



JDRF Northern CA Inland TypeOneNation Summit

February 8th, 2020

Presented by: Jude Restis

My Connection – Jude Restis



- **T1 diagnosis way back in 1972 – Currently using LOOP to manage my T1**
- **Supporter of the JDRF since 2004, JDRF Northwest (Seattle)**
- **JDRF connections:**
 - **Research Information Volunteer (RIV) from the start of the RIV program**
 - **RIV National Working Group, helping the continual development and improvement of the RIV program**
 - **Recently asked to serve on the JDRF Research Committee for the Artificial Pancreas program**
 - **JDRF Ride program coach, doing my 20th major destination fundraising ride this year**
 - **JDRF Seattle board of directors**



JDRF's Purpose

Our Vision:

A world without T1D

Our Mission:

Improving lives today and tomorrow by accelerating life-changing breakthroughs to cure, prevent and treat type 1 diabetes and its complications

Our Story

JDRF was founded:

Nearly 50 years ago, by concerned parents, at a time when all we really knew was that our children were getting sick



Today:

It is the single most powerful force and funder in the world driving T1D Research seeking both cures for tomorrow and treatments for today



Our Research, By The Numbers



Committed Over

\$2.5B

Cumulative Research
Funding Since 1970



Awarded

150+

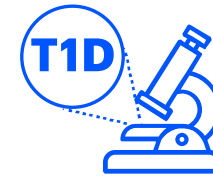
New Research
Grants In 2018



Currently funding

75+

Clinical Trials



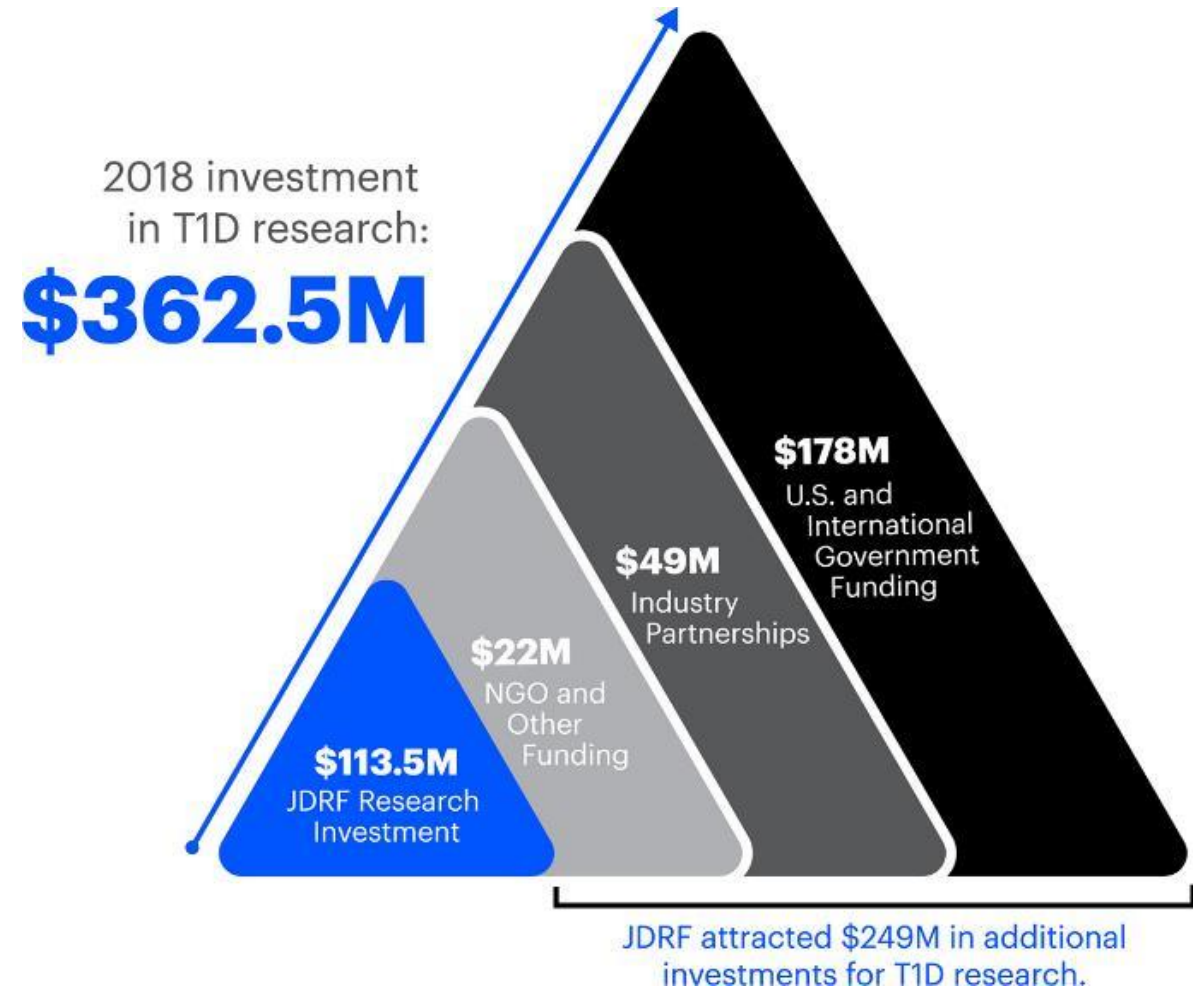
Funding Research in

21

Countries Across
The Globe

Our Impact on T1D Research

- Two years ago, we started tracking not just our grant funding, but how much additional investment in T1D research we are able to generate through advocacy, influence and partnerships
- **For every \$1 from JDRF, more than \$2 additional is invested in T1D research**



Our Aim: Accelerate Progress Across the Pipeline



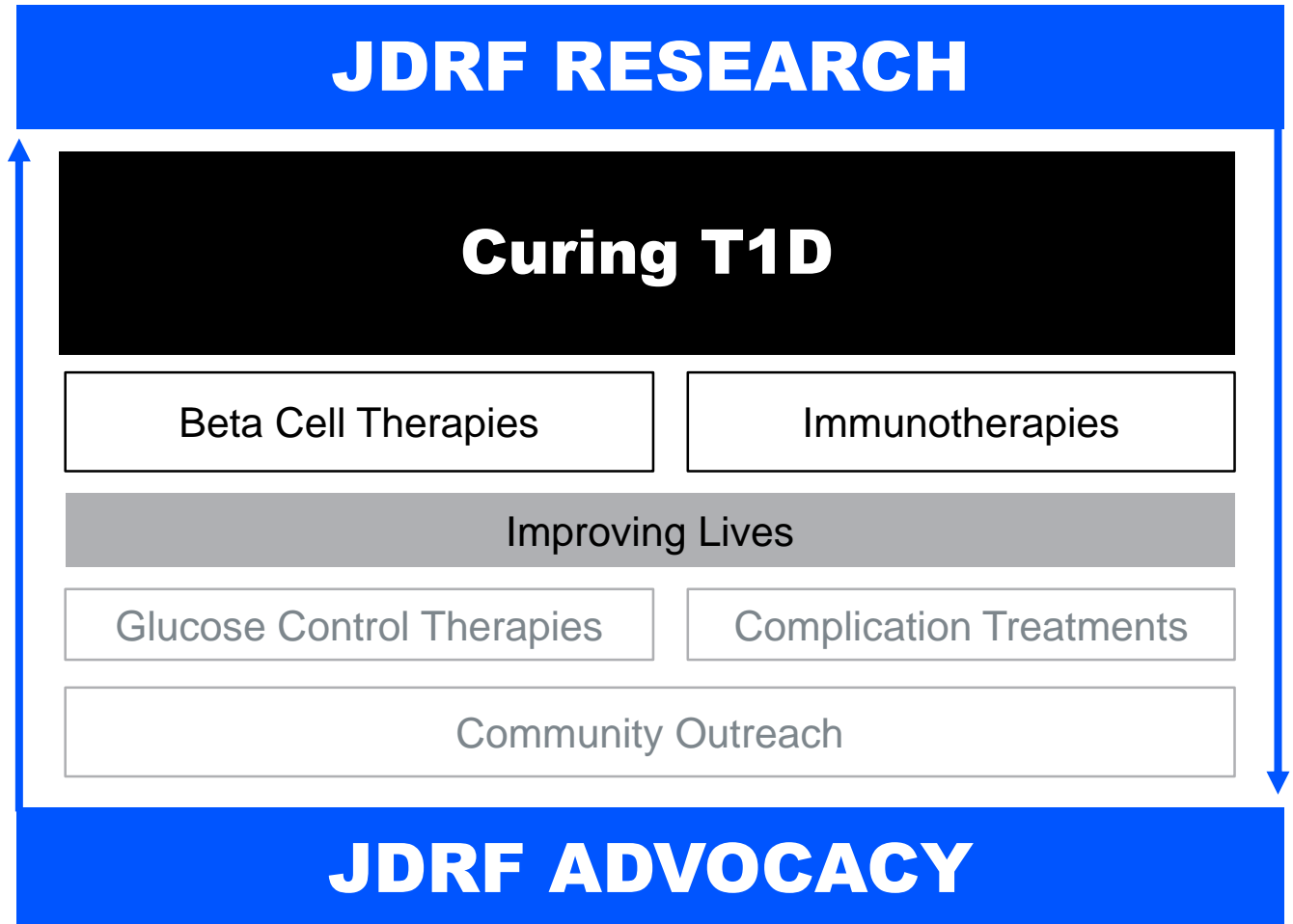
Every research project needs to progress from one stage of the “development pipeline” to the next, until it reaches its ultimate destination – the hands of the community members who need it

JDRF works with our partners to help accelerate the pathway of promising research

Our Approach

JDRF is focused on ***Curing T1D*** and ***Improving Lives***

Through *Research, Advocacy, Community Engagement* and *Strategic Partnerships*, JDRF fights to cure T1D and improve the lives of the T1D Community.



CURING T1D

CURING T1D

Immunotherapies



Stopping the attack on beta cells

Beta Cell Therapies



Creating insulin-producing beta cells

CURING T1D

We face two key challenges in Curing T1D

We must prevent, stop or reverse the loss of insulin-producing beta cells,

and the immune system's attack on beta cells.

Immunotherapies



Stopping the attack on beta cells

Beta Cell Therapies



Creating insulin-producing beta cells

Curing T1

Beta Cell Therapies

Beta Cell Replacement



Create surgically implantable insulin-producing cells with delivery devices that protect them from autoimmune attack while allowing them to release insulin.

Beta Cell Regeneration

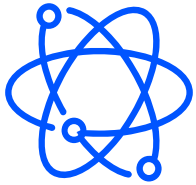


Stimulate existing beta cells into replicating and increase their function, even after a diagnosis of T1D.

Encapsulation Concept



Beta Cell Replacement Goals



Develop a reliable beta **cell source** so that every person with T1D can get this treatment



Find ways to **support the beta cells** so they stay healthy and functional in the body for an infinite amount of time



Shield the beta cells from immune attack to prevent the need for additional immunosuppressant drugs

Semma

Beta Cell Replacement Progress

JDRF
T1D Fund



- Formed to commercialize the ground-breaking research of Dr. Douglas Melton, who set out to make beta cells from human-derived stem cells with previous support from JDRF
- Semma, a JDRF T1D Fund- backed company, agreed to be acquired by Vertex for \$950 million, the largest transaction ever in a T1D cure-based therapeutic program
- Goal: manufacture beta cells at massive scale consistently and develop a method to deliver those cells safely and without rejection
- Represents a significant commitment to commercial development, and ultimately find cures for T1D

Beta Cell Regeneration Goals



Spur beta cell growth so that people with T1D can live without life-long external insulin



Help beta cells survive so the “honeymoon period” (immediately following diagnosis when the pancreas is still producing insulin) can last years or even decades



Protect functioning beta cells to reduce external insulin dependency

CURING T1D

Immunotherapies



Stopping the attack on
beta cells

Immune Therapies

Research has shown that immune therapies can interact with a person's immune system, training it to combat internal battles like cancer – or autoimmune diseases like rheumatoid arthritis and T1D.

While T1D remains one of the only major autoimmune diseases without an effective drug therapy, we are getting close.

Immune Therapies focuses on ways to keep the immune system from **attacking and destroying** beta cells, and to **prevent** the onset and advancement of T1D.



Immunotherapies

Prevention

Today T1D Impacts:
1 in 300 people in the US

In just 30 years:
It will be 1 in 88 people

We know that people are being diagnosed with T1D at a growing rate

We also know that there is increased risk in families with T1D

**Until we have found cures for T1D,
we must prevent or slow its progression
during its earliest stages**

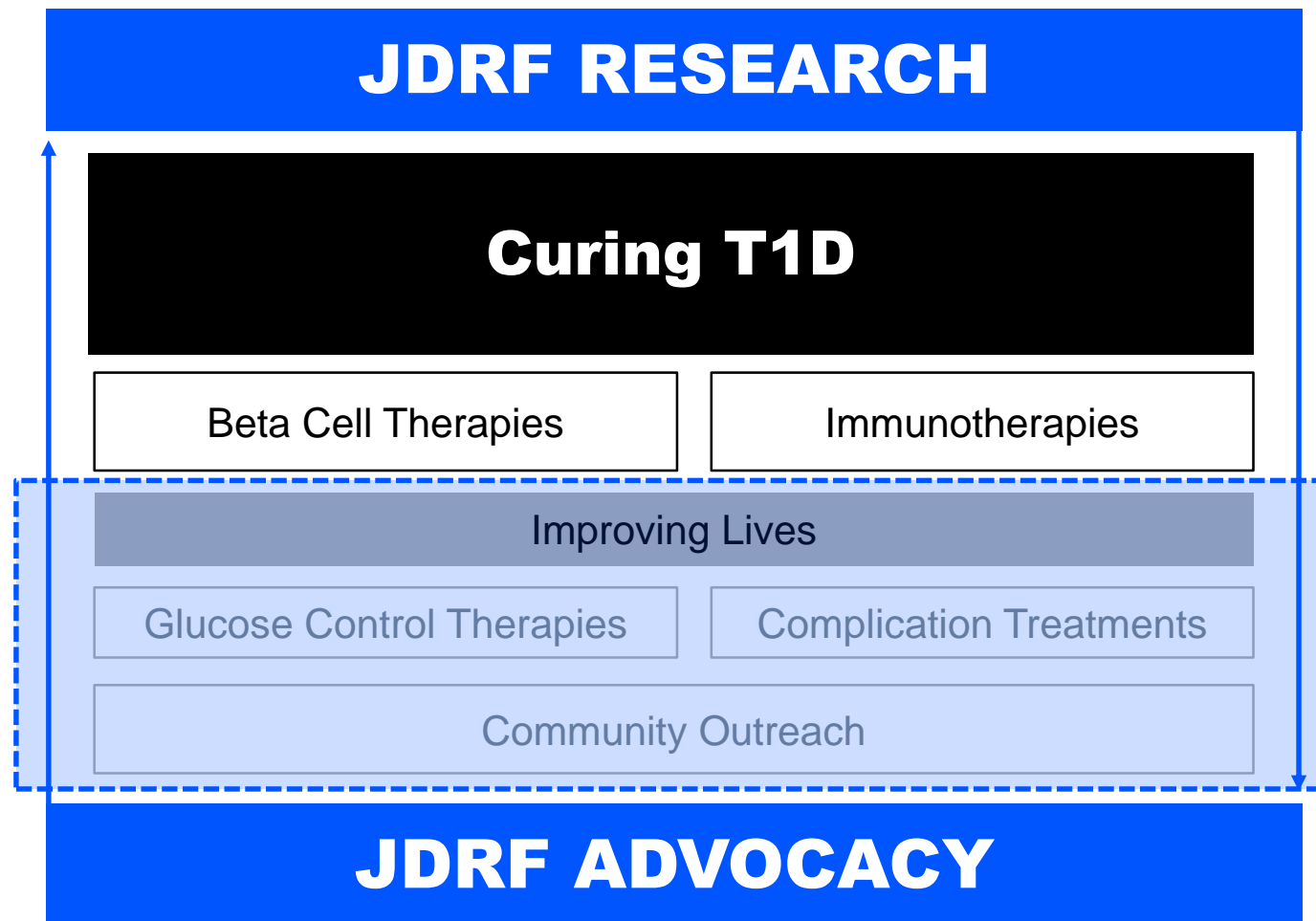
IMPROVING LIVES

As we are part of the T1D Community . . .

We understand the everyday struggles and stress that come with this disease and that the challenges of living a healthy and long life with T1D are very real.

We fight every day to advance research and technology that can reduce the burden of living with T1D and keep people as healthy as possible until we find cures.

We are striving to improve lives by driving research and work in [glucose control](#) and [complications](#) – which includes psychosocial wellbeing.



IMPROVING LIVES

Through Glucose Control



Maintaining glucose
balance for healthy living

Glucose Control Therapies

Less than 30% of people with T1D in the U.S. consistently maintain target blood-glucose control levels – meaning that 70% are at risk of serious health issues.

Glucose Control focuses on helping those with T1D manage glucose levels and overall metabolic balance, including improved artificial pancreas technology, developing next-generation insulins and developing new drugs that control glucose in novel ways.



Glucose Control Goals



Create next-generation insulins that will automatically respond to blood-sugar levels turning on and off as needed



Discover combination therapies using insulin and other drugs to dramatically improve daily blood-sugar management



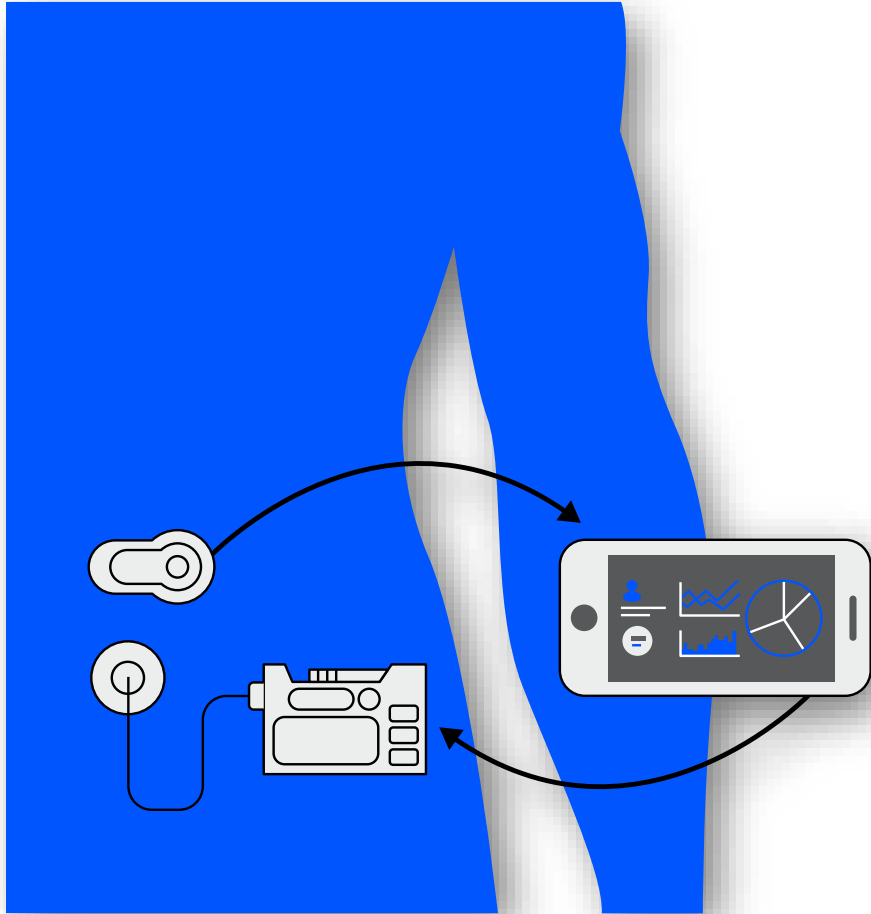
Prevent dangerous lows so that no one needs to worry about the risks of low blood sugar again

Glucose Control Artificial Pancreas

An AP connects to a CGM, monitoring blood sugar levels, then the AP automatically provides the right amount of insulin at the right time

JDRF was foundational in developing the artificial pancreas system, winning FDA approval and getting to market

We now are supporting work aimed at making them smaller, smarter and better



IMPROVING LIVES

Through Complications



Preserve kidney function and
eyesight through early intervention

Complications Therapies

We know that more than 90% of people with T1D develop eye disease within 20 years of diagnosis – and that 1 in 4 develop kidney disease.

We know that prevalence of suicide is higher among young adults with T1D.

Complication Therapies focus on accelerating therapies to prevent and treat kidney and eye disease and improving psychosocial well being.

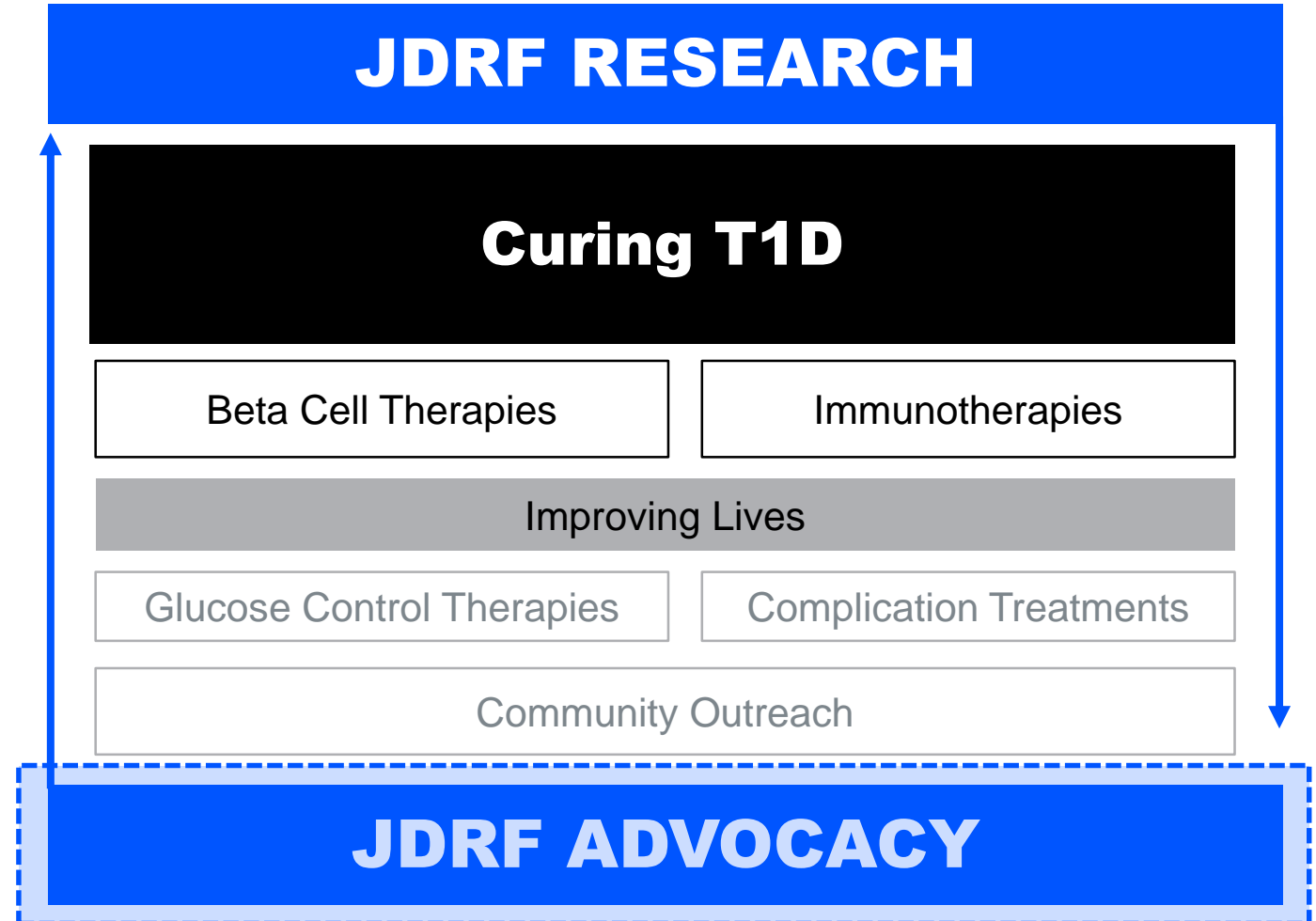


Advocacy plays a critical role in both
Curing T1D and Improving Lives.

Advocacy drives federal investment in T1D research through the Special Diabetes Program, which historically has been \$150M annually.

Advocacy helps accelerate regulatory approval through work with the Food and Drug Administration.

Advocacy also serves as the passionate voice of the T1D Community, fighting for coverage, affordability and choice.



Advocacy

In Addition to the SDP, JDRF Advocacy Also Drives



Coverage

Ensure T1D remains a protected pre-existing condition so that no one with T1D can be denied coverage due to their disease



Affordability

Manage the out-of-pocket costs for insulin and other tools so they remain predictable and reasonable



Choice

Give people access to all life-saving technology, from continuous glucose monitors (CGMs) to artificial pancreas systems

Psychosocial Burden

Psychosocial Strategy



Support research related to psychosocial factors in T1D that promote optimal health outcomes



Train health care professionals to improve patient education and clinical adherence to standards of care recommendations



Educate families about the psychosocial impact of T1D to improve the lives of those affected by it

Psychosocial Material Developed for Health Professionals

Type 1 Diabetes Distress: Identifying and Managing It

Diabetes can be a difficult and demanding disease for individuals to manage. The behavioral and emotional burden of this chronic disease and its management often leads to significant diabetes distress, a common problem that affects one-third to nearly one-half of adults and adolescents with diabetes.^{1,2} Fortunately, all clinicians can play an important role in identifying and managing diabetes distress in their patients.

What is diabetes distress?

Diabetes distress is defined as a range of emotional responses to the specific health condition of diabetes.¹ Symptoms vary across individuals but typically include feeling^{1,4,5}:

- Overwhelmed with the burden of managing a chronic health condition
- Afraid and anxious about complications and disease progression
- Defeated and discouraged when glycemic or behavioral targets, which may be unrealistic, are not met despite one's best efforts

With its cause focused specifically on diabetes, diabetes distress differs from major depressive disorder in many ways, but the two conditions often overlap and share some similar symptoms.^{1,4} Because of the similarities, diabetes distress can be misdiagnosed as depression, which can lead to individuals receiving inappropriate therapy.⁴ This misdiagnosis is also due, in part, to the similarity of common depressive symptoms with symptoms related to poor glycemic control (eg, lethargy, weight loss, insomnia).^{4,6} Distinguishing between diabetes distress and depression is crucial, as management strategies differ.^{4,5}

IMPORTANT

Compared with major depressive disorder, diabetes distress^{1,4,5}:

- Is defined within the context of a disease
- Is not considered to be a psychiatric disorder
- Is far more common
- Shares some similar symptoms but does not meet the criteria for major depressive disorder
- Is unlikely to respond to pharmacotherapy
- Is often directly linked to poor glycemic control and poor self-care (even at low levels of distress)

What is the best way to assess diabetes distress?

The American Diabetes Association recommends screening for both diabetes distress and depression as part of overall care for individuals with diabetes.⁷ The most widely used tools for assessing diabetes distress are the Problem Areas in Diabetes (PAID) scale, the Diabetes Distress Scale (DDS), and the DDS for type 1 diabetes (T1-DDS; Table 1).¹ Abbreviated versions of the first two instruments are available for initial screening of patients in busy practice settings.

The third instrument—the T1-DDS—is the only one that has been developed specifically for people with T1D. This tool differs from other tools in terms of its subscales, which focus on the following areas that have been identified as specific sources of distress for people with T1D:

- Powerlessness (discouragement about the disease)

TABLE 1. Diabetes Distress Assessment and Screening Tools

Assessment Tools	NO. OF QUESTIONS	TIME TO COMPLETE (MIN.)
PAID (Fisher, 2008)	20	10-15
DDS (Polonsky, 1995)	17	10-15
T1-DDS (Polonsky, 2005)	28	10-15
Brief Screening Tools		
PAID-5 (McGuire, 2010)	5	5
PAID-1 (McGuire, 2010)	1	1
DDS2 (Fisher, 2008)	2	1

Adapted from Sweeney LA, et al. J Family Pract. 2013;62(10):9-14.

Type 1 Diabetes Resilience: Recognizing and Developing It

Introduction

Type 1 diabetes (T1D) is a chronic condition requiring a lifetime of effective self-management for optimal outcomes, and those with T1D often face ongoing challenges related to the stress and burden of having a chronic disease.^{1,2} Broadly, they must learn to integrate self-management practices into daily routines, deal with the financial costs of the disease, and face potential social stigma or even discrimination associated with having T1D.^{1,3,4} Additionally, they must learn to cope with difficulties in achieving and maintaining glycemic goals and other treatment targets and slowing the onset of diabetes-related complications.^{1,3} Even sleep may be negatively affected.⁵

Despite these challenges, many individuals with T1D are resilient and able to thrive and live healthy, satisfying lives? What is their secret? Researchers are now working to answer that question by studying "diabetes resilience," with the goal of learning what people with T1D can do to successfully manage their disease, regardless of the difficulties it presents.^{6,8}

Resilience: A Goal Worth Working Toward

Although resilience has sometimes been thought of as a personality trait, it is better defined as the achievement of positive outcomes in the face of adversity or significant risk.^{9,10} Examples of resilience in T1D may include maintaining good quality of life, attaining glycemic targets, minimizing risk of complications, and avoiding hypoglycemia, diabetic ketoacidosis, and diabetes-related hospitalizations.^{8,11} It is also important for those with T1D to have good experiences in other parts of their lives, such as satisfying social relationships and successes at work.⁹

Defining resilience as the achievement of positive behavioral and health outcomes in the face of stress—rather than as a fixed trait that people have or don't have—makes room for the possibility that most individuals can become resilient in some areas of their lives and that this resilience can be developed as new challenges or situations arise.¹² For example, a child with T1D may be struggling socially and in school but, with encouragement and support from parents and doctors, works hard to implement more glucose monitoring and insulin injections, thereby demonstrating resilience in management behaviors.⁹

Fostering Resilience in Individuals

Each person with diabetes has a unique set of strengths, beneficial behaviors, positive attitudes, and support systems that they use to cope with challenges and support positive behavioral and health outcomes.⁹ Clinicians can help patients cultivate resilience by identifying these strengths and finding ways to leverage them to support diabetes care.¹³

Minimizing T1D-Related Family Conflict and Improving Communication

INTRODUCTION

Persons with type 1 diabetes (T1D) must engage in a number of complex daily tasks related to diabetes management, including monitoring glucose levels, insulin administration, attention to carbohydrate intake and physical activity, and treatment of high and low blood glucose levels. Diabetes management is demanding, and family members are important sources of support for individuals living with diabetes. However, working with parents or partners on diabetes management brings its own challenges, particularly when family members may have their own expectations for diabetes care.

Family conflict around diabetes-related tasks is fairly common and is a normal response to the relentless demands and worry associated with diabetes management. However, conflict can also hinder optimal diabetes management. In fact, family conflict is associated with multiple negative health and social outcomes for individuals with type 1 diabetes (T1D), including¹:

- Less frequent blood glucose monitoring
- Higher glycated hemoglobin (HbA1c) levels
- Avoidance of diabetes-related tasks, such as carrying supplies for treatment of high or low blood glucose levels
- Higher diabetes-related distress
- Lower health-related quality of life
- Less frequent engagement in collaborative problem solving

Thus, increasing positive interactions around diabetes care and decreasing conflict can help improve relationships, diabetes management, and glycemic control. This handout discusses potential areas of family conflict and practical interventions to address conflict. It will also provide context for this information in a case scenario.

WHAT ARE SIGNS OF FAMILY CONFLICT?

During a clinic visit, you may see several behaviors that point to family conflict:

- Negative communication by the parent or partner (eg, critical, coercive, or hostile language such as, "I can't believe your HbA1c level is 9% again. I'm done helping you.")
- Silence from the person with T1D and conversation dominance from the parent or partner
- Use of blaming or shaming language (eg, "bad" HbA1c or glucose levels, "failing" to attain health goals, "cheating" on carbohydrate intake, "snacking" food or snacks)
- Overt disagreement about diabetes tasks/responsibilities
- Disengaged behavior from the parent or partner of the person with T1D
- Tearfulness or irritability in the patient, parent, or partner

It can help to directly ask the person with diabetes about their support team, including who helps out with diabetes management and how loved ones help or hinder diabetes management. This can provide important information about the role of parents and partners in diabetes care and potential areas of conflict.

POTENTIAL CAUSES OF CONFLICT

T1D Life Stages
Different life stages tend to bring different types of challenges and conflict related to diabetes management.

Adolescence. Adolescence is a uniquely challenging developmental period, and adolescents and parents must negotiate roles and responsibilities for diabetes care. As adolescents become more independent, they may challenge parental authority while turning their focus to socializing with peers, forming new relationships, and experimenting with alcohol, tobacco, and other drugs.² Some family conflict at this life stage is a given, but persistent or high levels of family conflict have a negative impact on diabetes management and health.³ Ineffective parental involvement (eg, nagging, scolding, giving orders, blaming) is associated with poorer health-related quality of life and suboptimal adherence to care and treatment plans and glycemic control.⁴

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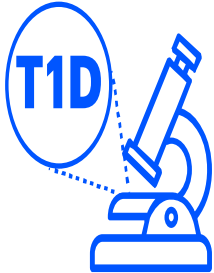
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1 of 5

You Can Help!!

Clinical Trials are Essential to Get Thru the Pipeline



Discovery
Research

Translational
Research

Regulatory
Approval

Healthcare
Coverage

Clinical Adoption

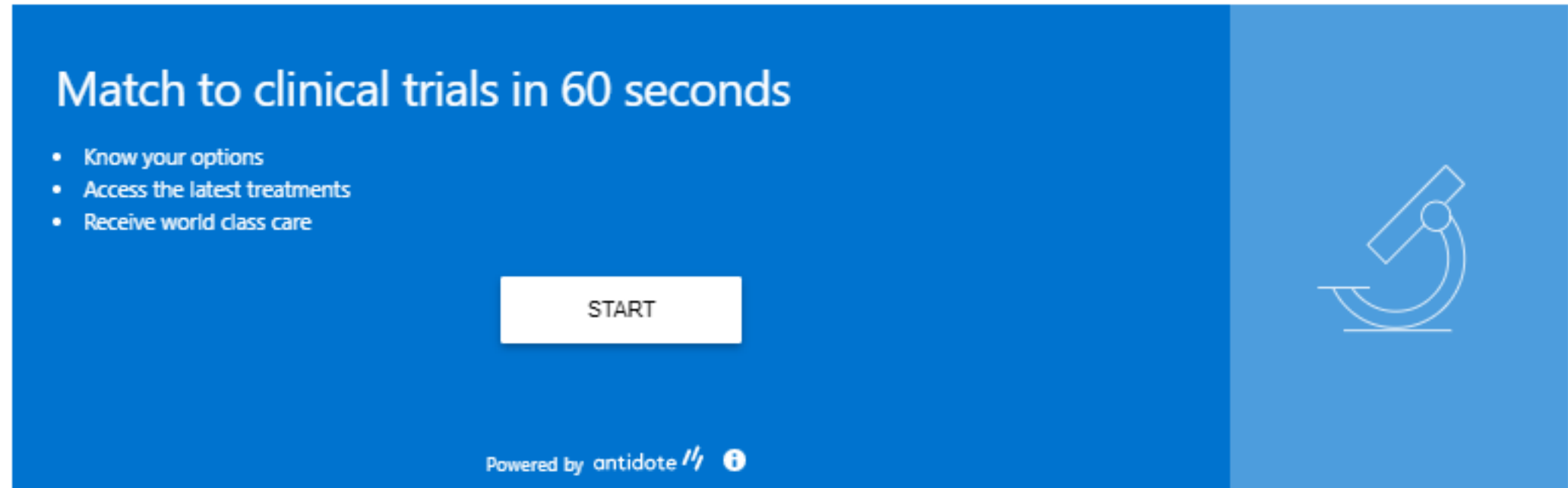
Why Clinical Research is Mission Critical and a Challenge



- More than 80% of the trials are delayed due to slow patient recruitment, resulting in:
 - lengthy trials,
 - delays getting answers,
 - increased costs and
 - disincentive to sponsors to test potential therapies
- Faster enrollment is essential to find better treatments and cure T1D

How to Find a Clinical Trial



Clinical Trials Connection jdrf.org/clinical-trials



Match to clinical trials in 60 seconds

- Know your options
- Access the latest treatments
- Receive world class care

START

Powered by antidote  

The screenshot shows a blue-themed interface for finding clinical trials. It features a prominent heading, a list of benefits, a large 'START' button, and a 'Powered by' section with logos for 'antidote' and an information icon. On the right side, there is a white line-art icon of a microscope.

Matching Tool

Resources Available To You

General Resources

NIH	<ul style="list-style-type: none">Clinical Trials and YouGlossary of Common Terms in Clinical Research	https://www.nih.gov/health-information/nih-clinical-research-trials-you https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms
NIDDK	<ul style="list-style-type: none">Information on Clinical TrialsVideo: NIDDK Director: The basics of clinical trials	https://www.nidDK.nih.gov/health-information/clinical-trials https://youtu.be/36Sd8WpgR94
FDA	<ul style="list-style-type: none">Clinical Trials—What Patients Need to Know	https://www.fda.gov/patients/clinical-trials-what-patients-need-know

Specific Resources for T1D

JDRF Clinical Trials Promotion Handbook	https://jdrforg-my.sharepoint.com/:b:/g/personal/amulvey_jdrf_org/EaJToT3od3BGg0rQpkoiuLoB2IjUidVee3xYkNyijAsD4Q?e=7sycFZ
Type 1 Diabetes TrialNet	https://www.trialnet.org
Immune Tolerance Network	https://www.immunetolerance.org

Turning Type One into Type None

JDRF is the leading nonprofit global funder of T1D research because of our dedicated supporters and passionate volunteers



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BETA
SOCIETY

Thank You / Questions

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