Letter from the Editor

Hello,

I just read Elizabeth’s college admissions essay. She was writing about a hurdle that she had overcome. She also wrote that having diabetes is like running a lifelong marathon and you must keep running. The hurdle she was proud of conquering was not diabetes, it was something else. I won’t go into that hurdle, but she went on to say that living with diabetes made her strong enough to jump that hurdle. It took a little while for her words to sink in. I was proud and sad and then proud all over again. This is exactly what we had hoped for when she was diagnosed almost 17 years ago—that one day, diabetes would just be a part of life, not a major, daily, constant hurdle and battle. Granted, it is daily, and yes it can be a battle, but it isn’t constant. I was proud that she was balanced, but I was sad that living with diabetes is so normal and then I was proud that she is so very strong. Her strength inspires me and I can be a little less afraid of letting her go.

Elizabeth has been in a transition period this year. She is finishing up her Associates Degree at a local college and she is practicing being an adult while we—her advisors and sometimes critical parent—look on and nod. Diabetes is hers now and we have begun learning how to just stand by and support her. I think of the day we met our endocrinology team at Seattle Children’s when she was 2 years old and I wish I could tell my scared and distraught self that we would make it through childhood and she would grow to be a strong and amazing person. I can’t go back in time and I don’t know if I truly would want to, but I can tell parents who are just beginning this journey, and parents in the middle, and parents in transition, like we are, that we have good kids. Yes, we deal with ‘dumb ol’ diabetes, but we can find balance. We can be kind, we can be thankful, we can be careful, and we can trust that when the time comes when we are no longer the main care givers, our kids will know how to keep running in this life-long type 1 diabetes marathon. We can believe that there is always—always—something new on the horizon to make their run easier and we may soon see the reason for their running cured.

We will transition into the biggest fans and supporters of our first adult child with type 1 diabetes. Jonathan has three more years at home, so we don’t have to completely give up the T1D parent life, but this will be our last letter. Thank you for all the years of support and care. We wish you the very best. We will need each other. Cheers.

Andy, Renea, Elizabeth, Katarina, Jonathan and Zariah Zosel

Interview with Alex Dugdale

Alex Dugdale is 26 years old. He teaches, plays sax, tap dances, and he has type 1 diabetes. I caught up with him the other day and he agreed to be interviewed for Diabetes Matters. Alex lives in an apartment on Queen Anne in Seattle. He was followed by our diabetes team here at Seattle Children’s for many years.

Gail Watts, LICSW

When were you diagnosed with diabetes? I was about to start middle school and one night I got up in the night and didn’t know what was going on. I was kind of scared before going back to bed. The next morning my mom knew that diabetes was a possibility and I went to Seattle Children’s, where I was admitted. My mom says she has only seen my dad cry twice and my diagnosis was one of those times.

What does your work life look like? I work for Bishop Blanchet High School where I teach beginning band to 8-8th graders. (Continued on Page 2)

Diabetes Matters — Spring 2016, published twice a year. Issue No. 29
Seattle Children’s Hospital—Research Foundation 4800 Sand Point Way NE, Seattle, WA 98105

Spring 2016
A newsletter for kids with diabetes and their families

Diabetes Matters

Interview with Alex Dugdale — Continued from Page 1

I get my jazz fix at Edmonds-Woodway High School where I work with their 2nd jazz band. I also teach jazz saxophone to seven private students. When I was performing at a jazz club in the University District I played with a group called FADE. The club no longer exists, but our group has gone on to play in many locations such as Tulia’s and Capital Cider. I am in my second year of graduate school at SFU where I am working towards a Masters of Education.

How do you fit the diabetes into your performance? Performing music is exciting to me, so my blood sugars can easily drop. I check before a performance and then I check again when we take 20-minute breaks in-between sets. If I’m playing sax and tap dancing for two hours I keep my pump connected and will have a 60/40 mix of diet root beer and regular root beer to sip on if I need to. But if I have a 45-minute set of tap dancing coming up, in the second set then it’s easier. I just disconnect my pump when I’m half through the first set. If I feel low I’ll just tell the audience that the rhythm section is going to do a trio number. I’ll then check my blood sugar and take care of myself while they’re playing for the audience.

Do you have a “go to” snack? Yes. 4-6 ounces of San Pellegrino Sparkling Fruit or a fruit snack.

Have you had any rough times with your diabetes management? It was really tough when I went across the country to college at the Eastman School of Music. I loved my time there, but I was off my ADHD medication for two years and was very busy with school, so I found it hard to have a regular schedule. In my junior year I even needed to be hospitalized once due to an illness that turned into DKA [ketoadisosis]. I made it through tough, and when I returned to Seattle I reestablished a schedule and am proud to say I’ve done really well since then.

What advice do your parents give you about your diabetes? When I was young they helped me calculate exact doses for my favorite foods. We got it down to a science. I just had trouble in college and let it go. Now, I would say my parents still will ask, “How did you go to the doctor’s appointment got?” and if I’m sick or something they will remind me that it’s helpful to do some extra checking of blood sugars. I also just enjoy myself.

Do you do anything special to acknowledge your diabetes anniversary? I do not—never even entered my head. My challenge has been to make diabetes a priority in my life. I have a chronic condition and it’s at the top of my list to take care of.

How/where do you find inspiration? Almost everywhere! I’m someone who loves to be around others to recharge…more on the extrovert-ed side. There are lots of people who I love and care about. I get inspiration from going to a show with friends or looking out my kitchen window at the Space Needle with the 12 on it! I love teaching music and playing music. I want to be able to completely express myself in my music, so I want to take the best care of myself that I can. Emotion and expression are so important to me. When I dance I want to be able to feel my feet move, and when playing music, I want to feel my fingers on the sax. Dancing, playing sax, writing a song—all are personal expressions. I also just enjoy myself and want to have a long, full life.

What do you want other young people to know about living with diabetes? Things come up. Accept that diabetes is a part of your life. This is what I know: I tap, play sax, I teach and I have diabetes.

Remembering Joanie Warner

Erin Alving, ARNP, CDE

It is with heavy hearts that we share the news of Joanie Warner’s passing. Joanie was a nurse practitioner on our Endocrinology and Diabetes team from 2006 through 2013. Her career at Seattle Children’s goes back to the early 90s when she worked for many years as a clinical nurse specialist in Cardiology. Joanie was such a special person, beloved by coworkers, patients, and families. We are so grateful for her significant contribution to kids with diabetes and their families at Seattle Children’s. From her volunteer time on the ADA camp committee and long hours at camp, to writing protocols and guidelines for how we manage kids with diabetes, to her dedication to patients and families—Joanie worked above and beyond the call of duty. We were always amazed at Joanie’s tireless upbeat, humorous, and enthusiastic approach to her job at Seattle Children’s. We will always remember Joanie’s smile, humor, and kindness. She is missed more than we can say.

Alex Dugdale — Spring 2016, published twice a year. Issue No. 29
Seattle Children’s Hospital—Research Foundation 4800 Sand Point Way NE, Seattle, WA 98105
A Perspective on Diabetes

Gail Watts, LICSW

I recently had the good fortune to listen to and speak with William Polonsky, PhD, CDE when he presented in Vancouver, British Columbia at the International Diabetes Federation’s World Diabetes Congress. Dr. Polonsky is a seasoned psychologist who has worked for many years with individuals who have diabetes. His message is consistent with that of Barbara Anderson, PhD and Richard Rubin, PhD, who are also leaders in the diabetes psychosocial arena and whose knowledge and skills have informed our work at Seattle Children’s. I asked Dr. Polonsky if I could use a few of his slides for this short article because I thought it might be helpful to some of you.

As you know living with diabetes can be quite the balancing act! And because there is so much balancing to do, and it is just so constant, there are times when it feels precarious. You often hear about the target A1C of 7.5%, which can feel elusive as you are out there living your life every day. When your child’s numbers are less than stellar, there may be times that you fear you are putting your child’s health at risk or that you are failing in some way. And then there’s the data about complications from diabetes, which is scary! Trying to ensure that everything that can be controlled is controlled can send a parent into overdrive.

Over the past 30 years there have been tremendous advances in diabetes care that have significantly reduced the incidence of severe complications from diabetes.

The slide below shows data from 1978 about the rate of the most severe complications experienced by those living with diabetes over the course of 30 years. Note the high rates of severe vision loss, amputations, and nephropathy—complications that are possibly among your greatest fears. These were the times when there was no A1C, improved insulins or insulin delivery systems, and access to quality health care was anything but assured.

The outlook is vastly improved, thanks to the many advancements in diabetes management. This is a message of great hope and one to really embrace. This hope, along with holding realistic expectations, can be helpful as you go forward. If your son or daughter’s A1C is above the target 7.5, please know that any positive behavioral change can make a difference. If you focus on good habits, outcomes typically follow. A realistic expectation for you and your son or daughter might sound like this: HEALTHY CHOICES MOST OF THE TIME. This expectation can be lived into each day and helps to create general well-being and life-long healthy habits. We encourage you to take full advantage of your diabetes team—your medical provider, the nurse educator, dietitian, and social worker. We are all here to consult with you and your children.

References


Deckert T, Poulsen JE, and Larsen, M. Prognosis of Diabetics with diabetes onset before the age of thirteente. Diabetologia. 1978; 14: 363-370.

Comments can be directed to either: Andrew & Renea Zanol at reenazanol@gmail.com or Gail Watts; gail.watts@seattlechildrens.org

What’s faster than a speeding locomotive and able to leap through cyber space in a single bound? This newsletter can sent electronically! If you would like to start receiving this newsletter by email, please send your email address information to eretta.levine@seattlechildrens.org. We will continue to send the newsletter by U.S. mail unless otherwise notified.

Let’s move forward to 2009 and look at the next slide, showing rates of the same complications for those living with diabetes 30 years later.

T1D Complications After 30+ Years

(Continued on Page 4)
What’s Happening

Community Events

National Sibling Day Celebration: April 22 & 23, 2016, 9am-3pm, Bellevue
This two-day event will be a sibling facilitator training, workshops on sibling issues for family members and service providers, gatherings of Sibship providers from Washington State and elsewhere. For more information, contact Don Meyer at donmeyer@sibingsupport.org or 206-297-6368.

Panther Camp: July 25-July 29, 2016, Camp Beracha, Black Diamond (near Auburn, WA)
Panther Camp is a day camp for children ages 4 through 13 with type 1 diabetes. For more information visit https://www.daps.info/panther-camp.html.

ADA Camp Sealth: Aug. 1-6, 2016, Vashon Island
A 75-year tradition, ADA Camp Sealth offers children with diabetes the opportunity to experience an incredible camp with the support of leading medical staff. Camp is held at Camp Sealth on Vashon Island, WA. For more information visit www.diabetes.org/ada/camps/sealth.

4th Annual ConnectTID Family Camp: October 2016, Stanwood
ConnectTID Family Camp will be held at Warm Beach Camp in Stanwood, WA, about 50 miles north of Seattle. Camp registration will likely open during the summer months. For more information, visit the ConnectTID website http://connecttid.org/family-camp.

Networking

ConnectTID
Bringing people together who are impacted by type 1 diabetes through events, programs, social media, and professional education and support activities. Upcoming events include: tween (9-13) and teen (14-18) activities, summer picnic, fall family camp. In 2015, it was held in October, and parents’ nights out. For more information and upcoming dates of events visit www.connecttid.org or visit the Facebook page www.facebook.com/ConnectTID.

JDRF Coffee Talks
JDRF offers Parent Coffee Talks as a way to connect and find support in the T1D community. This group is made up of recently diagnosed families and those that have more experience dealing with the highs and lows of TID.

People interested in attending Parent Coffee Talks should contact Karine Roetgers, JDRF Outreach Manager, kroetgers@jdrf.org.

For more information, visit http://northwest.jdrf.org or contact Karine Roetgers, JDRF at 206-708-2240.

Camp

Family Camp at Camp Leo: May 28 & 29, 2016, Federal Way
Camp Leo’s first ever Family Camp is an overnight camping experience filled with fun activities and diabetes education for the entire family! For more information visit www.campleo.org or 206-486-8486.

Camp Leo: July 2016
Camp Leo for children with diabetes is dedicated to providing an overnight camping experience for children with Type 1 diabetes. For more information regarding camp dates, please visit the Camp Leo website www.campleo.org.

POKE/D: Parents of Kids Experiencing Diabetes

ADA Camp Sealth
Every year ADA Camp Sealth offers children with diabetes the opportunity to experience an incredible camp with the support of leading medical staff. Camp is held at Camp Sealth on Vashon Island, WA. For more information visit www.diabetes.org/ada/camps/sealth.

ConnectTID Teen Group
This teen-organized group is for ages 13-18 and plans events throughout the year. This group also serves as camp counselors for ConnectTID’s annual Family Camp. For more information, visit www.ConnectTID.org.

ConnectTID Retreat: June 25 & 26, 2016
The 2016 ConnectTID Retreat is a 1- to 2-day retreat for adults, teens and young adults with type 1 diabetes (T1D). For more information, visit http://connecttid.org.

Diabetes Classes

Advanced Pump Class and Insulin Dose Adjustment Class
Ask for the class schedule at your next clinic appointment.

Insulin Dose Adjustment Email
Remember, for newly diagnosed patients who utilize the insulin dose adjustment line, another way to contact us is by email. Please contact ENDONURBS@seattlechildrens.org for more information.

Parent Designated Adult (PDA) Classes
A three-hour class for adult volunteers who would like to help your child with diabetes-related tasks during school. For more information or to register for a future class, please contact Yetta Levine at 206-987-5037 or yetta.levine@seattlechildrens.org.

The Family Side of T1D—Friday, October 21, 2016 at Seattle Children’s Hospital
This is a forum for parents, caregivers, and healthcare providers to get their questions answered about the psychological and social aspects of T1D within the family unit. The panel will include guest psychologists, professional health care professionals from Seattle Children’s Hospital. Visit jdrf.org/nw/events/familysideoft1d.

Parents of L1 KIDS Support Group, Seattle Campus
Little kids with Insulin Dependent Diabetes (L1KIDS) is a support group for parents of infants, toddlers and preschoolers with Type 1 diabetes. Parent-led groups meet Saturday mornings every other month from 10am-Noon at Seattle Children’s. Child care is provided. They also host a fun family picnic each July. To learn more or to RSVP, contact Laura Stamm, parent, at 917-755-3444 or laurastamm@hotmail.com.

Clallam County T1D Support Group: Port Angeles
This group meets Thursday evenings and is for both caregivers of children with T1D and T1D adults. For more information, contact Christina Hurst, chrust@co.clallam.wa.us or 360-417-2364 or 360-678-2020.

Upload Pumps and Meters Before Clinic
Please upload your glucose meter and/or pump at home.
If you do this the day before clinic it will make the check-in process go much faster. Please ask us at your next visit if you do not know how to do this. Thank you.

Workshops/ Support Groups

Diabetes and Me
A fun and informational workshop for children (ages 11-14) that focuses on how to cope with living with diabetes. Dates for 2016: May 7, Sep. 17, and Nov. 12 (10am – 1pm). Please contact Jessica Kopp (jessica.kopp@seattlechildrens.org) for more information or to register your son/daughter.

JDRF TypeOne Nation Summit: Oct. 22, 2016, 8am-3:30pm, Microsoft Commons, Redmond, WA
Top researchers and physicians will present the latest breakthroughs in T1D research. Local experts will lead inspiring and informative breakout sessions and there will be ample opportunity to connect with other T1D families, learn about the latest product technology, and discover new community resources. Lunch is included. For more information, visit http://northwest.jdrf.org/nw/events/typeonenation-summit-2016.

JDRF Northwest Events TypeOneNationSummit2016

What’s Happening — Continued from Page 5
**Nutrition & Diet**

**Crunchy Asian Chicken Salad**

Both kids and adults can enjoy this salad as part of lunch. Use Bston or bibb lettuce leaves and have this salad as a wrap.

**Salad:**
- 1½ cups finely diced cooked chicken (6 ounces)
- 6 canned peeled water chestnuts, rinsed and chopped
- 1 carrot, peeled and shredded
- 1 small celery rib, finely diced
- ½ cup diced apple, such as Gala or Golden

**Dressing:**
- 1 tablespoon natural peanut butter or sesame tahini
- 1 tablespoon seasoned rice vinegar
- ½ tablespoon soy sauce
- 1 small celery rib, finely diced
- ½ cup diced apple, such as Gala or Golden

**Directions:**
Combine the chicken, water chestnuts, carrots, celery, and apple in a bowl and stir to mix. Whisk the peanut butter, vinegar, and soy sauce until smooth. Whisk the dressing over salad and mix well. Sprinkle with nuts just before serving.

Serving size: 1 cup makes 3 servings

Nutrition information: 235 calories, 11 grams carbohydrate

**From:** Real Food for Healthy Kids by Tracey Seaman and Tanya Wenman Steel

---

**Team Focus**

Welcome to all our new staff!

Lina Merjian, MD — Lina Merjian is from Syria. She attended medical school at the University of Aleppo, Syria. She completed her residency at the American University of Beirut Medical Center in Lebanon and at the University of Texas Medical School in Houston, Texas. She did her endocrinology fellowship at Emory University School of Medicine in Atlanta. Her clinical interests are type 1 and 2 diabetes, cystic fibrosis related diabetes, disorders of growth and puberty, genetic syndromes, and pituitary disorders.

Alissa Roberts, MD — Alissa Roberts was born and raised in the Seattle area. She attended Pepperdine University in California. She then lived in Montana for a year doing research at the National Institute of Allergy and Infectious Diseases before attending Dartmouth Medical School in New Hampshire. After graduating medical school, she returned to Seattle in 2011 and recently completed her pediatric residency training at Seattle Children’s. She is now in her second year in the Pediatric Endocrinology Fellowship Program at Seattle Children’s. Dr. Roberts’s research interests include type 1 diabetes and exercise as well as adolescent health and transition to adult care in type 1 diabetes.

Angel Nip, MD — Angel Nip is from Hong Kong, China. She received her undergraduate medical degree from the Chinese University of Hong Kong and finished her pediatric residency at the Prince of Wales Hospital. She worked for two years with the diabetes and endocrinology team in Hong Kong before pursuing further training in the Pediatric Endocrinology Fellowship Program at Seattle Children’s. Dr. Nip is now a first-year pediatric endocrinology fellow with research interests in diabetes prevention and ways to improve glycemic control.

Sara DiVall, MD — Sara DiVall grew up in Wisconsin. She went to the University of Wisconsin, Madison. She attended medical school at the University of Wisconsin and completed her pediatric residency at Albany Medical Center in New York. She did pediatric endocrinology fellowships at the University of Chicago and Johns Hopkins University in Baltimore, Maryland. Dr. DiVall’s clinical interests are pubertal disorders, polycystic ovary syndrome, pituitary disorders, and growth disorders.

Lauren Cohen, RN — Lauren Cohen is a registered nurse from Los Angeles, CA. She joined our team in March 2015. She received her BSN from the University of Michigan in Ann Arbor. After working for a year and a half as a nurse at Children’s National Medical Center in Washington, DC in the pediatric intensive care unit, she returned to Seattle, working as a pediatric ICU nurse at Seattle Children’s before joining our team. Lauren is continuing her education at the UW as she studies to become a pediatric nurse practitioner.

Rachel de Castro, RN — Rachel De Castro has been part of Seattle Children’s for over 10 years. She started as a nurse tech while earning her BSN from Seattle University. After working in adult and travel nursing for a few years, she returned to Seattle and to Seattle Children’s. She has worked on the Medical Unit and in Urgent Care. Rachel has been with Endocrinology and Diabetes since July 2015.

Jamie Weber, LSW, AIC — Jamie Weber joined our team in September 2015 when she became the South Clinic social worker. She works with Erin Alving, ARNP and Tran Hang, RD on Wednesdays when patients are seen for diabetes follow-up care in the South Clinic. Jamie graduated from Westmont College in Santa Barbara in 2007 and earned her Master of Social Work at the UW in 2013. Jamie has served in a variety of roles in social services for the past 10 years, primarily as a mental health therapist for adolescents and adults.

Julie Schleicher, MSW, LCSW — Julie Schleicher is a clinical social worker from eastern Massachusetts and is new to the Seattle area. She graduated from the University of Connecticut School of Social Work with a Master of Social Work in 2005. Since that time her primary work has been in community mental health providing psychotherapy services to children, teens, adults, and families. Her personal experience with type 1 diabetes and interest in health and well-being led her to the Seattle Children’s Endocrinology and Diabetes team.

Paula Wo, MFR, JD, CD — Paula Wo is a pediatric dietitian who believes in optimizing wellbeing through creative and practical nutrition education. She has developed diabetes education materials such as a T1D toolkit; a carbohydrate counting module as part of an online insulin pump training program: "Eating Smart As Easy As 1,2,3" (a resource for youth with T2D); and a cooking program for kidney patients.

Nikki Novack, CMA (AAMA), MA-C — Nikki Novack was born and raised in Southern California and also has called Orlando, Florida her home. She moved to Seattle in 2001. She was employed in grocery management and turned towards the medical field in 2012. Nikki has been a certified medical assistant for two years. She is the back office medical assistant, working closely with the providers and RNs.

Maria Tolentino, CMA — Maria Tolentino is a certified medical assistant in the clinic. Maria was born in the Philippines, was raised in San Diego, and grew up in Antipas County. Maria received her medical assistant certification from Everest College in 2014. Seattle Children’s Endocrinology and Diabetes clinic is Maria’s first job out of school. Her younger sister has hyperthyroidism and her stepfather has diabetes. Working in endocrinology has allowed Maria to better understand the diagnoses of her family members.

Jonnelle Hendrix, CMA — Jonnelle Hendrix is a certified medical assistant and has worked in the Endocrinology and Diabetes clinic since April 2014. She was born and raised in Seattle. Jonnelle had been a caregiver for Prader-Willi patients for three years when she decided to go to school to become a medical assistant. Jonnelle is pursing her nursing degree while working at Seattle Children’s.

Marian Armas, CMA — Marian Armas grew up in Seattle. She recently joined our team as an administrative assistant. She has been at Seattle Children’s for 3 years, first as a float CMA (certified medical assistant) and then as a float family service coordinator. Marian is studying health administration at Bellevue College.