

FALL 2013

the barton Spirit! newsletter

# **Campers Participate in the Bionic Pancreas Study**

by Kerry Greenan, NP

A team of researchers descended on Clara Barton Camp and Camp Joslin this summer with the goal of advancing cutting-edge diabetes research.

The human pancreas constantly regulates the body's glucose level by lowering it with insulin, made by the beta cells of the pancreatic islets, and by raising it with another hormone called glucagon, made by the alpha cells of the islets. The normal production of both hormones is lost in type 1 diabetes. Researchers at Boston University have developed a bionic pancreas that attempts to replace these functions. It is made up of several communicating devices: a continuous glucose monitor, insulin pumps to deliver insulin and glucagon, and a computer algorithm running on an iPhone, which automatically decides how much insulin or glucagon to give.

Similar to a real pancreas, the bionic version continuously assesses blood glucose and makes a new decision about how much insulin or glucagon to deliver every five minutes without any input from the user (this is referred to as "closed-loop" glucose control). The bionic pancreas requires only the patient's body weight to get started. Then it continuously adapts to the user's daily insulin needs, which can be greatly affected by stress, diet, exercise, and changes in hormones.

The Summer Camp Study was the culmination of almost a decade of work to develop and fine-tune an algorithm that can appropriately dose insulin and glucagon. Animal studies with pigs began in 2005, and the first studies with volunteers with type 1 diabetes began in 2008. Study participants in the early trials were hooked up to large

devices on the clinical research floor of Massachusetts General Hospital and were largely confined to a hospital room for one to two days at a time.

A leap forward occurred in early 2013, when a portable version of the bionic pancreas was approved by the FDA for use in research studies outside the hospital. So far 16 adults have completed outpatient experiments as part of the Beacon Hill Study. The volunteers wear the bionic pancreas for five days and five nights. They are free to roam downtown Boston, eating whenever and whatever they like and exercising at a health club. Some have been able to go to their jobs as usual because their places of work were in the study area. At night they stayed in a hotel near Massachusetts General Hospital. Early results show that the bionic pancreas works well for adults doing their usual activities.

The next huge step was to find out how the bionic pancreas would work for children, and Clara Barton Camp and Camp Joslin provided the ideal environment for this test. This summer 32 campers and staff, ages 12-20, wore the bionic pancreas for five days while participating in their usual camp activities. During another five-day period, the volunteers wore a continuous glucose monitor to collect data but treated their diabetes as they normally would. This will allow researchers to compare the performance of the bionic pancreas to the usual diabetes care at camp.

The Camp Study team was led by Steven J. Russell, MD, PhD, an endocrinologist from Massachusetts General Hospital, and Edward **See Pancreas, Page 5** 

# "Jammin' With Friends" — Bret Michaels Fundraiser

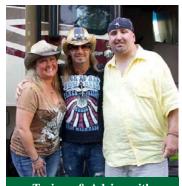
It may be the title of his new album, but on July 8<sup>th</sup> at J. Anthony's in North Oxford, MA, 400 attendees felt they truly were "Jammin' With Friends" as Bret Michaels and his band took the stage for an unforgettable evening.

The excitement and chatter within the community kicked off early in the day when residents and passersby witnessed the tour bus towing the "Rock My RV" trailer traveling toward the venue. Local band Childz Play opened the evening while Bret hosted a "meet & greet" outside his tour bus for several lucky fans.

While this was an amazing evening, it would not have happened without the vision, tireless efforts, and determination of Oxford residents Adrian and Teriann Krasinskas who sponsored and organized the event. Several times throughout the evening, they were asked what prompted them to bring such a well-known superstar to the community and their response was heartwarming. It was their way of thanking the community for all of the support they received after Adrian was injured in the Station Nightclub fire in Warwick, RI, ten years ago and also their way of helping to celebrate Oxford's 300<sup>th</sup> anniversary. The first concert the couple attended after the fire was a

Bret Michaels concert. Realizing Bret, who was diagnosed with diabetes at the age of six, was such an advocate for diabetes, they felt it was a perfect fit to host the event to help send children with type 1 diabetes to camp.

Concertgoers felt the diabetes connection immediately as Bret explained the challenges of the disease, calling himself a human pincushion and explaining to guests that diabetes is mental as well as physical because you have to



Teriann & Adrian with Bret Michaels

mentally be in the game to manage the disease. Bret strongly supports the fight against diabetes. When Bret won NBC's Celebrity Apprentice in 2010, he donated his winnings to the American Diabetes Association. As he performed Aerosmith's "Walk this Way" song, he dedicated it to those who live with the disease. **See Bret, Page 5** 

# **Clara Barton Camp**

By Alumna Abby (Hout) Mason

Abby has written a book about Clara Barton Camp called <u>The Most Wonderful Place in the World</u>. Abby started as a camper and then worked for many years as a counselor at CBC. All proceeds from Abby's book benefit The Barton Center. The book may be found on www.etsy.com, search Clara Barton Camp Book or go to our facebook page for a link.

My camp journey started twenty-two years ago when I was seven years old. When my parents drove me three hours from my home in Albany, New York, I am sure they had no idea the seed they had planted. For twenty-two years, I have seen camp grow and change, people come and go, but one thing that remains the same is the magic this place creates. While I cannot be at camp every day, it is always in my heart. While I cannot talk to my camp friends every day, they are still my family.

I love camp. It just seemed so natural to write a book about camp! In recent years, my CBC world has changed. It has had its losses, its gains, and its triumphs. It got me thinking—we all have a story, we all have a family tree, and the Camp Family is no different than my biological family. So the questions sort of took over. Where did camp come from? Who put in the time to make camp what it is? How has camp changed? What is the future of camp?

We all know Clara Barton's Birthplace and land were purchased by the Universalist Women who worked with Dr. Joslin to open a camp for girls with diabetes, but there had to be more. With a little bit of research, a lot of driving and a great deal of help from Harvard University, Kylee Walsh, Lynn Butler, and numerous alumni as far back as the 1940's, I was able to piece together a little bit of the past. I learned so much from doing this project about where the roots of CBC are, and why we have the traditions we have. It was humbling. For over 80 years, Clara Barton Camp has continued its mission set forth by a small group of women, a medical team, and eight campers.

The book started out as a small project to learn more about the history of camp and raise money for The Barton Center, but it has turned into a tale of history, memories, and forgotten tales that have impacted the lives of generations of individuals with and without diabetes.

Remember back to the first time you stepped foot on the grounds of Camp. Whether you spent a day or a lifetime at CBC, you have experienced one of the following:

- You have shared a smile with someone you didn't know.
- You have made a lifelong friend.
- You have danced with one of those Joslin Boys (and found that they are not that icky!).
- You have eaten dinner without your hands (sloppy I know!).
- You have gone swimming at 6 a.m. JUST BECAUSE!
- You have rolled around in the mud because it was fun!
- You have conquered a fear (giving myself my own shot was mine).
- You have made cookies without a recipe!
- You have learned that there is a world outside of your diabetes.
- You have let a child mush food or other product into your hair to make them smile.
- You have gotten up at 2 a.m. every night to make sure a child was safe.
- You have sung at the top of your lungs and banged on tables.
- You have been thrown in the pond against your will and LOVED it!

We all have had our time at the most wonderful place in the world; we have all felt its magic and come away being a better person because of it. We recall when twelve short days felt like a lifetime that you never wanted to end—twelve days filled with hope, humor, and magic. As



alumni, we are the future of Clara Barton Camp and Camp Joslin. We, as alumni, are the reason Camp continues to exist. Alumni for generations have kept the magic alive, and I challenge each one of you to continue to keep it alive. Continue to spread the word about camp, continue to attend events, and continue to donate your time and resources, let's add more branches to The Barton Center family tree. Please just picture yourself sitting in front of the campfire with your arms wrapped around your closest friend singing taps, or hugging your friends hoping you never have to leave and counting down the days until next year. You, too, can continue to make a difference in the life of a child with diabetes.

CBC will always have a special place in my heart and I hope that it does the same for you!











# **Camp Joslin**

It only makes sense that coming back to a unique and special place would lend itself a unique and special feeling. It's a feeling that many who have ever experienced being at Camp Joslin know about. Turning down that road into camp, being greeted by the signpost that has been hanging there for an age, with the prickly trees on either side creating a canopy of shade, making it around the bend into sunlight. A special sort of sunlight that you only get in the outer reaches of western Massachusetts. One that illuminates the fields, makes the greens seem greener, a kind of intangible energy that reflects back into you, almost preparing you for what comes ahead. There's nothing quite like coming back onto these grounds after an offseason that seemed to drag on forever. For a first timer, it might seem like any other summer camp for kids, but for those of us who have experienced it, the butterflies that begin to flutter in our stomachs are a culmination of emotions trying to prepare us for all the good things that are about to come. A nervous sort of energy, but a positive one. One that brings us back to center, reminds us of why we're here and what we're trying to accomplish. It's truly like stepping away from your home and family to go to your other home and family. Few places can evoke so many powerful emotions and memories for so many people over such an extended period of time, and it is a testament to the spirit of Camp that lives on; empowering families and changing

In terms of our overall mission, the 2013 summer at Camp Joslin was wildly successful. We had many returning campers and staff in addition to the many new faces we added to our Camp Joslin family. We were lucky enough to have many special guests come onto camp, including Hope on Two Wheels (a bicycling group raising money for diabetes awareness), professional basketball player Omri Casspi, and Ironman triathlete and motivational speaker Jay Hewitt (who once again ran his yearly biathlon here at camp). We also sent the Helmsley Charitable Trust team on the hike to heck, had a special performance from local talent Hero on Hold, and were even privileged enough to bring in Ed Damiano and Steven Russell to host a study on the bionic pancreas! It was wonderful to have such a diverse group of guests come in and speak to, inspire, and motivate the campers; but it was also a two-way street! Scott Kasper of Hope On Two Wheels told us after one of the opening campfires that he "came here to inspire us, but it's you guys that inspire me!" It was wonderful to have people come onto camp who can help us in our mission to empower children living with diabetes while also giving our guests the chance to see our mission in action.



Veterans of Camp Joslin will be pleased to know that all of our essential traditions have survived and are flourishing in tandem with a new wave of fun activities, songs, and games that are fresh to Camp. This year the music and drama programs blossomed, with each respective group performing a song or improv games during the talent shows. We also brought in the sport Quidditch from the Harry Potter universe, modified for the less magically inclined, but nonetheless a ton of fun! Lawn games made a triumphant return, from croquet to badminton and horseshoes. Counselors even used their creative minds to create new games such as awning ball. Camp traditionalists need not worry as all the

classic sports are still being played, such as gaga, soccer, and hockey, with the return of camp leagues such as the JBA (Joslin Basketball Association). We also had a ton of fun with classic evening programs such as Indian Council, Kangaroo Court, Reverse Scavenger Hunt, and Name that Tune, amongst others. Additionally, there was a plethora of special days and education games, including a Greek-mythology-themed detective game, diabetes olympics, classic counselor hunts, diabetes jeopardy, and even nutrition challenges in the mess hall, including the "Golden Plate Challenge," where the healthiest eaters on camp can win a prize!

Summer 2013 was an incredible summer with incredible experiences, and the positive energy that surrounds the program is sure to carry over into our fall, winter, spring programs! One of the reasons why Camp is such a special place is because of how welcoming and accepting it is. It's a place where one can't help but feel comfortable, and it's our hope that you will return again for another summer or program to be a part of our mission to help others living with diabetes. You are always welcome at Camp Joslin and always remember, YOU ARE OUTSTANDING!

# **Campership Raffle Winner**

Congratulations to Alden Fitz who won our Campership Raffle.
Alden's parents were very excited to win a two-week session for Alden for next summer. The winning ticket was drawn at the end of Family Camp.













### **Barton Day Camp**

Day camp once again hit the road this summer making stops in Connecticut, Massachusetts, and New York. You could hear us singing down the streets of New York City or in the quiet suburbs of Old Westbury, Connecticut.

The campers at Rainbow Club enjoyed a shaving cream fight. Many campers attended our optional overnight to get a taste of what residential camp might be like and enjoyed Gaga, a movie, and even a laser light show. Parents attended our *Let's Talk Program* specifically for parents. We had many new professional presenters this year from the diabetes field and learned a lot about advances in technology and research.

Boston Day Camp started with a tour of Fenway Park. We sat in the oldest seats and heard about the Red Sox rise to glory. On Tuesday, campers got a bit wet as we chased the mutant cod fish through the Boston Harbor on Codzilla. We also enjoyed a planetarium show at the Museum of Science. During the rainy days, we hunkered down at Mass College of Pharmacy & Health Sciences with fun art projects and a movie on five screens!

Our Worcester Day camp felt right at home on the Clara Barton Camp property. Campers enjoyed running around on lower rec and swimming in the pool. The campers, CITs, and staff went on the Hike to Heck. This is an epic mud hike at the Camp Joslin site. Through lost shoes and mud to our waists, our campers' giggles traveled through the hills at Camp Joslin.

At our Western New England Day Camp located at Smith College, our campers had fun playing on the fields and swimming in the pool. Staff introduced games such as Cattle Wrestler to our campers. One highlight was our parent performances where there was an art show, a skit about healthy choices and diabetes, and a song about being a Barton camper.

In New York City, we found ourselves visiting Central Park Zoo, the Hayden Planetarium, and Barton Day Camp's first trip to the Intrepid. Although Barton Day Camp was stuck in the rain a few times during the week, the campers' spirit and singing voices were strong as we walked to and from our home base at Mount Sinai Hospital.

Our last two weeks were spent in Old Westbury. The campers enjoyed making their alter-ego aliens out of clay and swimming every day. The highlight of their week was the capture the flag game during color wars. One of our biggest camps, there were 71 people with diabetes during Week 1. One of the campers who was new at camp said, "Wow, I really am not alone."

The campers at all day camps enjoyed the new diabetes education games that were part of every weekly schedule. A camper favorite was "Who's up Next?" Campers would answer diabetes trivia questions in order to move the next teammate to the front of the line. Campers learned about who discovered insulin and where. They all now know the name of the dog that first received insulin, do you?

As the summer came to a close, it was with huge hugs and tears that we said goodbye. It was a wonderful summer because of the amazing campers, helpful CITs, and dedicated staff. Thank you!























# **Family Camp**

Family Camp began with an intense game of Banana Olympics, which called for all families to name and decorate a banana and then compete against each other in an array of tasks with their banana as their representative. The mood of enthusiasm, empowerment, and competiveness that was fostered during Banana Olympics lingered throughout the week as the families faced off in other camp classic events such as Cookie Bake Off, Name that Tune, and CITIES. The guardians even got to put their schoolyard kickball skills back to the test as they competed in a Parents vs. Campers kickball game. All of the families also spent an afternoon at Camp Joslin's beautiful waterfront. Throughout the session, all guardians participated in multiple hands-on discussions with our Certified Diabetes Educator while all of our campers participated in interactive diabetes education sessions with our Health Care Team members. The remainder of the session was saturated with staple CBC and Camp Joslin games, such as Army Rangers, Capture the Flag, Jazzersize, and GAGA. Campers, siblings, cousins, parents, grandparents, and staff alike all had an incredible week and cannot wait for next year!



### **Clara Barton Birthplace Museum**

Civil War Poetry now has a connection with campership. During the summer of 2012, Kenneth Postalwait paid a visit to the Birthplace Museum. While wandering through the museum, he told us about a series of books he was writing in conjunction with the war's 150<sup>th</sup> anniversary. Kenneth himself will tell you he is a bit of a character. Born in North Carolina and currently living in Texas, he grew up in a military family and is a roofer by trade. One wouldn't suspect he is also a poet.

# \$300K Donation from Longtime Supporter

The Barton Center has received a \$300,000 gift to our campership endowment fund, the largest personal donation ever made to this fund. Money generated by this endowment fund is used to help children with financial need attend our programs.

The late Brooks H. Carpenter, formerly of Morgan Hill, California, made the generous gift. He was originally from Rhode Island and visited Clara Barton Camp annually when he visited family in Massachusetts. Mr. Carpenter was the son of Beatrice B. Carpenter. Mrs. Carpenter was a member of the Women's National Missionary Association of the Universalist Church, which founded the Clara Barton Birthplace Camp in 1932 for children with diabetes, shortly

after the discovery of insulin.



Thomas Lynch (left) and Gordon Carpenter (right)

"We are very grateful that the Carpenter family has actively supported The Barton Center and its programs for decades, serving on the board and advising staff on countless issues," said Board Chairman, Thomas C. Lynch.

The donation was presented by Brooks Carpenter's brother and estate executor, Attorney Gordon A. Carpenter.

# His book now published, Kenneth met up with us at the museum again this July and shared information about his book. *Red Hawk: A Civil War Journal* is a portrayal of a grave digger on the battlefield during the Civil War paying homage to Clara Barton for her work with the wounded and dying. Red Hawk or Ronzel, portrayed by Kenneth, tells the story of a man who serves to save lives and remember soldiers to their families through tribute songs and poems. He works with Clara during several months of the struggle and they share a "platonic romance," inspiring him to record her heroism in his journal and their special closeness in several songs. In September of 2012, Kenneth portrayed Red Hawk during an anniversary celebration for the American Red Cross in Washington County, Maryland.

Kenneth did not just stop in at the museum by chance this summer. Along with leaving us with signed copies of his book, he wanted to share a surprise. It seems after his initial visit and tour, during which time he also gained some history of The Barton Center and the programs we offer, he gave thought to how he might be able to help. Kenneth wanted to let us know that he has set up a fund begun with proceeds from the sale of his book and would like those proceeds to be donated to the Barton Day Camp Campership Fund. He is hopeful that next year those proceeds will be enough to allow at least two children to attend our Day Camp Programs.

#### Pancreas—Continued from Page 1

Damiano, PhD, an engineer from Boston University. A study staff of more than 20 people from MGH and BU was needed to complete the study including doctors, nurse practitioners, nurses, and engineers, who monitored the study participants around the clock. The camp counselors and health care staff also played a critical role monitoring the safety of volunteers and collecting data.

The Summer Camp Study volunteers were an extraordinarily dedicated group of individuals who became partners with the researchers. Because of their cooperation and enthusiasm for the project, the team was able to collect data on 160 full days of closed-loop blood glucose control and the same number of usual care days, which they are working hard to analyze for publication in the near future. The campers who volunteered got a sense of what it would be like to have a bionic pancreas automatically control their blood sugar. Although the current research device is much larger than the final device will be, many of the campers said they would use it even in its current form to get good blood sugar control with a lot less work. The goal for next summer is to do a similar study in the camp including younger volunteers, ages 6-12.

The research team from Mass General Hospital and Boston University cannot begin to express their gratitude to the study participants, parents, camp staff and everyone else who helped to make this study a huge success. It is truly the first of its kind, and it would not have been possible without Clara Barton Camp and Camp Joslin.

## Diabetes Fairs

Many thanks to our exhibitors who attended closing day at our camp sessions this summer. Camper families appreciated speaking with representatives from the following companies:

American Diabetes Association
Animas Corporation
Glu
Insulet Corporation
Medtronic Minimed
Nova Diabetes Care
Novo Nordisk Pharmaceuticals
Roche Diagnostics
Sanofi-Aventis
Shuga Trak
Tandem Diabetes Care

### **Bret Michaels—continued from Page 1**

While Adrian and Teriann may have been strangers before their generous efforts on behalf of The Barton Center, they have become two of the most amazing friends, even joining campers and staff for lunch and seeing firsthand the difference they have made. Adrian's parents who joined them on their camp visit, are familiar with the organization. Adrian's mother grew up near camp and still remembers hearing the sounds of camp songs echoing down the road. Adrian's father worked as a facilities assistant at camp many years ago.

"Jammin With Friends" was a night that will not soon be forgotten. Thank you Adrian, Teriann, Bret, J. Anthony's, and all who made this such an unforgettable night!

# **Calendar** 2013-14





For more information or for registration forms, please visit www.bartoncenter.org.

# FALL MAGICAL WEEKEND

October 12-13, 2013

Coed, Ages 2-10

Are you feeling the spirit of Halloween? Parents bring your children to camp and join us for a fun-filled weekend with lots of great games and activities, such as trick-or-treating around the pond, arts and crafts, and much more. Casual learning and teachable moments related to diabetes management will abound.

# NOVEMBER WACKY WEEKEND

November 15-17, 2013

Coed, Ages 6-16

Missing summer camp? Thinking about trying camp next summer? Then this is the weekend for you. Come alone or bring a sibling or friend without diabetes and give camp a try! Jampacked with zany activities, diabetes education, fun, and more!

#### WINTER CAMP

December 27-30, 2013

Coed, Ages 13-17

During this four-day program, campers will learn about communication, personal responsibility, exercise, nutrition, and other teenage diabetes issues while having lots of fun in a relaxed, camp atmosphere.

#### FEBRUARY WACKY WEEKEND

February 14-16, 2014

Coed, Ages 6-16

Same rules as November... Join us for a weekend of fun and adventure.

#### SPRINGTIME FAMILY CAMP

March 21-23, 2014

Coed, All Ages

A jam-packed weekend filled with fun activities and diabetes education for the whole family! Moms, dads, brothers, cousins, grandparents, friends, and anyone else you consider your family can come play and learn at Springtime Family Camp. Whether it's singing around the campfire, or eating nutritious and delicious meals, we encourage you to make camp your home and build new and lasting family friendships.

#### **BARTON OPEN HOUSE**

April 6, 2014 1 p.m. to 4 p.m. Coed, All Ages

This is your opportunity to come to camp to see what Barton summer camp programs are like at Clara Barton Camp, Camp Joslin, and Barton Day Camps! Spend the afternoon enjoying a sample of camp life. Choose to spend time at Clara Barton Camp, Camp Joslin or Barton Day Camps program. Snacks and laughs are on the menu!

#### **CAREGIVERS WEEKEND**

April 18-20, 2014

Coed, All Ages

Do you have family members who are willing to look after your child with diabetes "if only they understood what diabetes is all about?" Are you, as a parent, looking for a "diabetes tune-up?" Then Caregivers Weekend, one of our most popular programs, is the right fit for your family. Send your child to camp with grandma, grandpa, or auntie and uncle, or bring your family for a weekend of learning while having a blast! Everyone will leave camp with a better understanding, knowledge, and confidence about diabetes and taking care of the ones they love!

# **Special Events** Update

**Upcoming Events**—For more information or to RSVP for events, please call 508-987-2056 or visit our website at www.bartoncenter.org.

#### **Barton Campership Fund Run**

September 29, 2013 Begins at 10 a.m.

Join our motorcycle ride presented by the Steel Horse Sisters. The ride begins at Sheldon's Harley Davidson in Auburn and ends at Camp Joslin (50 miles, back roads). Enjoy food and entertainment at the end of your ride. Registration will take place at Sheldon's from 8 a.m. to 9:45 a.m. For more information, please go to our website and click on Events or email: events@bartoncenter.org.

#### **Annual Auction**

October 26, 2013 7 p.m. to 10 p.m.

Please join us at the Penta Dining Hall at Camp Joslin in Charlton for our annual auction hosted by the Alumni Association. The evening will feature both silent & live auctions, appetizers, dinner, desserts, and dancing. For more information or for sponsorship opportunities, please call 508-987-2056, Ext. 2003 or email events@bartoncenter.org.

#### The Apple Run/Walk for Diabetes

November 2, 2013 9:30 a.m. walkers 10 a.m. runners

This five-mile road race/walk begins and ends at the Brookfield Apple Orchard, 12 Lincoln Road, North Brookfield, MA. The event is hosted by the Lions Club of the Brookfields and The North Brookfield Youth Center. All proceeds will benefit Clara Barton Camp and the Diabetes Research Team at UMass. To register, or for more information, please email Marty Toomey at mtoomey\_nbyc@charter.net or call Marty at 774-200-0938 or visit www.brookfieldslionsclub.org.

#### Annual St. Patrick's Road Race/Walk

March 15, 2014 12:30 p.m. start for walkers & 1 p.m. start for runners

This four-mile sanctioned event can help raise money toward your camp fee or the general campership fund. Recruit family and friends to walk or run with you to help raise money through pledges toward your summer camp fee or for the general campership fund. This event is followed by a buffet and prizes! All forms will be available online in early 2013.

# Spring Work Day at Clara Barton Camp and Camp Joslin May 3, 2014 9 a.m. to 3 p.m. Coed, All Ages

Spend the day getting each camp ready for the summer! This is a great way to earn your own camp fee or raise money for someone else! You choose which camp you would like to work at for the day. Lunch is provided.

#### CLARA BARTON BIRTHPLACE MUSEUM PROGRAMS

#### **Annual Holiday Open House**

January 5, 2014 1 p.m. to 4 p.m.

FREE EVENT

Join us for the annual Holiday Open House. Learn of the life of Clara Barton who was born on Christmas day as you tour the museum decorated for the holidays. Refreshments will be served. An American Red Cross blood drive will simultaneously take place in the Chabot Health & Education Center.

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the barton **Spirit!** newsletter of

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