Living with Diabetes

I recently spoke to Ashley and her mother who have been living as a family with diabetes for 25 years. I was interested in learning more about how diabetes has changed over the years and how they have both coped with diabetes and all of its ups and downs. First I spoke to Ashley’s mother. She could remember so vividly the day her daughter was diagnosed with type 1 diabetes. Ashley spent 5 long days in the ICU at diagnosis and couldn’t walk. Ashley’s mom remembered how hard it was. She says that she remembers one nurse saying, “Things will get back to normal,” and she thought to herself, “No, this is the new norm.” Ashley’s mom said that soon after Ashley’s diagnosis, they decided that they needed “a team to get us through this,” so they decided they were going to travel to Joslin for Ashley’s diabetes care. Ashley and her mom both recalled the same story about their early years at Joslin. They call it the “oreo story.” When Ashley was very young, she wanted to eat Oreos. Ashley and her mom said that her Joslin team figured out how she could eat an Oreo at 10 AM and 3 PM when her insulin was peaking. Ashley recalls this was “the biggest deal.” Ashley’s mom said that after Ashley was diagnosed, she decided that Ashley “was going to do everything.” She said that they did things as a family that they never would have done if Ashley wasn’t diagnosed with diabetes because Ashley’s mom was “determined [Ashley] could do anything and she had to learn this at a young age.” Ashley’s mom and I spoke awhile about how diabetes care has changed over the years. I asked her what tips she would give to other parents who are new to diabetes and she said, “Find a team, get good care, don’t let anything get in the way, do it as a family, and look for the positives.” Ashley’s mom continued to explain “the positives” of all the wonderful places they have visited, the Junior Congress in Washington DC (where everyone was “drinking diet soda, counting carbs, and doing shots”) and all the wonderful people that they have met.

Hello Dolly: The Story Behind the New American Girl Doll Diabetes Care Kit

Written by Joslin Communications

Kids with diabetes have a lot to deal with in their day-to-day lives, but one of the toughest things they must face is feeling like they are different. So what do you do when a little girl wants her doll to have an insulin pump just like her? For Anja Busse, the answer was to ask one of the biggest companies in the world if they would add a diabetes kit to their dolls’ accessories. The outpouring of support, both from the company and the public, propelled one girl’s idea into a reality. For many children, their doll is more than just a plaything—it is a way to learn about the real world. Practicing on dolls can be very important for young children learning to deal with their diabetes care management. Micaela Francis, a Child Life specialist at Joslin Diabetes Center, explains that when children are in the Joslin playroom they are encouraged to play in ways that incorporate understanding diabetes. “Medical play allows the child to walk through the procedures they may experience at Joslin: blood draws or starting an insulin pump or a continuous glucose monitoring device,” says Micaela. “This allows them to know what to expect and feel more prepared for their upcoming procedure.” Dolls are especially helpful at this sort of play since children identify with them. But while there has been a push for popular doll brands to look more like real girls, it’s still rare to find toys outside of clinical settings that incorporate medical equipment as a normal accessory. The American Girl Company, which just celebrated 30 years in business, has been one of the few companies to offer customizable dolls resembling real-life-girls. They started with options for hair color, eye color, and skin tone and soon added more unique items like glasses and wheelchairs. “American Girl has a long-standing commitment to creating products that girls in various circumstances can identify with—from our Dolls Without Hair and with Hearing Aids to our iconic Wheelchair that’s been in our line for nearly 20 years, to name just a few,” says American Girl representative Stephanie Spanos in an email conversation.
Meet the Newest Members of the Joslin Pediatrics Team!

Lydia Lorang, MS, CCLS - Child Life Specialist

Lydia grew up as a military dependent. She was born in Seoul, South Korea and attended grade school in Germany and the southeastern region of the United States. She received her undergraduate degree at Florida State University and completed her child life internship at Cook Children's Hospital in Fort Worth, Texas. She then received a Master's of Science from Auburn University and conducted her own study entitled, "Examining the Relationship between Work Stress, Emotion Regulation, and Adult-Child Interactions among Family Child Care Providers." Lydia has worked in various hospitals throughout the United States including Children’s Healthcare of Atlanta, Kapiolani Women and Children’s in Honolulu, Hawaii, and Dallas Children’s Hospital. Lydia, her husband, and two children (ages 5 and 2) recently moved to Boston in January, 2016, after her husband completed a year-long training program in Garmisch-Partenkirchen, Germany. When she is not at work, Lydia enjoys spending time with her family, traveling, attending sports and music events, and finding hidden restaurant gems within Boston. Lydia is really excited to be working as a Child Life Specialist at Joslin so that she can continue to work with patients and their families to help them cope throughout their diabetes journey. She is also excited about Joslin’s cutting edge research program and hopes to partake in a pediatric research project in the future.

Louise Ambler Osborn, MS, RN, PNP – Nurse Educator

Louise grew up in Cambridge and Belmont, MA. She received her BA at Princeton University in comparative literature and also completed the Teacher Certification Program and became a 7th grade English teacher. Louise later went to the MGH Institute of Health Professions. Before coming to Joslin, Louise was a nurse at Maimonides School in Brookline and she cared for medically complex children for Franciscan Hospital Homecare. Louise was also charge nurse at Clara Barton Camp and a research assistant at MGH for a project on Neonatal Abstinence Syndrome. Louise loves building long-term relationships with families and says that, “I love kids of all ages. Their honesty, spontaneity, and low tolerance for pretense keep me grounded.” In her free time, Louise and her husband enjoy biking, hiking, sailing, and swimming in the ocean. She likes to sing, cook, garden, and knit. She also loves when her children, daughter (24) and her son (20) are in town. Something you might not know about Louise is that she is a classically trained singer and she played Princess Leia in an opera version of Star Wars…hair buns and all. Finally, Louise says, “I am thrilled to be here. It is a joy and a privilege to get to know you and to be entrusted with the care of your children.”

Alina Cheema, BS – Research Assistant

Alina grew up in Sharon, MA. She went to college at Brandeis University and graduated in 2015. Before Alina started working at Joslin, she had an externship in a pediatric medical office. She also worked as a clinical assistant in a surgeon’s office for a short period of time. Alina says that since she has started working at Joslin, she really enjoys interacting with patients and families and learning about their experiences with managing diabetes. Alina says that she is interested in the role of social determinants in accessing medical care, and she is particularly interested in the field of pediatrics and learning about how anticipatory guidance could be applied to the realm of managing diabetes. Alina likes to spend time with her friends and family doing things like ice skating or trying new restaurants. She also enjoys lattes, movies, and stand-up comedy. An interesting fact about Alina is that she enjoys creative writing such as prose and poetry and is currently attempting to write in the Urdu language. Alina says that, “I am happy to be working at Joslin and I look forward to meeting you through the different research projects in the clinic!”
Q: I wonder if my daughter would benefit from wearing a CGM but I don’t know much about it. Can you explain more to me about CGM devices?

A: You have asked a great question. CGM stands for a continuous glucose monitor. A CGM device measures interstitial fluid which is the fluid between the cells in the fatty areas of the body. There are three parts to a CGM – the sensor, transmitter, and receiver. The sensor is a small wire that is inserted under the skin, a transmitter attaches to the sensor and transmits the data to a receiver which displays the data on a screen. Some people think that if their child uses a CGM then their child will not have to check their blood glucose. Unfortunately this is not yet true. Individuals wearing a CGM still need to check their blood glucose to calibrate the sensor. Also CGM readings are not supposed to be used to treat a low or high blood glucose reading, because the CGM reading may not be as accurate as the blood glucose value. CGM devices do provide a lot of valuable information though. The CGM devices can provide information and patterns about what is happening with your child’s diabetes after meals, in between meals, and overnight. Another thing that families like about CGM technology is the alarm feature. You can set both low and high alarms for out of range values. When the CGM alarm goes off, then you can check your child’s blood glucose to see if the blood glucose value is out of range. If you would like to learn more about CGM, then you can contact your child’s health care team and you may also want to sign up for one of our monthly technology classes by calling 617-732-2603.
Which is why when Anja Busse was diagnosed with type 1 diabetes, she looked to American Girl to find a doll just like her. But while she saw dolls with guide dogs and epipens, she didn’t see any with diabetes supplies. “There’s even an allergy-free luncheon,” says Anja. “But I wanted to find one with an insulin pump like me.” She isn’t one to sit on the sidelines, so she decided (after getting permission from her mom) to post a video to the petition website Change.org to see if she could garner a response about including a diabetes tool kit in the American Girl accessory line. The feedback she received was both incredible and astounding. Anja and her mom Ingrid watched thousands of signatures pour in. “People were really excited about it. It sounded like [American Girl] really got slammed with a ton of letters and calls from people saying they really wanted it,” says Ingrid. There was no indication the petition had worked, so Anja kept busy with other diabetes projects like teaching local schools the difference between type 1 and type 2, starting a blog, and sending well wishes to kids with diabetes across the globe. And then about a year and a half later, Ingrid saw an article with a statement from American Girl hinting that a diabetes kit was coming out in January of 2016. “We’re very proud of our positive reputation for inclusiveness and we remain committed to exploring and expanding in this important area,” says American Girl representative Spanos of the newly included diabetes kit. The company also rolled out arm crutches along with their new diabetes kits this January. Within just a few short weeks, they have proven to be very popular. They sold out in February and are currently backordered until May. Although technically Mattel does not take suggestions for new products, they seem to have given a shout out to Anja’s idea. “They put an article about the kit with her picture on their Facebook page,” says Ingrid. “And when we saw it, we were like wow! That’s huge!” One of the best outcomes of this project is the community that has grown around the dolls. “When the petition started, we had a lot of people share that they felt alone,” says Ingrid. “And I know it’s a small thing to have a doll that’s like you but for a lot of these kids, it means so much.” Since the kits have come out, kids have shared their excitement over the new accessories on Anja’s Diabetic American Girl Doll Facebook page. “They send pictures of themselves with their dolls and they both have their insulin pumps on,” says Anja. “It’s been really cool to see those pictures and to see the girls smiling about having the kit for the doll. To be just like your doll is really amazing.” “By having a high profile toy such as an American Girl Doll with diabetes gives children a toy they can relate to,” says Micaela. “This opens the door for them to confidently talk about their diabetes. It allows the child to have a special item that is just like them to take wherever they go and teach others about what they go through on a day to day basis.”

**Past Events —Teddy Bear Clinic!**

On Saturday, March 19th, Joslin patients and their families gathered for the 13th annual Teddy Bear Clinic. The Teddy Bear Clinic is an opportunity for young patients, their friends and family to learn about diabetes and healthy habits while exploring healthcare. Each child received a new bear to care for, visiting stations like the nurse station where they checked their bear’s blood sugar and gave them insulin, the hospital, the pharmacy, the eye unit and so much more! This was our biggest event to date with 104 children in attendance. Everyone had a great time while continuing to learn about diabetes.

**School Nurse Program-** On Saturday, April 2nd, 90 school nurses from all over New England, including one school principal, gathered for an intensive full-day seminar that enabled them to further their education and training in diabetes management. The principal said he wanted to learn how to be a backup resource for their school nurse if she needed assistance with the students who have diabetes. Keep your eyes out for more school nurse programs happening this fall on Saturday, September 17, 2016 & Saturday, November 11, 2016.
**Research Opportunities and Resources**

**T1D Exchange**

*Description:* The Type 1 Diabetes (T1D) Exchange is a nationwide registry collecting information about children and adults with type 1 diabetes. The purpose of the registry is to gather information about people with type 1 diabetes to better understand the natural course of type 1 diabetes and the effectiveness of current treatments. Participation in the registry involves completion of a questionnaire about medical and family history including diabetes diagnosis and treatment and laboratory test results. Annual updates of information are also part of the registry.

*Recruiting:* At the Joslin, children <7 years of age being followed in the Pediatric, Adolescent, and Young Adult Section may be eligible to participate in this registry.

*Contact:* Alina Cheema at (617) 309-4477 or alina.cheema@joslin.harvard.edu

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**INSPIRE Study: Psychosocial Aspects of Artificial Pancreas Research**

*Description:* This study will explore attitudes toward diabetes technology and automated insulin delivery. Participation involves a one-on-one interview or focus group discussing attitudes toward diabetes technologies. The study visit can take place on the same day as your routine diabetes visit and will take about 30-60 minutes. The study will provide a parking voucher on the day of the study visit. Participants will also receive compensation for their time and effort.

*Recruiting:* Individuals who have had type 1 diabetes for 1 year or longer. Individuals who have family members or loved ones who have had type 1 diabetes for 1 year or longer.

*Contact:* Amanda Whitehouse at 617-309-4523 or amanda.whitehouse@joslin.harvard.edu

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**Type 1 Diabetes Risk Assessment — TrialNet**

*Description:* This study aims to identify youth and adults at risk for type 1 diabetes by testing for diabetes-related antibodies in relatives of people with type 1 diabetes. It involves a single blood test. People who test positive will be eligible for further testing and may be eligible to participate in prevention trials.


*Contact:* Sarah Szubowicz at 617-309-4493 or sarah.szubowicz@joslin.harvard.edu

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**Improving Family Management and Glycemic Control in Youth <8 Years Old with Type 1 Diabetes**

*Description:* This study will explore parental attitudes toward diabetes management in young children. It involves participation in a one-on-one interview or focus group. The study visit can take place on the same day as your routine diabetes visit and will take about 30-60 minutes. Parents will also complete surveys in clinic or at home, which will take approximately 30 minutes. The study will provide a parking voucher on the day of the study. Participants will also receive compensation for their time and effort.

*Recruiting:* Parents of youth under 8 years old who have had type 1 diabetes for at least 6 months.

*Contact:* Alina Cheema at 617-309-4477 or alina.cheema@joslin.harvard.edu

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**Patient and Parent Perceptions of Hypertension and Hyperlipidemia Management and Diabetes Complications**

*Description:* This study will explore parent and youth attitudes toward cardiovascular risk factors such as high cholesterol or blood pressure and diabetes complications. Participation involves one interview or focus group for approximately 60-90 minutes. Interviews can be on the same day as routine diabetes visits and will add an extra 60 minutes to the clinic day. The study will provide a parking voucher on the day of the interview or focus group. Participating teens and parents will also receive compensation for their time and effort.

*Recruiting:* Families of teens ages 13-19 who have had type 1 diabetes for 12 months or more.

*Contact:* Alina Cheema at 617-309-4477 or alina.cheema@joslin.harvard.edu

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**Pump and CGM Information**

*If you are interested in learning more about Insulin Pumps or Continuous Glucose Monitoring (CGM)*

**Get Connected**

Joslin discussion boards are moderated by Joslin staff and offer a safe place to ask questions about diabetes and to interact with other parents or teens living with diabetes. This is the link for the teen boards:

forums.joslin.org/JoslinDiscussionBoards/41.aspx

And this is the link for the parent boards:

forums.joslin.org/JoslinDiscussionBoards/42.aspx

Here are some other popular online forums -

- The American Diabetes Association forums: community.diabetes.org
- The JDRF forums: juvenation.org
- The Children with Diabetes forums: forums.childrenwithdiabetes.com
- Glu Community: myglu.org

**Camp**

You may consider sending your child to camp or visiting camp this summer. The camps also have weekend and school vacation activities year round. Here is contact information for diabetes camps in the New England area.

- **Camp Joslin/Ciara Barton Camp/Barton Day Camps**, N.Oxford and Charlton, MA: info@bartoncenter.org or 508.987.2056
- **ADA Camp Carefree**, New Durham NH: camp-coordinator@campcarefreekids.org or 603.219.2901
- **Camp Surefire**, W. Greenwich, RI: info@campsurefire.org or 401.474.1606
- **Jack Rua Camp for Children with Diabetes**, Rehoboth, RI: tnogueira@peopleinc-fr.org or 508.679.5233 or 774.627.2506

If you want to get general information about diabetes camping or about camps in other areas, you can visit the Diabetes Education and Camping Association website: www.diabetescamps.org
**Living with Diabetes (Cont. from pg 1)**

Finally, Ashley’s mom stressed that, “Joslin is a world renowned research facility and we are fortunate to receive the most up-to-date diabetes care. I would truly encourage all Joslin pediatric patients to take advantage of any research studies that they are invited to participate in...Ashley was able to take part in carefully controlled studies, help the greater diabetes community, and get some benefits, in return, like trying new diabetes technology.

A few days later I also got to speak to Ashley about her experience with diabetes. She said that she doesn’t remember everything since she was diagnosed with diabetes when she was 2 - but she does remember that when she was first diagnosed, her insulin didn’t work as fast and that when she got to try the newer insulins “it made all the difference.” She also remembers starting an insulin pump at age 13 and “getting her life back.” She said, “I didn’t really know how bad I felt” until she started the pump and started to feel so much better. After starting the pump, she remembers that she could suddenly stay at her grandmother’s house and “eat a big breakfast.” Ashley also recalled how meters have changed over the years. She said that the first meters took 60 seconds, then 45 seconds, then when it got to 30 seconds she thought she had “hit the jackpot,” and now her meter takes 5 seconds. I asked Ashley what has helped her cope with diabetes over the years and she said that her family has been so supportive. She said that her mom has been “amazing and has been on every field trip since preschool...my mom was the rock.” She then added, “My dad has been good too and my brother never complained.” She said, “My parents based everything around me – everyone would carry snacks when we went on any trip. They just always planned ahead.” Ashley also described her “amazing” Joslin support system of Dr. Laffel, Cindy, Laurie, Kerry, and Louise. She said “I have had the best team ever.” Ashley said that she is so lucky to have the huge support system of her family, relatives, friends, and Joslin. She said that with this support, she was “set up for success. It wasn’t always easy but we planned it out and we planned ahead and we worked around it.” Ashley said that she would advise other kids and teens with diabetes to “be very open...all my friends knew. My friends were amazing. My neighbor always had a juice box for me in her bag and she is still my best friend.” Ashley also talked about not being ashamed, “Be very open and honest and don’t be ashamed...be honest with yourself...you will have bad days...just don’t give up, just do [things] creatively.” Ashley finished by talking about her celiac diagnosis as being one of the biggest challenges for her so far. She was diagnosed with celiac one month before starting college. Ashley says, “It is possible to live a life with diabetes, just keep going...if you have a bad day, you will make it through, you just have to find out how you will make it through it.” Ashley just got engaged and is planning a gluten free, nut free, peanut free, sesame free, and dairy free wedding. Ashley we wish you all the best.

We want to thank you and your mom for sharing all that you have been through over the years. You two are an inspiration to families living with diabetes.

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**Spring Sailing** - Modified from “Dishing it up Disney style”

- *12 large hard-boiled eggs, cooled
- *2 tsp. mustard
- *2 tsp. apple cider vinegar
- *¼ cup light mayonnaise
- *2 red, orange, or green bell peppers
- *cumin or paprika (optional)

**Directions:**
*Peel the eggs and slice them in half, length wise. Scoop out the yolks and place in a separate bowl.
*Mash yolks with fork; add mustard, vinegar and mayonnaise; mix until smooth.
*Make the sails: cut each pepper into 1 inch wide strips, then cut the strips into 1 inch squares and then slice each square in half diagonally.
*Fill the egg white halves with the yolk mixture. Stick the sail upright into the yolk mixture; sprinkle with cumin or paprika if desired.

**Nutrition information**
* Serving: 2 egg halves
* Calories: 90
* Total Fat: 6g
* Total Carbs: 1g
* Total Protein: 6g

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**A few take home points:**
- As a family, embrace the diagnosis
- Do not let type I diabetes get in the way of your child’s participation in any activity
- Be hopeful that there will be new advances all the time
- Participate in research as you can help advance the field while helping your child and family.

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*Note: Sudoku puzzles are for entertainment purposes only and do not necessarily reflect the content of the newsletter.*
When six year old Lilah was having trouble doing her pump site changes, the Child Life team at Joslin sent her a sticker chart as an incentive to get her through her site changes. When she got all her stickers, she received a prize in the mail. Lilah’s grandmother, Ellen, was there when Lilah received her prize which spurred a conversation about giving to Joslin. Lilah’s mother and grandmother thought it would be fun and meaningful for Lilah to help choose items off the Child Life Amazon Wish List so that there were prizes for other children who received sticker charts. Lilah’s grandmother also raised three of her own children with Type 1 Diabetes and knows how difficult things can be for children and how something like a sticker chart has made a world of difference in their lives. See below for Child Life Wish List.

**Donation Spotlight**

When six year old Lilah was having trouble doing her pump site changes, the Child Life team at Joslin sent her a sticker chart as an incentive to get her through her site changes. When she got all her stickers, she received a prize in the mail. Lilah’s grandmother, Ellen, was there when Lilah received her prize which spurred a conversation about giving to Joslin. Lilah’s mother and grandmother thought it would be fun and meaningful for Lilah to help choose items off the Child Life Amazon Wish List so that there were prizes for other children who received sticker charts. Lilah’s grandmother also raised three of her own children with Type 1 Diabetes and knows how difficult things can be for children and how something like a sticker chart has made a world of difference in their lives. See below for Child Life Wish List.

**Child Life Wish List!**

Here is a link for items the Playroom can use:

http://www.amazon.com/gp/registry/wishlist/3KWHVGVU9BS2B/ref=topnav_lists_1

OR go to www.amazon.com and under “Wish Lists” type in “Joslin Diabetes Center – Child Life.”

Feel free to email childlife@joslin.harvard.edu and we will also send you the link.

We thank you ahead of time for your kind support!

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**Kids Sudoku Puzzle**

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**Beginners Sudoku Puzzle**

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**Share your achievements on The Pediatric Star Board!**

Bring in articles or pictures from your shining moments to share with the Joslin community.

Feel free to email:

childlife@joslin.harvard.edu

Answers on pg 6

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**Joslin Diabetes Center**

One Joslin Place, Boston, MA 02215

Pediatric, Adolescent and Young Adult Section: (617) 732-2603