiveness because it is an advisory group and does not have policymaking authority. Nonetheless, the Council has the potential to favorably impact cure efforts. We would like to see JDRF utilize the Council to comprehensively and aggressively incorporate the voice of donors, as they have at points in the past, in making decisions about research funding.

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Endnotes

1. Stenger, David P., (2003). The role of Lay Review Committees in diabetes research. *Diabetes/ Metabolism Research And Reviews*, 19, 271-279.
2. JDRF website as of June 1, 2013, The T1D Voices Council, retrieved from http://cdn.jdrf.org/wp-content/uploads/2012/12/T1D_Voices_Council.pdf
3. *ibid.*
4. *ibid.*

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