

JDRF

Northwest Chapter

JDRF Juvenile
Diabetes
Research
Foundation
International

dedicated to finding a cure

summer 2011

news

Junior Advocates Head to Capitol

When a cure for diabetes is found, it will be, in part, thanks to Sara, Kieran, Chloe, Jesse, Hugo, and Gus. They are the Northwest delegates to JDRF's Children's Congress. In June, they'll share their stories of life with type 1 diabetes and ask legislators in Washington, DC to support diabetes research and legislation.

Jesse Hoff of Bozeman, MT has had an extra challenge to deal with since his diagnosis four years ago—lack of medical resources in the state. He sees an endocrinologist who visits his town four times a year. "If my Mom didn't have the ability to take me out of Montana, I would have died last year," Jesse wrote to Montana's Senator Max Baucus, who chairs the Senate Finance Committee that oversees federal research funding. Jesse, 16, looks forward to personally conveying his message to this important leader on Capitol Hill.

Brothers Hugo and Gus Compton of Anchorage, AK share a love of cartoons, animation, lacrosse, and skiing—except when they have to deal with a frozen glucose meter on the mountain. Adventurous and passionate, Gus and Hugo educated their classmates and teachers about type 1, and started a JDRF Kids Walk to raise funds and awareness. Next, they're planning to make a movie about the disease. Down the road, Gus, 10, would like to be a comic strip illustrator. Hugo, 11, wants to open a bakery with low-sugar treats for kids with diabetes.

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TYPE 1 x 2

SWEET, AUBURN-HAIRED LIAM SANDERS, 12, remembers feeling a little off in the fall of 2009. He lost weight, lacked energy, and didn't even want to play with his three brothers. For his younger brother Aidan, 10, it was one late-night trip to the bathroom that confirmed a harrowing new reality for the Mill Creek family—two boys diagnosed with type 1 diabetes just six weeks apart.

Their parents Joan and Brent Sanders were reeling from the shock. "It was a devastating diagnosis the first time," recalled Joan. "There are no words to describe the depths of our despair the second time."

The boys, though frightened and confused, adapted quickly to tubes and devices attached to their bodies, changes to food and exercise routines, and round-the-clock blood sugar monitoring.

"They showed amazing grace, strength, and courage in accepting their new 'normal,' in absorbing all the information to manage the disease, and doing what they need to do," said Joan. "And each has a brother to support him in a way the rest of us cannot."

After the double diagnosis, Joan and Brent read articles and books, talked to other people with the disease, and scoured the internet for resources to learn how to best care for their sons, who now require constant attention. "It's a family effort to manage," said Joan, but they've learned how to maximize their efforts for two kids.

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WHAT ARE THE ODDS?

A child born today has a 1% chance of developing type 1 diabetes. That number jumps to 8% if a sibling has it and as high as 18% if they share a specific genotype. Birth order matters too, says professor Åke Lernmark at Lund University in Sweden. Research has shown that an older child will most likely get the disease first, which was the case with Liam and Aidan.

Northwest News

SEPTEMBER RESEARCH UPDATE

On Sept. 24, the JDRF Northwest Chapter will host top scientists from the U.S. and Sweden to share developments on recent research, new insulin, progress on the artificial pancreas, benefits of exercise and type 1, and more on Sept. 24 at the Microsoft campus in Redmond. Contact the office at 206-838-5153 or jdrfnorthwest@jdrf.org for upcoming details about our Seattle-Sweden Diabetes Awareness Day Events.

BRI DOCTOR USES JDRF GRANT FOR AUTOIMMUNE PUZZLE

Benaroya Research Institute's Dr. Srinath Sanda, a clinical investigator, received a five-year, \$700,000 grant from JDRF to focus on the diabetes autoimmune process. Sanda hopes to find a way to preserve functioning insulin-producing cells in newly-diagnosed patients. People who keep these remaining cells longer have a lower rate of complications and better diabetes management.

A HOMERUN FOR TYPE 1

Take your family and friends out to the ballpark and support a great cause! JDRF is hosting diabetes awareness events at the July 15 Tacoma Rainiers game and the Aug. 17 Seattle Mariners game. Call 253-761-5638 or e-mail Shane at ssantman@tacomarainiers.com for Rainiers tickets. Visit mariners.com/jdrf for Mariners tickets.

SEATTLE TRIAL FOR NEWLY DIAGNOSED

JDRF is enrolling people ages 14–35 who've been diagnosed in the last three months to participate in clinical trial at the Pacific Northwest Diabetes Research Institute in Seattle. Scientists are testing a drug that may slow or stop the progression of type 1 diabetes. Visit pnri.org/clinicaltrials to learn more.

GOV. DAY PAYS BIG DIVIDENDS

During JDRF's annual Government Day this spring, advocates from every state visited Washington, DC to encourage their legislators to support acceleration of the artificial pancreas project. JDRF is working hard to fast-track FDA approval of out-patient trials. Advocates also thanked legislators for supporting the Special Diabetes Program, which provides \$150 million for federal research for two years. Scientists in our state received \$36 million of the total.

DESTINATION HOPE

Ready for an exciting, life-changing challenge? Join Team Northwest on the ride of a lifetime! JDRF Ride to Cure events take place in Burlington, VT (July 28–31), LaCrosse, WI (Aug. 11–14), Tahoe, NV (Sept. 9–12), Death Valley, CA (Oct. 13–16), and Tucson, AZ (Nov. 17–20). Our trainers will help you prepare to ride from 25-100 miles. Make new friends cycling along scenic routes while raising money for a cure. Learn more at jdrfnwride.org or e-mail Susan at shorst@jdrf.org.

Junior Advocates (continued from p. 1)

Second-grader **Chloe Lilley of Port Orchard, WA** and her grandparents hand out brochures and post type 1 information online to spread awareness to as many people as possible. Chloe, 8, enjoys being a Brownie and taking jazz dance classes. Her strong spirit is helping her adapt to a new life. Chloe's grandfather says, "I'm trying to be as strong and supportive as she is, but she's a tough act to follow."

Kieran Boyle of Seattle, WA is determined to live a full, fun life and find a cure for type 1 diabetes. Kieran ('Kiki') is an excellent skier and basketball player with professional sports aspirations.

Kieran, 15, has met with state lawmakers and corporate executives to ask for their financial support for JDRF. He's been very successful. "Kiki's Incredible Team" is one of the top family fundraising teams for the Beat the Bridge to Beat Diabetes event in Seattle.

Diabetes has not slowed **Liberty Lake, WA resident Sara Grozdanich, 15**, since her diagnosis in 2007. She plays varsity soccer; competes in track and cross country races; and skis all winter while maintaining straight A's in school. She's won several awards for sports, academics, and her resilience and positive attitude about diabetes. In her spare time, Sara participates in JDRF events and discusses her disease with legislators.

THANK YOU to the sponsors of the 2011 Nordstrom Beat the Bridge to Beat Diabetes for your unwavering support and helping us raise over \$1.3 million for diabetes research!

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THANKS to the generous organizations who supported the South Sound Walk to Cure this year!



Kitsap Bank and Metro Parks Tacoma

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Nearly two years later, they've streamlined Aidan and Liam's care and involved them at every step. Both boys wear pumps, change infusion sites the same day, analyze their pump logs, and suggest tweaks to their insulin protocol.

Joan maintains a straightforward, positive approach to her sons' health and the effect it has on their lives. "Having a child diagnosed with diabetes is a major event, and your life will never be the same. But it's very important to keep everything in perspective. Managed properly, diabetes should not prevent your child from doing anything that other kids do."

She stresses the importance of keeping a positive outlook for herself and her family. "Your child's attitude about diabetes is, in large measure, a reflection of your attitude. It's vital to approach diabetes management as matter-of-factly as possible," she advised. "It can be difficult, but it's very important."

"It's a lot of work to keep these boys healthy—and an extraordinary amount of effort to keep them ordinary." To that end, this close-knit, resilient family is determined to give Liam and Aidan a normal life despite the 24/7 worries and complications of a life-threatening disease.

Aidan and Liam snowboard, play year-round sports, hang out with friends, and include type 1 advocacy among their extra-curricular activities. These remarkable boys have raised funds for JDRF research, served as Beat the Bridge youth ambassadors in May, and recently shared their experience with type 1 diabetes on KING TV's New Day Northwest morning show.

Their optimism grows with their involvement in the diabetes community and knowledge of promising scientific advances. "JDRF is a big part of our lives because they're helping kids like me and Aidan live a normal life," said Liam. "We really have a lot of hope. We've got geniuses working on a cure."

Events Calendar

July 15	Diabetes Awareness Night/S. Sound Walk Awards Party	Tacoma Rainiers Game, Cheney Stadium, Tacoma, WA
July 28–31	Ride to Cure	Burlington, VT
Aug. 11–14	Ride to Cure	LaCrosse, WI
Aug. 17	Diabetes Awareness Night with the Seattle Mariners	Seattle, WA
Sept. 9–12	Ride to Cure	Tahoe, NV
Sept. 24	JDRF Northwest Chapter Research Update	Microsoft Campus, Redmond, WA
Sept. 25	Spokane Walk to Cure Diabetes	Riverfront Park, Spokane, WA
Oct. 13–16	Ride to Cure	Death Valley, CA
Nov. 17–20	Ride to Cure	Tucson, AZ
Nov. 25 – Jan. 1, 2012	Gingerbread Village	Sheraton Seattle, Seattle, WA

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

Volunteers! Help Us Support the Diabetes Community!

The JDRF Northwest Chapter is recruiting outreach volunteers to educate and support people with type 1 diabetes at every stage of life. There are many ways to help:

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- **Become a mentor** Coach volunteers to provide e-mail or phone support to families and individuals in Washington, Montana, and Alaska. Outreach volunteers offer emotional support and practical advice to people grappling with a new diagnosis, managing diabetes at school or work, considering new products, and other issues.
- **Organize social events for adults** Help to coordinate events that may feature a panel of speakers with type 1, endocrinologists and researchers, or people using continuous

glucose monitors (CGM) and other new devices. These informal gatherings are opportunities to exchange information, share experiences, and meet other adults who understand the disease.

- **Connect with the healthcare community** Provide hospitals, doctors, and school nurses with type 1 diabetes resources. These include the JDRF Bag of Hope for newly-diagnosed children and teenagers, a toolkit for adults, online and in-person support programs, updates on CGM insurance coverage, materials for school staff, and other resources.

You can make a significant contribution by reaching out to others in your area. Get involved by contacting the JDRF Northwest Chapter office at 206-838-5153 or e-mailing Outreach Chair Barbara Bendrick at barbarabendrick@hotmail.com for more details.

Keep updated while conserving resources.

Sign up for our eNewsletter at jdrfnorthwest.org/subscribe today!



dedicated to finding a cure

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