JDRF Northern CA Inland TypeOneNation Summit

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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.

2018 investment in T1D research: $362.5M

JDRF attracted $249M in additional investments for 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.
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
Betacell Replacement Progress

• 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.
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.

**Today T1D Impacts:**
1 in 300 people in the US

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

An AP connects to a CGM, monitoring blood sugar levels, then the AP automatically provides the right amount of insulin at the right time.
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.
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
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 up to 40% of adults with diabetes. However, it can also 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. Symptoms include: increased anxiety, irritability, or anger; depression; emotional exhaustion; and decreased appetite. Diabetes distress can be exacerbated by depression, which can lead to individuals engaging in inappropriate therapy (ITB) behavior. This is due to, in part, the misinterpretation of hypoglycemic episodes as symptoms of depression.

With diabetes distress specifically on diabetes, diabetes distress differs from major depressive disorder in many ways, but the two conditions often overlap and share some common symptoms. It is crucial to consider diabetes distress even in patients who meet criteria for major depressive disorder, as diabetes distress can be as problematic as depression, which can lead to individuals engaging in inappropriate therapy (ITB) behavior. This is due to, in part, the misinterpretation of hypoglycemic episodes as symptoms of depression.

What is the best way to assess diabetes distress?

The American Diabetes Association recommends assessing both diabetes distress and depression as part of all care for individuals with diabetes. The most widely used tools for assessing diabetes distress are the Problem Areas in Diabetes (PAID) scale, the Diabetes Distress Scale (DDS), and the DCS for type 1 diabetes (DCS-T1D). (See Table 1: Assessments of distress for type 1 diabetes and type 2 diabetes.) For both diabetes distress and depression, it is recommended that the patient be seen at least once per year.

Type 1 Diabetes Resilience: Recognizing and Developing It

Introduction

Type 1 diabetes (T1D) is a chronic condition requiring lifelong management for optimal health. Those with T1D often face ongoing challenges related to the stress and burden of having a chronic disease. Early evidence suggests that resilience, or the ability to adapt and grow in the face of adversity, is linked to better health outcomes and quality of life in people with T1D.

Resilience: A Goal Worth Working Toward

Although resilience has been viewed as a personality trait, it is better defined as the combination of positive emotions in the face of adversity or significant stress. Examples of resilience in T1D may include maintaining good quality of life, managing stress, and managing stress, and diabetes-related complications. It is also important to note that resilience is a complex, multidimensional construct that can be influenced by various factors, including genetic, environmental, and psychosocial factors.

Defining resilience as the achievement of positive behavioral and health outcomes in the face of adversity creates a new lens for how people can work together to reach resilience. This approach recognizes that people have the ability to adapt and thrive in the face of adversity, and that resilience can be developed through interventions and support from healthcare professionals.

Fostering resilience in individuals

Each person with diabetes has a unique set of strengths, beliefs, and priorities. It is important to identify these strengths and tailor interventions to support diabetes care.

Minimizing T1D-Related Family Conflict and Improving Communication

Introduction

Type 1 diabetes (T1D) management can be a complex and challenging undertaking, requiring ongoing attention to the needs and demands of the family. However, conflict can be an important aspect of managing T1D, and understanding the role of family conflict in the management of T1D can help families work together more effectively.
You Can Help!!
Clinical Trials are Essential to Get Thru the Pipeline
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

Matching Tool
## Resources Available To You

### General Resources

| NIH | • Clinical Trials and You  
| NIDDK | • Information on Clinical Trials  
|      | • Video: NIDDK Director: The basics of clinical trials | [https://www.niddk.nih.gov/health-information/clinical-trials](https://www.niddk.nih.gov/health-information/clinical-trials)  
|     |                                               | [https://youtu.be/36Sd8WpgR94](https://youtu.be/36Sd8WpgR94) |
| FDA | • Clinical Trials—What Patients Need to Know | [https://www.fda.gov/patients/clinical-trials-what-patients-need-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/EaJToT3od3BGG0rQpkoiuLoB2ljUidVee3xYkNyijAsD4Q?e=7sycFZ](https://jdrforg-my.sharepoint.com/:b:/g/personal/amulvey_jdrf_org/EaJToT3od3BGG0rQpkoiuLoB2ljUidVee3xYkNyijAsD4Q?e=7sycFZ) |
| Type 1 Diabetes TrialNet | [https://www.trialnet.org](https://www.trialnet.org) |
| Immune Tolerance Network | [https://www.immunetolerance.org](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.
Thank You / Questions

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