JDRF IMPROVING LIVES. CURING TYPE 1 DIABETES.

Research at JDRF

The JDRF Research Partnership
The Role of Volunteers in Research Decisions

Since its founding, JDRF has built a research program that has placed the perspective of people living with type 1 diabetes (T1D) and their families at the center of the research funding process. Over the years, the amount of research that JDRF funds annually has exploded from a few hundred thousand dollars in those early years to more than an estimated $110 million in 2012. Along the way, JDRF itself has matured from a small start-up to a sophisticated global operation.

JDRF's own evolution has been manifested in many ways. For example, where once JDRF had no Ph.D. scientists on staff, today it has 26 such individuals with a wide range of scientific experience, including several with their own personal connections to T1D. As JDRF's internal scientific team has grown, our ability to lead and influence the global T1D landscape has been strengthened. And that has been critical, given the pace of research progress. Over the last decade, we have seen the development of new treatments and therapies, the substantial increase in funding of T1D research by the National Institutes of Health, the growth of global partnerships with governments and foundations, and the rapid-fire development of exciting and promising new avenues of research (often driven by JDRF). Amid this dizzying change, JDRF has had to continually reassess everything—our priorities, our research strategies, and even how we make research funding decisions.

But one thing hasn't changed, and never will change: T1D patients and families—the volunteers who provide the funding, the passion, and the energy that has made JDRF the most successful and important force in the global T1D community—remain deeply integrated into the JDRF research program.

The balance of this paper provides an overview of the many ways in which JDRF volunteers can engage with the research process, and it highlights JDRF's ongoing commitment to operating a transparent, inclusive, and patient-driven research effort.

I. Funding Research and Setting Research Priorities and Strategies

JDRF volunteers directly engage in providing a patient perspective in making research funding decisions and setting research priorities and strategies through no fewer than four vehicles: the Research Committee, Research Evaluations, Research Workshops, the Strategic Alliance Committee, and the newly announced Type 1 Diabetes Voices Council.

The Research Committee (RC)

The RC is a committee of the JDRF International Board of Directors. In fiscal year 2012 the RC consisted of 23 JDRF volunteers chosen annually by the chair of the JDRF IBOD based on input from the Nominating and Governance Committee and the RC chair. The RC has responsibility for approving both JDRF's long-term and annual research strategy and priorities, approving the annual JDRF research budget, establishing metrics to monitor progress, and approving projects with a budget of more than $500,000. These latter projects represent about 80 percent of total research dollars (projects under $500,000 are approved by the CEO but go through the same process and must meet the same standards as larger ones). Prior to approving a specific funding opportunity, the RC must determine that adequate due diligence was conducted, including both internal and external peer review, and that the project fits within the approved funding priorities and strategy for JDRF.

All members of the RC are volunteers, a fact that preserves and enshrines the guiding principle and hallmark of JDRF: that those who are most affected by the disease, and who have themselves raised the money for research, will determine how funds are spent.

Research Evaluations

Research evaluations are held periodically to assess progress and status reports on specific funded programs to ensure alignment of future direction. Typically, the evaluations involve JDRF scientists, outside scientific reviewers, and the funded investigator. Again, JDRF volunteers participate in these evaluations.

The Type 1 Diabetes Voices Council (T1DVC)

The newly created T1DVC will break new ground in the area of volunteer engagement in the JDRF research program. For the first time, JDRF will have a body with a mandate to represent the broadest spectrum of views, concerns, and perspectives from across the entire T1D spectrum. Its members will include adolescents, young adults, and older adults with T1D, truly giving powerful meaning to the JDRF commitment to be relevant to people living with T1D at all ages and all stages of the disease. But the T1DVC will go even further. It will include parents of both children and adults with T1D, spouses of persons with T1D, even siblings and grandparents of T1D patients. T1DVC members will be drawn entirely from JDRF chapters and international affiliates, a democratic selection process that will ensure that we build and sustain a vibrant pipeline of new volunteers. The T1DVC will meet three times a year and will give the RC, the IBOD, JDRF scientists, and JDRF-funded researchers systematic advice and counsel on where JDRF should focus its resources to meet the full panoply of needs and interests of the entire T1D community.

Strategic Alliances Committee (SAC)

As JDRF looks more and more at ways to bring products to the market, the SAC plays a vital role in ensuring that the structure and terms of industry partnership agreements are consistent with appropriate business guidelines adopted by JDRF. SAC volunteer members periodically (at least annually) assess the effectiveness of JDRF partnerships and look for changes in industry practice or the industry environment that may be relevant to future JDRF partnerships. In addition, the committee volunteers assist in evaluating the commercial attractiveness of needed technologies and, importantly, how JDRF can help fill gaps and attract further investing initiatives to high-priority areas of scientific interest.

II. Spreading the Word

Beyond their role in directly making research decisions and setting priorities, JDRF volunteers are offered a wide range of opportunities both to learn about the research program and to educate their fellow volunteers on where we are going and how we are doing. There are two primary vehicles for this: the JDRF Speakers Bureau and the JDRF Research Information Volunteers Program. Both reflect JDRF's commitment to operating a transparent research program and taking our research program directly to our community so that volunteers around the world, many of whom lack the time or resources to travel to New York, can gain a deeper insight into the work we do.

Speakers Bureau

The JDRF Speakers Bureau recruits and trains volunteers to travel the country explaining the research program, its objectives, progress, successes, challenges, and disappointments to chapter boards, donors, and others. Speakers also explain and report on other JDRF organizational initiatives and programs. The goal of the Speakers Bureau is to create and enhance support for JDRF by effectively communicating our unique mission, goals, activities, accomplishments, and leadership. Speakers also stress our value proposition, tailored to the needs and interests of specific audiences.

Volunteer speakers are selected precisely for their ability to communicate clearly, effectively, and persuasively about the prevailing state of T1D research, JDRF's role in that research, and JDRF's overall priorities, programs, and operations. At the same time, speakers create a personal connection with the audience by sharing their own stories in the context of JDRF's mission, successes, and goals.

Research Information Volunteers (RIVs)

The RIV Program is a partnership between staff and volunteers to disseminate JDRF research information to chapters and affiliates. JDRF chapters and affiliates annually identify one or more volunteers, typically members of local boards, to participate in the program. RIVs are provided training and background information on JDRF research programs, activities, and progress. These volunteers participate in monthly one-hour webinars on various research topics, processes, and issues and have the opportunity to interact directly with JDRF scientists. Calls are held at various times and are recorded to enable participation across worldwide time zones. With their training, knowledge, and tools, RIVs communicate the exciting and motivating JDRF research information in numerous local settings such as local JDRF board meetings, Walks, Galas, research updates, annual chapter meetings, outreach events, and other community meetings. RIVs also are a valuable resource for JDRF's research team, as they can share perspectives from the field, which can give JDRF unique insight into the hopes, concerns, and priorities of its grassroots members.