

## North Carolina Chapter

**DECEMBER 2020 - T1D COMMUNITY INSIGHTS** 



### A Parent's Perspective...

In January 2018, at the age of 10, Cameron Hanley was diagnosed with T1D. It was at that point that life changed in so many ways for Cameron and our entire family. T1D has now been a part of our lives for so long that Scott and I don't need an alarm to wake us up at 2 am to check on him. Counting every carb Cameron eats and monitoring his activities can be overwhelming. As a parent of a child with T1D, I wish I could say it's easy (I say this after Cameron has had to put on a new insulin pod twice today!), but it's all part of our family's new normal.

What made—and continues to make—this journey manageable is the community that JDRF connected us to as soon as Cameron was diagnosed. JDRF gives us knowledge, hope, and connections to the "T1D club," who are extremely supportive and truly our cheerleaders. I hope you are able to get connected and find your cheerleaders, too!

**Gidget Hanley**, Piedmont Triad Board Member

## JDRF SPRING EVENTS

- JDRF Ride
   Register Winter 2021
- TypeOneNation SummitSpring 2021
- Triangle & Eastern
   Hope Gala
   May 1, 2021
- Triad Hope GalaMay 15, 2021
- National Spring One Walk DayMay 23, 2021

Newsletter sponsored by:







66 I'm the strong type, when T1D gets you down, always get back up and fight it.

-Lila Tellone

# GREAT T1D PODCASTS & BOOKS TO ADD TO YOUR LIBRARY

# **Podcasts**

#### "Diabetes Connections" by Stacey Simms

Diabetes Connections – hosted by Long-time broadcaster, blogger and diabetes mom Stacey Simms. She interviews prominent advocates, authors, speakers and asks the hard questions. Great for parents of T1D kids, adults with type 1 and anyone who loves a person with diabetes.

#### "Diabetics Doing Things" by Rob Howe

Diabetics Doing Things, tells the stories of a community who is out in the world accomplishing their goals. It offers encouragement, positivity, tools, tactics, hacks and hope for everyone with type 1 diabetes, while educating the general public on the hopes, struggles and thoughts of the type 1 diabetic community.

#### "The Huddle" by American Association of Diabetes Educators

The Huddle ADCES is proud to bring you a new podcast for your personal and professional growth. The Huddle: Conversations with the Diabetes Care Team features perspectives, issues and updates to inform your practice and elevate your role.

#### "The Leap" by The Diabetes Family Connection

The LEAP hosted by Diabetes Family Connection is a brand new video and podcast series, where they track down and interview inspirational folks living with type 1 diabetes, who have stepped outside of their comfort zones and taken a LEAP of faith.

# **Books**

#### **Bright Spots & Landmines** by Adam Brown and Kelly Close

Adam Brown's Bright Spots & Landmines is a highly actionable guide, he shares the food, mindset, exercise, and sleep strategies that have had the biggest positive impact on his diabetes – and hopefully yours too!

#### **Raising Teens With Diabetes** by Moira McCarthy

The teen years with diabetes on board are a challenging time for parents and anyone who cares about a child with diabetes. Diabetes mom, author, and advocate Moira McCarthy, is a no-nonsense, honest approach at not just surviving but thriving in those years from a mom who has been there.

#### Shia Learns About Insulin by Shaina Hatchell BSN, RN, CDE

Follow Shia and her parent's journey from finding out about this new diagnosis to learning about how insulin works in the body. Best part - IT RHYMES!

#### **Think Like a Pancreas** by Gary Scheiner

Few diabetes books focus specifically on the day-to-day issues facing people who use insulin. Diabetes educator Gary Scheiner provides the tools to "think like a pancreas" -- to successfully master the art and science of matching insulin to the body's ever-changing needs.

#### The World's Worst Diabetes Mom by Stacey Simms

Stacey Simms' parenting philosophy is "not perfect, but safe and happy". Raising a happy and healthy child with type 1 diabetes, as well as any siblings, requires flexibility, planning, and a great sense of humor above all else. It's a journey full of challenges, but you are not alone.

# **Looking for Ways to Get Involved?**

#### **Join JDRF Community Meet Ups**

Every month our chapter hosts zoom calls for families and adults living with T1D. These meet ups are the one hour out of a month to spend with people who "get it". The calls offer new perspectives, tips and tricks for all situations, and a lot of laughs when you need it most. Our community is the best part of T1D, and we want you to be part of it!

- Parent Meet Ups The second Tuesday of every month at 7:00pm on zoom.
- Adult meet Ups The last Thursday of every month at 7:30pm on zoom.
- Request an Outreach Volunteer connection This group of veteran T1D families are trained and ready to support you through texts, phone calls, coffee meet ups, or playdates (when it is safe.) They are ready to help you learn the "art" of living with T1D.

To request a connection with an OV or register for zoom meet ups please email Anne Sutton at asutton@jdrf.org.

#### **Become an Advocate**

Becoming an advocate is easy. You can advocate from anywhere, at any time, and be any political party. Your story and your voice help advance T1D research and ensure that all people living with T1D have access to therapies they need. We need you to share your story and change the future of T1D. Become an advocate at jdrf.org/advocacy and click join today!

#### JDRF's advocacy priorities for 2020:

- Invest in Innovation: Advocate for continued funding for the Special Diabetes Program (SDP), which provides \$150 million a year in T1D research.
- Ensure Regulatory Frameworks that Promote Innovation: Ensure United States regulatory policies provide clear and reasonable pathways for scientific research and therapy approvals.
- Promote Access to Life-Changing T1D
   Breakthroughs: Advocate for coverage, affordability and choice of T1D therapies in the health care system and for national policies that protect those with pre-existing conditions like T1D.

#### **Become a Fundraiser**

JDRF has multiple ways that you and your family can jump in and raise funds for the life-changing T1D research that will one day find a cure.

- JDRF One Walk is the largest T1D event in the world! It is a community celebration for those living with T1D and the research advancements we've all worked to achieve. Dedicated families, friends and companies raise money to improve the lives of those living with T1D, until it is no longer a threat. Register at walk.jdrf.org
- JDRF Ride isn't just a weekend of cycling—it's a global community with an ongoing commitment to find a cure for T1D. No matter where you live, how you choose to ride or how far you go, you'll be surrounded by the T1D community—fellow riders, coaches, friends and family, cheering you on at every milestone. Register at ride.jdrf.org



- JDRF Gala is an amazing evening focused on one purpose, raising funds to support JDRF's mission to find a cure for T1D. The night beginnings with cocktails, silent & live auctions and ends with Fund A Cure. All gifts donated during the Fund A Cure portion of the night go 100% to funding life changing T1D research!
- Team JDRF provides entry into some of the country's most exciting challenge events—including marathons and triathlons. Register at team.jdrf.org
- JDRF Your Way if you don't see a fundraising option you love, create your own; using our "Your Way" platform. Sending out donation links is a breeze, tax letters will be emailed for you, and donation will be tracked so it is easy for thank you notes after your event. All you need as an idea you love! Register at Yourway.jdrf.org

# **Get Connected**

Email: northcarolina@jdrf.org

Website: JDRF.org/northcarolina

### Facebook:

JDRF Greater Western Carolinas JDRF Triangle / EasternNC JDRF Triad

#### Twitter:

@JDRFGreaterWestern Carolinas @JDRFEastern @JDRFTriad

## Instagram:

@JDRFGWC @JDRFTriangle / Eastern NC @JDRFTriad

# Get in Touch

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# TID Research You Need To Read

Updates from the Teplizumab Trial: You're Not Going to Believe the Results.

Last year, at the American Association for Diabetes (ADA) Scientific Sessions, a drug, called teplizumab, was able to significantly delay—for over two years—the onset of type 1 diabetes (T1D) in participants with a high risk of developing the disease. This was the first ever study in humans to show a delay in the onset of T1D. But it doesn't stop there. JDRF has updated results, and this is big. The investigators were able to follow up on the individuals who didn't develop clinical diabetes, and the effect of teplizumab had been sustained: 50% of those treated with teplizumab remain diabetes-free, compared to only 22% of those taking placebo, and the **delay in diabetes onset was close to 3 years** (35 months). These were presented by **Emily Sims, M.D.**, an assistant professor of pediatrics at Indiana University and a JDRF-funded investigator, at ADA's Scientific Sessions.

Additionally, the participants, both the teplizumab and placebo groups, had a progressive decline in the biomarker that measure's the body's ability to produce insulin—C-peptide—preceding the trial. But the teplizumab team found that production of C-peptide actually went up following treatment with teplizumab, especially in the first 6 months after treatment. Like, teplizumab could reverse the downward trajectory of C-peptide loss that was there before the trial.\* Um, wow. And there's more: the increases in C-peptide were correlated with induction of a state of "exhaustion" in "bad" immune cells. Like, they literally took a punch and lost the ammo to keep on attacking the beta cells. Wow (again).

So, could the exhaustion of "bad" immune cells result in not getting T1D or significantly slowing down the time to getting it? Well, we're not there yet, but we're close, and closer to a day when T1D might be prevented, forever.

JDRF Leadership: JDRF funded one of the first clinical trials of this drug, results of which were integral to the teplizumab prevention trial. The study in this report was conducted by TrialNet, a T1D trial consortium funded by NIDDK and by the NIH's Special Diabetes Program for which JDRF is the leading advocate. Multiple studies involving samples and data from teplizumab trials have continued to receive JDRF funding. Teplizumab (now called PRV-031) is currently being tested in a phase 3 clinical trial in people recently diagnosed with T1D, headed by Provention Bio, a company with an investment from the JDRF T1D Fund. If successful, this could become the first immune therapy approved for T1D.
\*In the placebo group, C-peptide still declined.

By Alexandra Mulvey