



Newsletter of the Pediatric, Adolescent, & Young Adult Section



Joslin Clinic
Volume 5, Issue 2
Spring-Summer 2009

Can You “Picture a Cure” for Type 1 Diabetes?

Andy McKeever can! Read Andy's story below about how he used his love of photography to raise money for diabetes research.

I was diagnosed with type 1 diabetes when I was 7 years old. I was diagnosed with hypothyroidism less than a year later. My family and I work really hard with lots of help from the Joslin Diabetes Center, but I still get sick sometimes and my blood sugar control is not always as good as I'd like it to be. I miss school more often than I would like and sometimes having diabetes interferes with other activities. It's my hope that future generations of kids won't have to live with diabetes, so I decided to do something to help make that dream come true.

I love photography and wanted to use my talents to raise money for diabetes research. Last year I formed a business called AndyArt and started selling note cards featuring my photographs to raise money for Joslin. With encouragement from some friends and professional artists, I also decided to organize a silent auction. I wanted to hold it in November, which is American Diabetes Month. The “Picture A Cure” silent art auction was held on November 7, 2008, in Great Falls, Montana, where I live. The auction featured some of my

photography, the work of several prominent artists, and gifts and products from local businesses. The event was attended by about 75 people and raised \$1,500 for research at Joslin. The highest selling piece was my photograph,

Morning on the Missouri (see photo), which sold for \$400.

In addition to raising money for diabetes research, my goal in organizing the silent auction was to inspire others, especially young people, to get involved in causes that are important to them. Each one of us, no matter how small, has the power to make a difference in this world. It takes courage and commitment, but we can all find ways to help make this world a better place. I'm only 12 years old... just imagine what you could do!

(written by Andy McKeever)



Diabetes Education Program for School Nurses

The annual **Diabetes Education Program for School Nurses** will be held on **Saturday, September 26, 2009**, at the Joslin Diabetes Center. The program, sponsored by Joslin and the American Diabetes Association, provides school nurses with up-to-date information about type 1 and type 2 diabetes, treatments, tools and technologies, and diabetes management in school settings. Encourage your school nurse to attend!

For more information, contact Laurie Higgins at 617-732-2603 or laurie.higgins@joslin.harvard.edu.



Summer Magic

The warm weather is here and that means it's nearly time for one of Joslin's favorite events — **Summer Magic!** Join other families on **Wednesday, July 15, from 5 to 7 pm** for a fabulous evening of games, crafts, dinner, and... **a magic show!**



For more information, contact:

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jennifer.douglass@joslin.harvard.edu or
Courtney Seiter
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Insulin Pump... Is it for you?

Upcoming pump classes:

- Wednesday, July 15
- Friday, July 17
- Friday, August 7
- Wednesday, August 19
- Wednesday, September, 16
- Friday, September 18

Classes are held from 3:30-5:00 pm.

For more information, call 617-732-2603.

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Meet the Newest Members of the Joslin Pediatrics Team



Stephanie Ellis – Medical Assistant

Stephanie grew up in the nearby towns of Easton and Raynham, MA. She received her Medical Assistant Certification from the Everest Institute. Before coming to Joslin, Stephanie was a receptionist at Pediatric Associates of Norwood and Franklin. She loves working in pediatrics because she loves children and getting to know their families. In her free time, Stephanie enjoys cooking, baking, writing poetry, and spending time with friends.



Sandra Loeb Salsberg, MD – Pediatric Endocrinologist

Dr. Salsberg may be familiar to some families, having done her fellowship in the combined Joslin-Children's Hospital Pediatric Endocrine Training Program. Originally from Poughkeepsie, NY, Dr. Salsberg attended college and medical school at Cornell University and completed her pediatric residency at the University of California, Irvine. One of her interests is diabetes research related to obesity. In her spare time, Dr. Salsberg likes to run, hike, cook, and spend time with her family.

Q&A


Q: What is a "whole grain" food?


A: Whole grains, or whole grain foods, contain the entire seed of the grain, unlike "refined grains", in which much of the seed is removed during processing. Whole grains have more of the nutrients that keep you healthy — like protein, antioxidants, B vitamins, vitamin E, magnesium, iron, and fiber. According to the U.S. Dietary Guidelines, children and adults should eat at least 3 servings of whole grain foods every day.




Q: How can I tell if a food is whole grain?

A: Many companies are adding a label to their products to help people know what foods contain whole grains. This label is called the "Whole Grain Stamp". There are different types of stamps to look for:

 **The Basic Stamp** — If a product has the **Basic Stamp**, it has at least half a serving of whole grain (8 grams).

 **The 100% Stamp** — If a product has the **100% Stamp**, it has one full serving of whole grain (at least 16 grams). In addition, all of the product's grain ingredients must be *whole* grains.

 **The Menu Symbol** — When you're eating at a restaurant, you may see the **Whole Grain Menu Symbol** next to an item on the menu. If a menu item has the Whole Grain Menu Symbol, it has at least half a serving of whole grain (8 grams).



THE BASIC STAMP

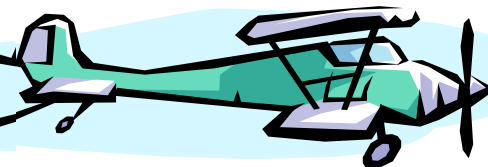


THE 100% STAMP



Graphics courtesy of Oldways and the Whole Grains Council.
For more information, go to: www.wholegrainscouncil.org.

Research Opportunities at Joslin



New Study Examines GAD Injections in Recent-Onset Type 1 Diabetes

Description: This study is looking to see if 3 injections of a protein called GAD will help people with newly diagnosed type 1 diabetes continue to make some of their own insulin. The investigators are looking at the progression of diabetes in people who receive GAD injections compared to those who get placebo injections (injections that look the same but have no GAD). The study involves 13 visits over 2 years and follow-up visits every 6 months for an additional 2 years.

Recruiting: Individuals, ages 16-45*, diagnosed within 3 months prior to the first injection

*After initial safety review, the study will expand to include ages 10-45, then ages 3-45.

Contact: Debbie Conboy, RN, BSN, CDE, at 617-732-2647 or debbie.conboy@joslin.harvard.edu, or Heyam Jalahej, MD, at 617-732-2524 or heyam.jalahej@joslin.harvard.edu



The Tolerance Study

Description: This study is trying to better understand what causes type 1 diabetes to help find new ways to prevent or reverse the disease. The study is being done with researchers at Harvard Medical School and is funded by the Juvenile Diabetes Research Foundation. The study visit includes the completion of questionnaires and a blood draw.

Recruiting: Individuals, ages 18 years and older, both with and without type 1 diabetes

Contact: Roxanne Phillips at 617-732-2481 or roxanne.phillips@joslin.harvard.edu

The TaWC Study

Treatment and Weight Concerns in Diabetes

Description: This study looks at diabetes treatment, eating habits, and adjustment to living with diabetes. Study visits occur at regular follow-up appointments and involve completing surveys.



Recruiting: Youth, ages 10-17, with type 1 diabetes, either recently diagnosed or planning to start insulin pump therapy, along with a parent or guardian

Contact: Katherine Pratt at 617-732-2699 x4633 or katherine.pratt@joslin.harvard.edu, or Hugh Murphy at 617-732-2699 x4632 or hugh.murphy@joslin.harvard.edu

Type 1 Diabetes Risk Assessment

The Natural History Study – 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.

Recruiting: Parents, children, & siblings, ages 1-45, and cousins, grandchildren, nieces, & nephews, ages 1-20, of people with type 1 diabetes

Contact: Heyam Jalahej at 617-732-2524 or heyam.jalahej@joslin.harvard.edu

Networking Coffees for Parents

The Joslin pediatric team is working with the JDRF (Juvenile Diabetes Research Foundation) to lead local parent groups (called “Networking Coffees”) around Massachusetts. These parent groups usually take place in the homes of JDRF volunteers and provide a place to meet other parents of children with diabetes and learn more about diabetes.



The networking coffees are held every month except July and August; days and times vary each month. Joslin providers have led recent groups on a variety of topics. Deb Holtorf, NP, BC-ADM, led a group about sibling issues in February. Margie Lawlor, MS, CDE, led a group about travel in April. Michael See, MS, RCEP, led a group about sports and exercise in May. In the near future, Debbie Butler, LICSW, CDE, will lead a group about coping with diabetes stressors.

For a list of upcoming networking coffees, go to: www.jdrf.org/networkingcoffees.

Recipe: “Make a Splash” Refreshers

Ingredients:

- Your favorite no-sugar drink mix (like Crystal Light or Diet Snapple)
- Water (to make drink mix)
- Sparkling Water



Directions:

- (1) Choose any flavor no-sugar drink mix (you can even mix two together!)
- (2) Make a pitcher of no-sugar drink using the directions on the package.
- (3) Pour into ice cube trays and freeze for at least 4 hours.
- (4) Eat the flavored ice cubes plain or add them to regular or sparkling water for a colorful treat!

Nutrition Facts:

(serving size: 8 oz)
Calories: 0
Fat: 0 g
Carbohydrates: 0 g



An Interview with Marilyn Roby: Growing Up with Diabetes

Marilyn Roby has had diabetes for 57 years and has been a Joslin patient for 56 years. She is an expert in organizational development and has worked with companies such as Ford and Sprint to find ways to help them achieve their goals more effectively. Marilyn now works with non-profit organizations. She recently spoke to the Joslin pediatric research team about her experiences in motivating people to change their behavior. She also spoke with Heidi Pound about the role diabetes has played in her personal and professional life.

Heidi: How were your parents helpful in managing and dealing with your diabetes?

Marilyn: I was diagnosed with diabetes when I was 5 years old. My brother was diagnosed 6 years later at age 14. Diabetes management was fully integrated into my family's lifestyle. Family meals were important and everyone ate the same things. My mother said that the "diabetes diet" (that's what she called it) was just a good, healthy way to eat.

Heidi: Was this helpful?

Marilyn: Tremendously, because I was never made to feel different. There was no temptation either, because the "bad" foods were just not in the house.

Heidi: How did your parents' involvement in your diabetes management, or their support, change as you got older?

Marilyn: My parents attended lots of diabetes classes and they always brought me, even when I was very young. I was always involved in my diabetes care. Things probably started to change when I was 9. I started going to Clara Barton Camp and my knowledge began to surpass my parents' knowledge. I began to take more responsibility for my diabetes care.

Heidi: Were your parents still involved?

Marilyn: Oh, absolutely, in a supportive role. Then, when I was 11, my brother was diagnosed with diabetes. He was

already a teenager, so he immediately wanted more independence with his diabetes management. This helped my parents let go of some of the day-to-day management tasks with me as well. But remember, diabetes management was very different then. It basically consisted of a healthy diet and insulin shots 1 to 2 times a day. My insulin doses rarely varied because the amount of food I ate rarely varied. Today there's a lot more freedom and flexibility, which means more responsibility for everyone.

Heidi: Do you have any advice for teenagers with diabetes?

Marilyn: My diabetes management wasn't perfect as a teenager, but I learned that I felt better when my diabetes was in control. Today, pumps, meters, and continuous glucose monitors (CGMs) give you more options during the teen years when you might need a little extra flexibility.

Heidi: How did having diabetes influence your career path? Did you ever feel as though there was anything you could or couldn't do because of your diabetes?

Marilyn: Diabetes wasn't a big deal in my house, so it never occurred to me that it would be an issue as far as a career. My parents never gave me a reason to believe I couldn't do whatever I wanted to do, and whatever I chose to do, I was expected to do it well.

Heidi: Do you have any advice for young adults who are thinking about a future career path and how diabetes may impact their choices or future plans?

Marilyn: I think it's important for families to realize that, while diabetes doesn't directly affect your career path, it can indirectly affect how successful you are. Diabetes makes you self-reliant, teaches you the value of planning, prepares you to handle new situations, and makes you accountable for your actions and their implications. These are all very valuable traits in the business world.

Joslin Teddy Bear Clinic Draws a Crowd

The 6th annual Joslin Teddy Bear Clinic was held on Saturday, March 14, 2009, at the American Diabetes Association Diabetes EXPO in Boston.

Over 200 families attended the Teddy Bear Clinic. Children brought their teddy bears, dolls, and favorite stuffed toys (see photos at right). Popular booths included the Dental Station and the Hospital Stay.



Special thanks to Novo Nordisk for sponsoring this event.





CORNER

CAMP JOSLIN CLARA BARTON CAMP

CAMP

What Makes Camp Special? Joslin Staff Reflect on the Positive Impact of Camp

Many members of the pediatric team have worked at Camp Joslin or Clara Barton Camp. Lisa Kuhn, a pediatric diabetes nurse educator, was a nurse at Camp Joslin for 3 summers. Dr. Cielo Alleyn, a pediatric endocrine fellow, is looking forward to spending a week as a physician at Camp Joslin for the second summer in a row. Below, Lisa and Cielo share their thoughts about the positive impact camp can have on both staff and campers.

What do you think kids gain from going to Camp Joslin or Clara Barton Camp?

Dr. Alleyn: I believe attending Diabetes Camp can be an invaluable experience for kids in many ways. One unique experience is getting to interact with, and learn from, other children and young adults with diabetes.

Lisa: Camp is one of the few places where having diabetes is the norm. I'll never forget my first summer working at Camp Joslin. At my first opening night campfire, the camp director said, "Raise your hand if you've had diabetes for less than 1 year... if you've had diabetes for 5 years... 10 years... 25 years... 45 years!" By the time he was finished, the majority of staff and all the campers held their hands high in the air. The expressions on the new campers' faces were priceless.

How do you think kids' experiences at Camp Joslin or Clara Barton Camp impact them?

Dr. Alleyn: In the short-term, kids gain knowledge about diabetes management skills such as blood glucose

monitoring, insulin shots, and balancing nutrition and exercise. Kids have fun at camp, learn new skills, and become more confident at the same time. They also learn diabetes teamwork.

Lisa: In the long-term, camp offers the opportunity to make life-long friends who become an extended diabetes support team/family. Camp also gives kids a better knowledge of diabetes in general and of their own personal diabetes management. Camp can help provide kids with the tools they need to live long, healthy lives with diabetes.

Have your experiences at Camp Joslin been helpful to you as a health care provider at Joslin? If so, how?

Dr. Alleyn: Spending time with the kids at camp (rather than in a doctor's office) gives me a better sense of their everyday lives. I learn a lot about the obstacles kids face managing their diabetes every day and the tools they use to overcome these challenges.

Lisa: Yes, definitely! My experience with diabetes actually started at Camp Joslin. Working at Camp Joslin provided me with many great opportunities and really gave me a love and passion for working with kids and families who live with diabetes. What started as a summer job led to my current career as a diabetes educator.

For more information about Clara Barton Camp or Camp Joslin, go to www.bartoncenter.org or call 508-987-2056.

Family Camp – August 16-20, 2009

Join the Barton Center for a fun-filled weekend of games, outdoor adventure, delicious food, and diabetes education at Family Camp. Spend time with your family and meet other families as well! For more information and to register, go to: www.bartoncenter.org.



Joslin Launches Updated Teen & Parent Internet Discussion Boards

Joslin launched the pediatric Internet discussion boards in 2001 to support both Joslin and non-Joslin patients and families living with diabetes. The Joslin discussion boards were recently updated with new and improved software. Currently there are separate message boards for teens with diabetes and for parents, as well as several message boards for adults with diabetes. The discussion boards provide a



safe and convenient place for people with diabetes and their families to communicate with other people living with diabetes and to ask diabetes-specific questions. The pediatric discussion boards are moderated

by Debbie Butler, LICSW, CDE, and other members of the Joslin pediatric team. Recent postings include discussions about diabetes management during the summer holidays, how to cope when your child is diagnosed with diabetes, and the pros and cons of insulin pump therapy. To check out the teen and parent discussion boards, go to <http://forums.joslin.org/JoslinDiscussionBoards> and click on the "Pediatrics" link at the bottom of the page. To post a message on the teen discussion board, you must be 13 or older.

The discussion boards should not be used for urgent situations or as a substitute for medical or mental health treatment.

KIDS' PAGE

Whole Grain Word Search



Can you find the 19 whole grains listed below that are hidden in this puzzle? Names may be forward, backward, up and down, or diagonal.

B G T M A K E T S U L A G A
 R E K R M E B Q P A H D N C
 F Q I A I S O U E T S T A O
 S C A C L T V S L M B I M F
 E H F H L N I J T G G X A L
 M A R Y E C R C N T P Q R H
 N A P E T A E S A H B U A T
 I W D I N U L E U L O W N R
 A H B O Q O H S A E E Z T D
 R Z U U B W L E W H S G H A
 G N L A K B I P N A Y K L W
 T X G C R H A L W E M M E R
 U A U K C O G Y D O F B X E
 M B R T R U L Q E R T Y U M
 A E H R V I J U S C I T C R
 K V A B S O R G H U M C E Y
 I F D A F R C Y L D K S E A
 A E Q U I N O A L O A L K F
 T G M P T C R Y B W R L H W
 W H E A T U N E T A L M R G
 R A B Q A I E A B G T E F F

Teen & Parent Fenway Tour

Over 70 teens and parents came to the Joslin Teen & Parent Fenway Park Tour on May 20 (photos below). A Fenway Park Tour for kids ages 8-12 and their parents will be held on Wednesday, August 12. Stay tuned for more information!



Special thanks to Novo Nordisk for sponsoring this event.



AMARANTH
 BARLEY
 BUCKWHEAT
 BULGUR
 CORN
 EMMER

FARRO
 KAMUT GRAIN
 MILLET
 OATS
 QUINOA
 RICE



RYE
 SORGHUM
 SPELT
 TEFF
 TRITICALE
 WHEAT
 WILD RICE



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