Joslin Patient Helps to Pass New Senate Bill

Skye Archibald (11y/o) recently presented in front of the NH Senate Health and Education Committee regarding Senate Bill 71, which she wrote in conjunction with her parents. This bill allows for the administration of glucagon by non-nursing staff when a nurse is not present in a school environment.

Skye was diagnosed with type 1 diabetes 2.5 years ago at the age of 9. Skye was the only child in her elementary school to have diabetes and it was a learning curve for everyone. One of the problems she encountered was the availability of nursing staff during after school activities. Skye wanted to play sports, and attend dances, field trips, and enrichment activities but was worried when she learned no one was available to help her with her diabetes care. When investigating options for caregivers, her family learned that many NH schools don’t have full time nurses at all and rely on the goodwill of teachers and emergency personnel to handle student care.

In NH, the administration of glucagon is only allowed by nursing staff. Skye felt this was a dangerous situation for students such as herself and also for students who do not have the benefit of having a nurse on staff. To raise awareness and ensure the safety for students, Skye wrote Senate Bill 71, allowing the administration of glucagon by non-nursing staff when a nurse is not present in a school environment. Administration is voluntary and training can be provided by the nursing staff or parents.

The bill was sponsored by NH State Senator, Nancy Stiles, and Skye testified in front of the Senate Committee explaining her position and the importance of this bill. She was met by opposition from the Board of Nursing representatives but remained strong in her convictions. The bill passed the NH Senate and then moved on to the House where it recently passed at the end of April. The final step will be a public signing with the NH Governor, Maggie Hassan!

Nutrition—Why is it so Important

Did you know that March is National Nutrition Month? In honor of national nutrition month, we sat down with Heidi Quinn, one of our pediatric registered dietitians, and asked her about the important role that nutrition can play in diabetes management.

Q: What do you think are the main reasons to meet with a Joslin Dietitian?
A: As you know, carb counting is a key component of diabetes management and healthy eating is important for everyone in the family. Regular visits with the dietitian on your diabetes care team can help you stay on track with both of these goals.

Q: How often should we meet with a dietitian?
A: The American Diabetes Association recommends annual visits with a dietitian as part of a comprehensive diabetes care plan. This is especially important for children and adolescents whose needs change as they grow. A review of the diet to be sure they are getting the right amount of calories, protein, vitamins, and minerals at each stage of growth is one of the ways the dietitian on the team can help. We can also help with your insulin pump therapy by going over how to use some of the advanced features on your insulin pump that can help cover difficult meals, like pizza.

(Cont’d on page 4: NUTRITION)
Meet the Newest Members of the Joslin Pediatrics Team!

Jessica Ellis – Part-Time Medical Assistant
Jessica Ellis grew up in Plymouth, MA and moved to Boston in December of 2013. She attended Lincoln Technical Institute where she completed her Medical Assisting program and did an internship at Mashpee Family Medicine. Before coming to Joslin, Jessica worked at Jordan Hospital and is currently also working at Panera Bread. Jessica loves getting to know all the patients and their families. She enjoys how children have their own personality that makes them unique. In Jessica’s free time, she loves to read, watch movies, cook and explore Boston. Jessica also used to figure skate.

Past Events:

Teddy Bear Clinic
Joslin patients and their families gathered for the 12th Annual Teddy Bear Clinic. The Teddy Bear Clinic is an opportunity for young patients and their friends & family to learn about diabetes and healthy habits, while exploring healthcare. Each child received a new bear to care for. At the nurse station, the children checked their bear’s blood glucose and gave them pretend insulin injections. The children and bears also had the opportunity to visit the hospital, yoga, and camp stations. Everyone had a great time while continuing to learn about diabetes.

School Nurse Program
On March 14th, 90 school nurses from all over New England, including four nurses from Hong Kong, gathered for an intensive full-day seminar that enabled them to further their education and training in diabetes management. Another school nurse program will take place again in the fall on September 26, 2015 & November 14, 2015. More information to come soon.
Q: My child was diagnosed with diabetes a few months ago and I have been scared to leave him with a babysitter. My neighbor used to babysit for us but I am worried she is too young to manage my child’s diabetes.

A: This is a very common question and it is a great issue to bring up with your health care team. Some families try to find a babysitter who has type 1 diabetes. There may be a high school student or college student nearby who has diabetes and is interested in babysitting. You may also want to see if one of your family members would be comfortable taking care of your child. There are a number of ways to help prepare a caregiver. At Joslin, we offer classes in the spring and fall for caregivers to learn about diabetes. It is also possible for family members to meet 1:1 with a Joslin nurse educator to learn more about diabetes during one of your child’s visits. The Barton Center also runs programs for caregivers. We’ve heard of families who “swap” with another family in town that has a child with diabetes – so you could watch their child one evening and then they would watch your child another evening. Finally, some families like to stick with their current babysitter and train their babysitter about diabetes.

The American Diabetes Association (ADA) has a website link about babysitters:

The ADA has also developed a sheet that you can complete to leave with your babysitter. You may want to use this as a guide and develop your own plan:

In the beginning, you may choose to go out after a meal for a short period of time until you are more comfortable leaving your child for longer periods of time with the caregiver. Good luck!

Upcoming Events:

Summer Magic
Wednesday July 15, 2015
5:00PM -7:00PM
at the Joslin Diabetes Center!

Enjoy entertainment from a magician, magical arts and crafts, and get to know other Joslin Pediatric families. Pizza will be provided (gluten free also available). Please RSVP by July 8th to Micaela Francis at childlife@joslin.harvard.edu or 617-309-4528.

Diabetes in College
How to prepare for a successful transition to independence

For juniors/seniors in high school and freshmen in college and their parents

The program is offered from 5:00 pm – 7:00 pm on the following dates (pick one to attend):

Thursday, May 14th
Thursday, June 11th
Thursday, July 9th

Dinner will not be served

For more information or to sign up:
Please contact Louise Crescenzi at 617-732-2603

Fenway Park Tour!

Wednesday, August 19th from 1:00-3:30 p.m., for 8-18 year olds!

Join us at Joslin for an afternoon of fun! Enjoy getting to know the history of Fenway Park while meeting other Joslin Pediatric families. Light snacks will be provided. Each family receives two complementary tickets (one for a parent/guardian and one for the child). You may be able to purchase additional tickets for another family member for $10 a ticket (must be paid prior to the event). Please call us for more details if you would like to purchase additional tickets. We have a limited number of tickets available, so reserve your tickets early. A waiting list will be created if needed. To reserve your place on the tour, please, RSVP to Jen Griffin at childlife@joslin.harvard.edu or 617-309-4529.
Q: What are some of the challenges you hear from families when they meet with you?
A: Changes in schedules – juggling work, school, and sports, and eating away from home especially as children enter adolescence; these all impact the kinds of meals and snacks your child eats. Providing ideas for healthy snacks, managing the timing of snacks around physical activity, ideas for quick heart healthy meals on the go, and assesses of vitamin/mineral supplementation needs are all things the dietitian can help with.

Q: Are there other things that you address with families?
A: We also meet with children with celiac disease or food allergies. A nutrition assessment is important to make sure these children are meeting their nutrient needs within their dietary limitations.

Q: Is there any recent research findings related to nutrition therapy for individuals with diabetes?
A: Studies have shown that medical nutrition therapy can reduce A1c on average by 1% for individuals with type 1 diabetes. (reference: The AADE desk reference , third edition)

### Mini Fruit & Cream Cups

**Ingredients:**
- 12 mini cupcake liners
- 12 vanilla wafers
- ½ cup low fat vanilla yogurt
- ½ cup light cream cheese, softened
- 1 teaspoon lemon juice
- Sliced strawberries, kiwi, and whole blueberries

**Directions:**
1. Place liners in mini-cupcake pan. Put a vanilla wafer, flat side up, into each liner.
2. Whisk together yogurt, light cream cheese, lemon juice until smooth. Spoon 1 heaping tablespoon on top of each cookie then top with fruit slice/berries
3. Cover the pan with plastic wrap and place in the freezer until firm, about 1-1 ½ hours. Remove tray from freezer 15-20 minutes before serving.

**Nutrition information:**
- Serving size: 1 cookie
- Calories: 50
- Fat: 2.5g
- Carb: 5.0g
- Protein: 1.0g

Recipe Adapted from
*Dishing It Up Disney Style: A Cookbook for Families with Type 1 Diabetes*
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 help 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, individuals being followed in the Pediatric, Adolescent and Young Adult Section under 7 years old may be eligible to participate in this registry.

Contact: Jessica ElBach at (617) 309-4622 or jessica.elbach@joslin.harvard.edu
Ryan Busha at 617-309-4510 or ryan.busha@joslin.harvard.edu

SGLT2 Blocker Empagliflozin Study

Description: This study aims to find the best dose for children of a new oral medication already approved for use in adults with type 2 diabetes. The medication, called empagliflozin or Jardiance®, lowers blood glucose levels by increasing the amount of glucose "spilled" into the urine. Each participant will receive only a single dose of the medication. After an evaluation for eligibility that requires a single visit before breakfast, enrolled patients will stay at Joslin during the day and at the hotel across the street for 3 days and 2 nights so that blood and urine samples can be collected. There is a final study visit one week following this 3 day study period. The study will provide all supplies for the study, parking for visits, and hotel charges. There is reimbursement for time and travel.

Recruiting: Children and teens, ages 10 to 17, with type 2 diabetes to participate in a study of an investigational oral medication to control blood glucose levels. An investigational medication is one that has not been approved for use in this population.

Contact: Maureen Malloy at 617-309-1919 or maureen.malloy@joslin.harvard.edu
Kerry Milaszewski at 617-309-4154 or kerry.milaszewski@joslin.harvard.edu

GleeT1D Study

Description: GleeT1D is a study where researchers want to test if Gleevec® (imatinib mesylate) may be of benefit in slowing the body’s destruction of beta cells when given to individuals recently diagnosed with Type 1 Diabetes (T1D). The goal of this study is to preserve beta cells so that the body can continue to produce some of its own insulin. Even when insulin injections are needed, it is believed that insulin produced by the body can improve overall blood sugar control, make daily management of T1D easier, and may reduce the risk of long-term complications. Participation in the GleeT1D study will last up to 2 years and will involve taking pills (either Gleevec® or a placebo) once a day for 6 months and periodically coming in to Joslin Diabetes Center for follow up visits and lab tests.

Recruiting: Seeking individuals who have been diagnosed with type 1 diabetes less than 3 months ago and are 18 to 45 years of age

Contact: Brittany Resnick at 617-309-4148 or brittany.resnick@joslin.harvard.edu

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

Pump and CGM Classes

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

Please call the Pediatric Clinic’s front desk: 617-732-2603

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 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/Clara 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 803.219.2901
- 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
Audrey (10/yo) and Will (8/yo) of Beverly, MA hosted a Spirit Day at their elementary school last November. They asked their classmates to wear blue and pay $1 in honor World Diabetes Day. Will was diagnosed in November 2012. He is a patient of Lori Laffel, MD & Julie Griffith, PNP. Will is the only student in their school with type 1 diabetes, and Audrey wanted to share what he manages day to day. In the days leading up to it, she researched type 1 diabetes, then read her findings to her fellow students over the loudspeaker each morning. “I think Will and other kids with type 1 diabetes are really brave because those shots and fingerpricks really hurt and it never goes away,” said Audrey. The pair raised $215 in Will’s name for diabetes research at Joslin.

Jane was diagnosed with type 1 diabetes when she was 4 years old. Jane attends The George Kelly School in Chelsea and she is the only one with type 1 diabetes in her school. Jane and her mom wanted to educate the children and staff at her school about diabetes during the month of November, which is Diabetes Awareness Month. With the help of her mom, Jane created a bulletin board with facts about type 1 diabetes and gave a presentation to her 2nd grade classmates of about 60 children and 10 adults on what her life is like living with type 1 diabetes. In addition, Jane did a fundraiser on November 14th (World Diabetes Day) where the students were allowed to forgo their required school uniforms for 1 day and wear blue in support of Diabetes Awareness; each student had to bring in $1.00 as a donation. Jane also had her little brother’s school, The John Silber Early Learning Center in Chelsea, participate as well. Jane raised $702.85 to give to the Joslin Pediatric Department. It was her way of being able to give back to the wonderful care she receives, and she was excited to share her story with so many people of what it is like living with type 1 diabetes. She is a patient of Dr. Elvira Isganatis, MD & Ashley Atkins, PNP.

On March 22nd, Jordon and his family ran a fun event to raise money for Joslin. This was part of Jordon’s community service project for school. He chose Joslin because of the excellent care Jordon has received the past several years. He receives care from Dr. Anat Hanono, MD & Katie Wentzell, PNP. Teams came in and competed in friendly games including a basketball shootout, volleyball, puzzle challenge, hungry hippos, and an obstacle course run. Teams earned points along the way, including some for fundraising! The day turned out to be challenging and fun, with over $2,000 raised for Joslin! We had several businesses compete: Pediatric Dental of Plainville Ma, Environmental Systems of Attleboro, Hockomock YMCA youth leaders, and our local High School honor society.

Questions, comments, or suggestions?
E-mail childlife@joslin.harvard.edu or call 617-732-2603

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