



JDRF

Northwest Chapter

winter 2010

news

The Road to the Artificial Pancreas

During CEO Jeffrey Brewer's Seattle research update in October, he made it clear that JDRF is utilizing all of its resources to get the long-anticipated artificial pancreas into people's hands as soon as possible. "The JDRF measure of success is not what's happening in a lab or a clinical trial. It's when a doctor can prescribe it and you can benefit from it," he said to a crowd who's been waiting for this device for years.

JDRF is shifting its traditional focus on research to a more comprehensive game plan to further the development of this fully-automated substitute organ that will dramatically improve life for people with type 1 diabetes. JDRF continues to fund research on improved devices and algorithm development. It's also addressing non-research issues, and maximizing advocacy, government relations, and business partnerships to get the artificial pancreas to market as soon as possible.

"We're getting involved in areas that historically we haven't, but they're absolutely critical to get these products to people. Right now, the FDA is our biggest challenge, and JDRF has a unique role to play," he said. "We need to work with the regulatory agency and companies to find a pathway to get safe, effective products to market."

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LITTLE BOY, BIG TECHNOLOGY

"BEEP, BEEP!" Many two-year-old boys make that sound when they play with toy cars or trucks. Luke Bergman makes it when his blood sugar is dangerously low and requires immediate attention.

Luke was an active, good-natured 13-month old when type 1 diabetes arrived in the most frightening way. After his doctor missed the early symptoms, Luke came to the hospital in diabetic ketoacidosis, a condition that can quickly lead to coma or death. After an emotionally turbulent week, his stunned parents, Kristin Fitzpatrick and Erik Bergman, took him home. Now they faced a monumental challenge with little preparation: keep Luke alive in a 24/7 battle won by pricking his finger, adjusting his blood sugar, and inserting needles into his skin.

"It took months to shake the surreal feeling that this couldn't be happening—our baby couldn't possibly have diabetes," says Kristin. "The first month was a blur of checking blood sugar every few hours, seeing it go very high to very low. Trying to sort out the various causes and factors took everything we had. I didn't cry for the first six months because we were in survival mode. There wasn't time."

They were entering a foreign world that included responding to common blood sugar triggers (food, illness, exercise) and swings, controlling Luke's diet with the right amount of carbs, and delivering insulin.

Kristin and Erik opted for a pump, instead of shots, to handle the infinitesimal units of insulin Luke needs (.0005ml) because of his small size and weight. His pump is sewn into the back of his undershirt. The tubing that carries Luke's insulin supply runs down to his bottom or leg, areas with the most fatty tissue, and is inserted under the skin to deliver the life-saving hormone. He's adapted well, and wears it as he sleeps, plays, and gets into normal two-year-old trouble.

Learning to program the pump for an unpredictable, active toddler was a nerve-racking process of trial and error for his parents.

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WELCOME TO GINGERBREAD VILLAGE

See six scrumptious displays of culinary and architectural genius at the JDRF Northwest Chapter's Gingerbread Village at the Sheraton Seattle Nov. 23 to Jan. 2! Or view the displays online, vote for your favorite, and make a donation at gingerbreadvillage.org. Wherever you are, you can text "JDRF" to 20222 to donate \$10 from your cell phone! Thanks to our partners the Sheraton Seattle and Callison.

FAMILY LEGACY FUELS A CURE

We are very grateful to Erwin Kremen, of Bellevue, who left \$75,000 to the JDRF Northwest Chapter this year. Kremen's 12-year-old granddaughter has type 1 diabetes. His son Morris Kremen has been active on the JDRF board and in the diabetes community for many years. Visit jdrf.org/plannedgiving to start your own legacy.

GUIDE FOR NEW T1 ADULTS

JDRF's Adult Type 1 Toolkit covers the complex medical, psychological, and emotional aspects of the disease for recently-diagnosed adults. It can help with the initial diagnosis, day-to-day care, complications, and managing diabetes at work and home. There are resources to connect with other type 1 adults, who can give support and advice on specific issues. Download a copy at jdrf.org/adult.

ROCKER DONATES SONG TO JDRF

Seattle's Chris Ballew, known in the kids music scene as Caspar Babypants and in the rock world as the leader of the wildly-successful Presidents of the United States of America, is giving all the proceeds from his new song "Sugar Ant" to JDRF for the next six months! Download the song at babypantsmusic.com, where you'll find "This is Fun!," his new album for kids and parents, and a schedule of free shows in the Puget Sound area.

SPINNING FOR A CURE

The JDRF Northwest Chapter's cycling club wrapped up the fall Ride for a Cure season with over \$140,000 for research! A special shout out to Ernie Bakker, who rode across the country and collected more than \$20,000 in honor of his granddaughter with type 1. Join the club for local outings at jdrfnwride.org or national rides in fall 2011 at ride.jdrf.org.

SEEKING EVENT & MEDIA INTERNS

We're looking for responsible interns to tackle social media, communication, and special event projects. You might work on our Beat the Bridge to Beat Diabetes event or educate the public about type 1 diabetes. Get valuable skills that may help you land a job or change careers! Contact Marisa Hull at mhull@jdrf.org for details.

Events Calendar

Nov. 23– Jan. 2

January 30

April 16

April 17

April 23

May 7

May 15

May 21

Gingerbread Village

Jump Into Your Diabetes Community

Missoula Diabetes Research Update & Pool Party

Missoula Walk to Cure Diabetes

Bozeman-Billings Walk to Cure Diabetes

South Sound Walk to Cure Diabetes

Nordstrom Beat the Bridge to Beat Diabetes

Tee Off FORE a Cure Golf Tournament

Sheraton Seattle Hotel, Seattle, WA

Jump Planet, Bothell, WA

Splash Montana, Missoula, MT

Dornblaser Field, Missoula, MT

Starting in Billings, MT

University of Washington, Tacoma, WA

Husky Stadium, Seattle, WA

Coeur D'Alene Resort, Coeur D'Alene, ID

We always need volunteers to help with special events! Please contact us at jdrfnorthwest@jdrf.org or 206-838-5153 to learn more.

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Hope is on the horizon. The FDA has named the artificial pancreas a “critical path opportunity,” establishing it as a top goal. In November, the FDA held a public meeting with diabetes experts to discuss how outpatient studies should be conducted, a necessary step before these systems are available to patients.

Meanwhile, cutting-edge research continues around the world. Brewer highlighted an exciting study of UK patients who will leave the hospital and head home with their first-generation artificial pancreas in the next 12 months.

Insurance reimbursement is another significant issue. “Unless these products are paid for by private insurers, companies aren’t interested in making them,” said Brewer. Research is the essential link between continuing product development and coverage.

JDRF’s continuous glucose monitor (CGM) trial showed quantitative health benefits for patients, a key to reimbursement. “There was almost no coverage before the trial, and now up to 85% of people with private insurance have access to CGM. Until there’s proof and a measurable outcome, the insurance companies won’t pay,” as Brewer knows well.

He was the driving force behind JDRF’s Artificial Pancreas Project. After retiring from two successful Internet start-ups, Brewer donated \$1 million to JDRF in 2005 to jumpstart the project, which snowballed into new funds and clinical trials. He has a deep interest in seeing this project through: a teenage son with the disease.

With a father’s passion, proven business success, and a multi-faceted organizational approach, Brewer may be the one to fast-track this long-awaited bridge to a cure.

Learn more: artificialpancreasproject.com.

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They spent hours poring over data from the pump, weighing the leftovers from each meal (what he ate, what he didn’t), and tallying carbs. “We count as precisely as possible because, with little kids, your margin for error is practically nil,” says Kristin.

Luke’s caretakers also learned to manage his disease. Before his diagnosis, he was at a small in-home daycare run by a mother and daughter. They knew nothing about caring for a child with type 1 diabetes, but willingly learned out of love for the boy. Now Luke has a nanny who’s adapted well to the high- and low-tech aspects of his care.

Six months ago, Kristin and Erik added a continuous glucose monitor (CGM) as an extra safety net for their son. The CGM is a sensor inserted under the skin that gives a constant, general picture of Luke’s blood sugar, and sounds an alarm when it nears dangerous levels.

“BEEP, BEEP!” It’s either the CGM or Luke, who occasionally alerts his parents when he’s approaching hypoglycemia before the device. He’s also learning the benefits, and recently tried out “BEEP BEEP - JUICE?” on his dad.

“We hesitated because we hated slapping another device on him,” says Kristin. “I’d recommend it for little kids because their blood sugar is so volatile and they can’t alert you themselves. A CGM really makes the insanity more manageable, and takes some of the incredible stress out of daily life.”

These high-tech devices have made a significant impact on Luke’s health—his A1c level has come down over a point since his diagnosis a year ago. “We have much tighter control,” says Kristin. “When you think of the consequences of your kid living with this for the rest of his life and the risk of complications, being able to keep his blood sugar closer to normal is huge.”

They’ve been thrilled to see Luke return to his happy, easygoing self since achieving better control. But he’s still a normal two-year-old who enjoys saying “no” and perfecting the art of temper tantrums.

Hopefully as Luke grows, the technology will advance into fewer and smaller devices—and disappear altogether one day.

See photos of his Luke and his pump at jdrfnorthwest.org/bigtechnology.

How many more times will they prick their finger to stay alive?

LUKE, AGE 2: 4,740

CHARLA, AGE 43: 64,480

KYLE, AGE 8: 23,608

Join us by:

- * Donating through workplace giving campaigns.
- * Making a holiday donation or tribute.
- * Participating in a clinical trial.
- * Raising funds for Beat the Bridge, Walk, or Ride events.
- * Making a planned gift, stock donation, or charitable donation from your IRA.

Learn more at jdrfnorthwest.org/GIVING, or call 206-838-5153. Thank you.

FOR TYPE 1 DIABETICS, each day brings new questions: Is that a regular headache or one caused by high blood sugar? Break out the testing kit to find out. Am I cranky after a long school day, or is my blood sugar low? Prick my finger to check. It's 2am, and I'm hot and sweaty. Are the covers too warm or are my glucose levels off? Turn on the light, then check for the sixth, or eighth, or tenth time that day. Multiply that by 365 days a year, year after year, and you have very sore fingers that have felt the needle thousands of times. Having type 1 diabetes feels like a lifelong

chemistry experiment conducted on the body.

JDRF scientists are doing their own experiments into the causes and cure for this disease—and developing life-changing therapies like the artificial pancreas, drugs for complications, and beta cell regeneration.

With your support, we're funding hope for a future without diabetes. For the days without finger pricks. For the nights without 2am wake ups—so Luke, Charla, and Kyle can finally sleep peacefully all night long.

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dedicated to finding a cure

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