

JDRF T1D Voices Council



Bill Parsons

Co-Chair, T1D Voices Council (FY13–15)



A native New Yorker, Bill lives in Bethesda, MD, with his wife, Kerry, 11-year-old daughter, Natalie and eight-year-old son, Will, who was diagnosed with T1D at age three. Bill comes to the JDRF International Board of Directors from the Board of Directors of JDRF's Capitol Chapter, where he chaired the Major Gifts Committee. He continues to actively participate in the chapter's annual Walk, Ride, and Gala activities. Additionally, he spent almost three years on the Lay Review Committee, where he focused on beta cell and immune therapies. Along with Chief Scientific Officer Richard A. Insel, M.D., he now co-chairs the newly formed Type 1 Diabetes Voices Council.

Bill Parsons is Chief of Staff to Representative Chris Van Hollen (Democrat, Maryland). In that capacity, he is responsible for managing the daily operations of Congressman Van Hollen's Capitol Hill office. Previously, he served as legislative director to Congressman Van Hollen, where he oversaw the Congressman's legislative agenda, and as associate director for government relations at the American Council on Education, where he lobbied Congress on education policy.

Tanner Barton



Tanner Barton is a high school senior in Dublin, OH. Diagnosed with T1D at age eight and with celiac disease at age 10, Tanner is a top student and an accomplished athlete. Currently the captain of his high school swim team, Tanner has represented Ohio on a regional level and is a former State of Ohio age group

champion in the 50-yard and 100-yard butterfly events. Tanner has used an insulin infusion pump since age 10, and in addition to calculating his carbohydrate intake, he adheres to a strictly gluten-free diet.

As volunteers with the JDRF Mid-Ohio Chapter, Tanner and his family have participated in the JDRF Walk to Cure Diabetes for nine years and have supported and attended their local Gala for four years. Tanner has represented JDRF as a Youth Ambassador for several years and was a delegate at the JDRF 2009 Children's Congress. As one of only two teenage members of the chapter speakers' bureau, he is an accomplished speaker, and has made numerous research and personal presentations. Additionally, as part of the approximately 10 percent of people with T1D who also have celiac disease, Tanner brings an important firsthand perspective to the T1D Voices Council.

Rachel Brown



Rachel Brown is a registered dietitian living with her husband, Ryan, in Nashville, TN. A few weeks following their wedding in 2009, Rachel recognized symptoms of T1D in her husband, who was subsequently diagnosed with the disease. Rachel is now in training to become a certified diabetes educator. In

her efforts to better understand the burden of living with T1D and educate her patients with it, Rachel once wore a continuous glucose monitor and recorded her own blood-glucose levels for a week.

Rachel and Ryan captain the Brown Sugar team in the JDRF Walk to Cure Diabetes every year. Rachel was a founding member of the JDRF Middle Tennessee Chapter's Young Leaders Board, in which capacity she mentors others in the T1D community and helps promote the Promise Gala Late Party—an innovative fundraiser aimed at the young professional community in Nashville. Rachel has also worked with local news media to bring more attention to and educate the public about T1D.

Ethan Dunham



Diagnosed with T1D at age 13, Ethan Dunham has lived with the disease for nearly 20 years. He believes that having to pay such close attention to the highly nuanced interplay of food, exercise, stress levels, and other factors with insulin doses and blood-glucose levels made him a more health-conscious person

than he otherwise would have been, and positioned general wellness as a core priority through his adulthood. Being also keenly aware of the toll that T1D takes on individuals and families, he is deeply invested in JDRF's mission.

Ethan is vice president of organizational development for Cogent HMG, an industry leader in hospital medicine. He is also a visiting lecturer in human and organizational development at Vanderbilt University. He is a dynamic leader, speaker, and published author. For the past year, Ethan has served as the president of the Young Leaders Board of JDRF's Middle Tennessee Chapter. He has been instrumental in the success of the group, which has raised more than \$19,000 for JDRF during his tenure.

Ethan is the father of a young daughter, and in addition to better treatments today and a cure for those with T1D, he is particularly interested in efforts to prevent T1D in those at high risk for the disease. He would also like to see more energy and resources put into research of the psychosocial effects of T1D and family dynamics of those who care for people with T1D.

Sara Falconer



Diagnosed with T1D in 1974, Sara Falconer has seen dramatic changes in the treatment of the disease. She has been intrinsically involved with JDRF since the organization's earliest years. In addition to participating in the Walk to Cure Diabetes almost every year since the age of 10, Sara has completed bike-a-thons;

manned JDRF booths at health fairs; volunteered with the Southern Arizona Branch for many fundraising events; and spearheaded an adult T1D outreach and support group in her area.

Sara has vast experience as a community organizer. Professionally, she is the director of membership services for the University/Resident Theatre Association, a nonprofit organization that acts as a liaison between university and professional theater in communities across the country. She also coordinates a children's science program; directs plays in her own city; and teaches drama to young people.

While she remains steadfastly hopeful that a cure will be found in her lifetime, Sara is also interested in prevention, to help protect her nieces and nephews from developing the disease. For both efforts, she has participated in T1D clinical trials throughout her life. Sara has worn an insulin pump for nearly 20 years and currently also wears a continuous glucose monitor. As someone who has experienced retinopathy in both eyes and undergone both laser treatment and vitrectomies, she brings firsthand experience to the discussion of funding for better treatments, both for improved blood-glucose control and diabetic complications.

Dan Hair



Dan Hair is the father of an adult son with T1D. Sean Hair, now in his 30s, was diagnosed with T1D in 1991. In addition to serving on the boards of the San Diego and Los Angeles Chapters of JDRF, Dan was the founding board president of the Utah Chapter in 1995. He has served on JDRF's National Chapter Development Committee,

and is currently a member of its Audit Committee. Dan is also currently chairing the Utah Chapter Board of Chancellors.

As the Chief Risk Officer for the Workers Compensation Fund, a mutual workers' compensation insurance company based in Utah, Dan is well respected among his peers and is a well-known leader in his community. In 2011 Dan received the "Hope For The Future Award" from the Utah Chapter. Dan holds degrees from UCLA and USC and is a professional safety engineer by training. He and his wife, Caroline, are the parents of 4 other children. Dan and Caroline are members of the JDRF Beta Society.

Having raised a child with T1D through nearly two decades of treatment developments, he implicitly understands the impact of the disease and is passionate about finding a cure. He is particularly excited about JDRF's Artificial Pancreas Project and beta cell regeneration therapies now being researched.

"When I attended my first annual conference back in 1994 I met an elderly couple from Nebraska who had lost a son to diabetes many years earlier. Despite losing their personal fight against diabetes they were committed to continuing the efforts to make a better life for others. That was the moment for me when I knew I was all in and couldn't stop until we beat this disease."

Joan Ingram



Joan Ingram is the mother of four children, the two youngest of whom have T1D. Her daughter Lucy, now 12, was diagnosed at age seven. Her son Nick, now 18, was diagnosed at age 16. As a long-time, dedicated donor, fundraiser, and advocate for JDRF, Joan has exceptional knowledge of JDRF-funded research, and also of diabetes policy in the United Kingdom.

A resident of Aberdeen, Scotland, Joan has many years' experience in communications and business. She enjoyed a highly successful, 17-year career as a political broadcast journalist, during which she anchored a wide variety of political programs including the nationwide series aired from the Scottish Parliament. After completing an MBA, Joan moved into the world of business and established with her husband The Fifth Business, a company that delivers internal communications and change solutions to a range of blue chip companies, with particular emphasis on the oil and gas sector. The company now has offices in three countries. Earlier this year, Joan consolidated her business training with an executive education program at Harvard Business School.

Joan has extensive experience serving on review boards similar to the T1D Voices Council. She currently represents JDRF on the UK National Health Service (NHS) Scottish Diabetes Group, a committee established by the Scottish government to bring a consistent, high-quality approach to diabetes care throughout the country. The group comprises medical professionals and four lay people. This year, Joan was also appointed by the UK Health Secretary to sit on the independent NHS Pay Review Body, a group of eight people who review evidence and advise on the salaries of health-service employees across the country. Joan was instrumental in persuading the ruling party in Scotland to increase the number of children treated with insulin infusion pumps from two percent to 25 percent. This target will now be met by April 2013.

Nicole holds master's degrees in journalism and public health, and is currently seeking her doctor of public health degree from the University of South Florida.

Johan is one of the founding members of JDRF Netherlands. The organization's newest affiliate, JDRF Netherlands was established in 2010.

C. Jun Martz



C. Jun Martz is the grandmother and backup 24-hour caregiver of eight-year-old Trinity Martz, who was diagnosed with T1D at age five. She brings to the T1D Voices Council a firsthand perspective on the unique position of grandparents in dealing with T1D to support both their grandchildren and their children.

Jun enjoyed a successful career as a speech and language therapist in clinics and schools. She established the Speech Therapy Program for Prince William County, VA. She also spent 13 years with the United Cerebral Palsy Early Intervention Program, evaluating infants at risk, counseling parents on stimulation techniques, and working with nonverbal and severely language-delayed children. Jun also has a long leadership history with non-profit organizations. She spent 14 years on the board of the Schuylkill Symphony Orchestra (SSO), during which she established the SSO Guild and the Schuylkill Youth Orchestra and served a six-year term as president.

Jun and her husband, Uzal, have been dedicated donors and fundraisers for JDRF for three years. Jun is a member of the JDRF Triangle/Eastern North Carolina Chapter Board of Directors, serves on its Major Donors and Outreach Committees, and is past chair of family events. Jun has attended JDRF research summits and toured T1D research facilities. She and Uzal have participated in JDRF outreach efforts by giving presentations on T1D and JDRF-funded research, and by hosting dinners featuring research updates for T1D families.

Jean Norris



Diagnosed with T1D in 1986, Jean Norris has lived with the disease for 26 years. She has participated in the JDRF Ron Santo Walk to Cure Diabetes and served on the Gala Committee and the Executive Board (2006 to 2012), and as secretary (2009 to 2011) and nominating chair (2011 to 2012).

Diagnosed with T1D at the age of 21, Jean spent most of her life hiding her disease from others. In 2006 she joined the JDRF Illinois Chapter to work toward the cure. This avenue afforded her the opportunity to speak to others about the power of sharing information in T1D management.

Jean is a managing partner at Norton|Norris, a Chicago-based marketing/consulting/training firm focused on the higher-education sector. She is also a licensed master practitioner in neurolinguistic programming. In 2012, Jean and her son, Michael, published *No Sugar Added—Straight Talk from Those Living with Diabetes* (www.nosugaradded.org) to provide a voice for those successfully managing the disease and a resource for those newly diagnosed. All proceeds from the sale of the book are donated to JDRF. Jean and her husband, Vince, split their time between Chicago and Michigan with their dog, Spanky. Their son, Michael, is a senior at Eastern Illinois University.

J.R. Rhee



Father to an 11-year-old daughter who was diagnosed with T1D at age seven, J.R. Rhee is a member of the Board of Directors of JDRF's Northern NJ-Rockland County Chapter, where he volunteered as a member of the Strategic Planning Committee and the Annual Walk Committee. He is also a research information

volunteer for the chapter. His wife, Jennifer, is active on the Outreach Committee and is a mentor for newly diagnosed families. With his family and friends, J.R. has formed a Walk team for the past four years. He also helped his daughter initiate a Kids Walk to Cure Diabetes. J.R. lives in Emerson, NJ, with his wife and his daughter Rachel.

J.R. traveled the world working as an e-commerce consultant and e-commerce global project manager for a European company and many Fortune 500 companies for the last 15 years before he changed his career to become a public elementary school teacher. He now works for the New York City Public Schools as a second-grade teacher, helping underprivileged children find a love for learning and using technology to improve their academic skills. J.R. is a member of the Technology Education Committee at his school.

Sally W. Southard



Sally W. Southard was diagnosed with T1D when she was 10 years old and has lived with the disease for 47 years. Her mother was diagnosed with T1D at age 35, five years before Sally's diagnosis. Her great-grandmother also had T1D. In the 1960s, Sally and her mom had to sterilize glass syringes for their

once-daily injections of insulin the following morning, as well as test their urine for sugar with Clinitest tablets and test tubes. They have seen many changes and improvements in available treatment technologies since then. Sally began using an insulin pump when she was 30, as she felt the need to have good control of her blood sugar before getting pregnant. She had two normal pregnancies and deliveries. Also, she has had no complications involving eyes, kidneys, nerves or heart. Sally's mother has been on an insulin pump for 13 years.

Sally has been a member of the JDRF Greater Blue Ridge Chapter in southwest Virginia since 1981, serving as a chapter board member for two-year terms every three years. She has been a Denim and Diamonds Committee member since its inception five years ago and will be chair of the 2013 Gala. Sally has served on the Walk Committee and participated in the Walk to Cure Diabetes for the past 20 years, and she has delivered Bags of Hope to families when possible.

Sally is currently a pediatric nurse practitioner working in an asthma and allergy clinic for children. She has been a pediatric nurse in some capacity for 32 years and serves on several local nonprofit boards. She is chair of the Salem City School Board, which she has been a member for 17 years.

Theodore L. (Ted) Willke



Ted Willke was diagnosed with T1D 40 years ago. Starting with single shots of NPH, he learned to measure his blood glucose and started on an insulin pump in 1982 at a clinical trial at the Virginia Mason Clinic in Seattle. The AutoSyringe pump was called a “brick”; it was roughly the size of the original cell phone.

Ted joined the JDRF Lay Review Committee in 2004 and again in 2011 after finishing his service with the federal government. He has a connection with the Western Pennsylvania Chapter of JDRF. He started a newsletter for patients in the clinical trial called “PUMPERS.” It grew into a magazine with subscriptions around the world. Baxter Travenol took on publication while he remained the editor. T1D has been a life-long learning experience for Ted, with hard lessons in maintaining control and reducing his hemoglobin A1c. He is fortunate to have had no major complications, a result, he says, of maintaining tight control for 30 years.

Ted spent a career developing new technologies and ended his career heading a safety regulatory agency in the U.S. Department of Transportation. Previously he headed the Carnegie Mellon Research Institute. An engineer with degrees in aerospace, nuclear, and systems engineering as well as business administration, Ted also became a pilot after petitioning the FAA for years for the right to fly. Currently, he is restoring a 1946 Piper Cub and flies a 1947 Air Force trainer aircraft, an Aeronca L-16A.

