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The Mission of the Spina Bifida Association of Iowa is to promote the prevention of spina bifida and to enhance the lives of all affected.

Newsletter—Winter 2014

Hello!

Welcome to your winter edition of the SBAI Newsletter! I hope that this finds you warm, healthy, and happy! Surely spring is around the corner, right?

The Iowa State Snowmobile Association treated us to a wonderful winter event in January. There wasn't enough snow for snowmobiles, but they gave us a beautiful tour of Huxley on their UTV's. The new venue was awesome - lots of room for visiting, eating, and playing wheelchair basketball. A special thanks goes out to Sally Carmichael of ISSA for the lovely quilts and pillows that she made for the attendees. Our hearts go out to her and the Carmichael family as they grieve the loss of Dave Carmichael. He and Sally have been huge supporters of SBAI for many years. We will certainly miss Dave's warm spirit and friendly smile.

Please make plans to attend Education Day on March 29th. We will be in West Des Moines at Valley Church. This event is FREE - free educational presentations, free lunch, and free childcare for children ages 12 and under! Our committee is working hard to provide these things for you. Check your calendar and RSVP that you will join us. You **must** reserve your spot by emailing admin@sbaia.org with the number of people who will attend and the number and ages of children who need care.

Other dates that have been set are our annual picnic on June 22nd and Walk N Roll for Spina Bifida® on October 18th. Plan to attend all of these events. It is a wonderful way to meet new people, share stories, and realize that you are not alone!

Have you thought about joining the SBAI Board of Directors? Elections will take place this spring and we would love to hear from you! Please let me know if you have any questions.

Looking forward to seeing you soon!

Sincerely,

Sherri TeKippe, Chair
Spina Bifida Association of Iowa

SBAI Board of Directors

Chair—Sherri TeKippe
Chair-Elect— OPEN
Immediate Past Chair—Rod Tressel
Treasurer—David Siebrecht
Secretary—Stacy Picard

Member at Large—Dan Biller
Member at Large—Danette Brooks
Member at Large—Jessica Dane
Member at Large—Cheri Horstman

Committee Members

Snowmobile Liaison—Bruno Andreini
Governance—John TeKippe
Communication—Jodi Siebrecht
Webmaster—Adam Sutherland



Mark your Calendars!

- March 29—Education Day (pg. 4)
- June 22—Annual Family Picnic
- June 29— July 2—National Conference (pg. 5)
- October 18—Walk-n-Roll for Spina Bifida®

SpeediCath® Compact Set

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A Camp for Children with Spina Bifida.

Established in 1990, **Spirit Camp** was founded to improve the quality of life for those affected with spina bifida. Spirit Camp is dedicated to providing a supportive, educational program for children and is designed to enhance campers' self-confidence and improve their independence. It was developed to give children the opportunity to participate in a great childhood experience, while allowing parents the comfort of knowing their child is in a safe, barrier-free, environment under careful guidance by highly trained staff.

For more information, please contact
Marilee Kontz,

Sanford Children's Camping Coordinator, at
(605) 328-7157 or kontzm@sanfordhealth.org.
 Camp scholarships are available to children through the Children's Miracle Network. SBAI Assistance Programs, Campship Program, can be used to cover \$500 of the cost of camp (\$525).

Sanford Children's Spirit Camp is scheduled for July 27—August 2 at Camp Courage in Maple Lake, MN. Camper spots are currently available for boys only. All camper spots for girls are filled for this year, but you can call now to get on next year's waiting list.



United Way funds can be designated for the SBAI.

Iowa State Snowmobile Association Ride

No snow again! It is hard to imagine that on January 12, lemonade was more popular than hot chocolate. For the group of 125 people who gathered that day in Huxley, snow didn't really matter. Of course the ISSA family loves snow, but they don't need it to host a great party. They had the usual, grilled hot dogs and hamburgers, a craft table for the kids, Shriner's clowns and a ride around town. This year's ride was on Utility Task Vehicles (UTVs). The move to Huxley's Community Center made the day very enjoyable and allowed an opportunity for SBAI members to try wheelchair basketball. Thanks to Mike Boone and Adaptive Sports Iowa for providing the sports chairs.



Kally Wiskus and Michael Young display their quilts with Sally Carmichael.

Another wonderful part of the day was the quilt raffle. Sally Carmichael made two quilts, one for a boy and one for a girl, as a result of encouragement from her late husband Dave. You may remember Sally as the one putting your hot dog on a bun for you and Dave as one of the guys at home by the grill. They have served us at this event for many years. Another way they support SBAI is by making a quilt for the ISSA convention, auctioning it off and giving the proceeds to SBAI. After being diagnosed with ALS, Dave asked Sally to make two quilts that would actually go to children with spina bifida. When Sally was finished, she felt Dave's presence asking "what about the rest of them?" The result was 17 pillows that were handed out to everyone with spina bifida that day. What a great way to share their love.



Ashley Huseman takes off for her ride around Huxley.

Thanks to Bruno Andreani and our ISSA friends for another wonderful day together. As for the snow, we'll try again next year.



Tina Bannister and Ethan Mitrison prepare for their turn on the UTV.



Keri Siebrecht and Mary Helen Biller show off their pillows made by Sally Carmichael.

Attendees have fun playing basketball together in the gym.





Education Day Saturday, March 29 9:00 am to 3:00 pm

Valley Church,
4343 Fuller Rd.
West Des Moines 50266

Free lunch will be provided, and free childcare will be available for children ages 12 and under.

You **MUST** reserve your spot for Education Day by [emailing admin@sbaia.org](mailto:admin@sbaia.org) with the following information:

- Name
- How many people will be attending?
- Do you need childcare? If so, what are the ages of the children?

SCHEDULE

8:45 am - Childcare Opens for children 12 and under

9:00 am - Arrival & Welcome

9:15 am - **Dr. Doug Storm**, Pediatric Urologist, Clinical Assistant Professor,
University of Iowa Hospitals and Clinics

10:15 am - **Jennifer Downs** - LISW, Early Childhood Specialist with Area Education
(11) - Early Access, Individual Education Plans & 504 Plans

11:30 am - **Mike Boone**, Executive Director with Adaptive Sports Iowa

LUNCH

1:00 pm - **Monica Albers**, PT, ATC talking about
Intensive Pediatric Therapy

2:00 pm - **Sherri McMichael**, Executive Director with
Variety-The Children's Charity talking about
Kids on the Go/Ashley Okland Star Playground

2:30 pm - End of Day Wrap-Up & Discussion



"Strive for excellence, not perfection." -Ben Franklin



Please join the Spina Bifida Association (SBA) for the **40th National Conference to be held at the Disneyland® Hotel (Anaheim, California)**. Children and adults with Spina Bifida, their families, physicians, nurses, and other clinicians have the unique opportunity to gain information on the latest medical care and network on various issues which affect their lives and professions.

- Learn up-to-the-minute information about urology, orthopedics, neurology, neurosurgery treatment, and much more!
- Attend practical workshops and special programming that address your own interest areas.
- Network with various interest groups - from others living with Spina Bifida to health professionals and product manufacturers.
- Find out how researchers are paving the way for more knowledge about Spina Bifida.

Hear from leading Spina Bifida partners about the important role advocacy plays in our Community's success.

Register today at <http://www.spinabifidaconference.org/>

Find out why the SBA National Conference has earned its place as the world's premier educational event for the Spina Bifida Community.

My family has been to the National Spina Bifida Conference, so we know about all of the great things that can be learned as well as the friendships and connections that can be made. With that in mind, I would like to let you know that you can use SBAI's Campship Assistance Program to pay for up to \$500 of the registration fees for the National Spina Bifida Conference. Assistance can only be provided to those eligible for the SBAI Assistance Program (check the SBAI web site), but would be a great way to help you attend this conference. Please let us know if you have questions.

-David Siebrecht—Treasurer

How Sporting: Get Into a Game

Wellness experts remind us that a balanced life includes some form of regular physical activity. This becomes even more important for persons whose bodies must exert in extraordinary ways to accomplish daily tasks. A sport can become a way of using muscles that don't otherwise have an opportunity for use or a chance for pure enjoyment. Sports offer opportunities that are difficult to duplicate other ways: spirit of competition, thrill of winning, learning through loss, sense of belonging, value as part of a team, joy in accomplishment, discovery of ability, and more.

Some may approach athletic activity as a necessary evil if they approach it at all. The necessary part recognizes all the wonderful health benefits – mental, emotional, social, physical – gained from choosing an enjoyable sporting activity as regular exercise. The evil part (and, yes, “evil” is the wrong word, but it's the cliché) occurs when the sport and the person aren't well matched. I worry that a mismatch happens more often for people with restricted mobility. They may fall into a sport because it was one of the only available adapted ones. Or, as in our family situation, the person living with a disability becomes interested in a sport by default – tagging along as a fan or being encouraged by someone they respect to “give it a try.” Any of these might serve as excellent introductions to a potential lifelong hobby or form of exercise. However, everyone benefits from the freedom to continue exploring.

Some of the most charming Olympic stories have included a revelation that the athlete switched one sport for another because of scheduling conflicts (e.g., former hockey player Charlie White now wins medals and titles in ice dancing) or a desire to use a similar skill set for something new (e.g., sprinter/hurdler Lolo Jones now part of a bobsled team). As for me, I'm grateful I had a father who was a high school softball coach or I might never have known the beauty of dew-on-the-grass 7 a.m. practices or surprise-myself-I-did-it stolen bases. Of course, as I aged, I found new ways to be active. Last month I even vowed to tie on ice skates again just to see if I could still glide on ice.

Helping someone with a disability discover a sport well suited to his or her abilities also requires a string of trials and errors. Fortunately, the rewards surpass difficult efforts. When our son was in 6th grade, he insisted on making a supersized skateboard. He was confident that with the right board, he'd become a new breed of Tony Hawk. The hours our family spent shopping for the right supplies, helping him craft the board he had in mind, then holding our breath after he put on his safety gear and gave it a try remain treasured memories. His dream shifted after a few afternoons. Oh, well.

While his life as a skateboarder was extremely short-lived, it led to his next ventures: adaptive snow skiing and biking with a hand-powered bike. Skiing depends too much on geography and season to become as big a part of his life as he'd like. Biking hung in there for a while. So did recreational weight lifting. But now he's on the search again, and I have been reminded how important it is keep encouraging and inviting. Lately, it has been trips to the bowling alley to give his Elvis-themed bowling ball a workout; but as winter gives way to summer, we need will need to be more intentional about exploring options that can provide him a rewarding physical workout. If I'm lucky, I'll enjoy his way to exercise as much as he does. Regardless, we both need to keep trying.

Joy M. Newcom, in addition to being a mom of two adult sons (one with special needs), is a writer and the author of Involuntary Joy (www.involuntaryjoy.com). In this memoir, she chronicles her first five years as a mother, revealing the often unspoken thoughts and feelings that are familiar to parents and guardians of children with disabilities.

“A good plan today is better than a great plan tomorrow.” -Ben Franklin



At A-H-S-T in Avoca, IA



Wyatt Bargaquast set a goal when he was in 7th grade, he wanted to organize a fundraiser for something that was a part of his life, spina bifida. It was his idea for a STAR Event on community service through Family, Career and Community Leaders of America (FCCLA). Now as a junior in high School, Wyatt is an officer with this student led organization that has the family as the foundation and is designed to encourage leadership and community service. With some coaching from Mrs. Madson, one of Wyatt's teachers, he found the Spina Bifida Association of Iowa's website. Eventually he decided to host his own Walk-n-Roll for Spina Bifida® and donate the proceeds to SBAI. Wyatt contacted the association and the planning began. He designed and sold t-shirts and organized a pep rally complete with the band, cheerleaders and the wrestling and basketball teams. Wyatt's 17th birthday was approaching so he chose the closest Friday to that date and ordered cake to be served at the event.

When January 17 arrived, Wyatt and friends put up posters around the A-H-S-T school marking the route of the Walk-n-Roll for Spina Bifida®, set up the cake in the cafetorium and headed to the gym. Wyatt was the MC for his pep rally and started by telling the 7-12th graders a little about spina bifida. He then introduced David Siebrecht, the SBAI treasurer, and told about donating the money being raised to the association. After the pep rally, Wyatt and friends enjoyed time together eating cake and walking/rolling the hallways. At the time of the event, Wyatt had raised \$565 and donations were still coming in.

Mrs. Madson has reason to be proud of her student. Great work Wyatt!



Back row: Shawn Bargaquast, (Wyatt's dad), Patricia Bargaquast, (Wyatt's mom), Scott Bargaquast, (Wyatt's uncle), David Siebrecht & Mrs. Madson
Front row: Wyatt Bargaquast, Keri Siebrecht & Jodi Siebrecht

"A goal is a dream with a deadline attached." -Ben Franklin

Second Annual Special Egg Event - an Easter egg hunt for children with special needs and their families!

The purpose of the Special Egg Event is to provide a fun, safe, family environment that allows for children who may have difficulty participating in a traditional egg hunt to enjoy hunting for Easter eggs! Please join us for this one-of-a-kind event from 3:00 pm to 5:00 pm on Sunday, April 13th at Valley Stadium in West Des Moines, IA.

The egg hunt will have dedicated areas to accommodate children with specific special needs:

- **Quiet Hunt** for children on the autism spectrum or children with sensory processing difficulties who will hunt better in a quiet location.
- **Blind and Visually Impaired** children will hunt for eggs in an open environment with beepers inside each egg, allowing them to hear where the eggs can be found.
- **Children with Wheel Chairs and Mobility Restrictions** will have a dedicated area allowing them to hunt for their eggs using a magnetic pole. Inside each egg will be a magnet that will attach to the pole, making it easier for children to put each egg in their basket.

Siblings are also encouraged to participate in our general egg hunt. We want everyone in your family to have fun at the Special Egg Event.

In addition to egg hunting there will be food, carnival games, animals, and photos with the bunny of honor. Everything we do is geared towards making sure the whole family can enjoy the festivities of the Special Egg Event!

Learn more at <http://specialeggevent.com>.



Join us for the 7th Annual Eastern Iowa Adapted Sports Clinic and Paralympic Experience!



Saturday, March 29th, 2014

10:00 am - 2:00 pm

**Michael J. Gould Recreation Center
Kirkwood Community College, Cedar Rapids, IA**

FREE!

Friends and family welcome!

Experience hands-on learning in air rifle, archery, bowling, cycling, wheelchair tennis, and wheelchair basketball!

Special guest: Vern Willey
RAGBRAI expert and downhill skier

Pizza will be provided for everyone in attendance.
Enter for a chance to win door prizes!

For more information, contact **Sportability of Iowa**

UNI Adapted Sports Camp

for Young Athletes with Disabilities

Wednesday, June 18, 2013 at 3:00 pm—Saturday, June 21, 2013 at 3:00 pm.

University of Northern Iowa

The mission of the University of Northern Iowa's Adapted Sports Camp is to give qualified young people, ages 2nd grade-high school, with various lower limb disabilities around the State of Iowa, an opportunity to participate in various types of athletic events using a sports wheelchair.

The camp promotes wheelchair awareness and provides healthy recreational activities for kids with disabilities. Activities such as wheeling around campus with their teammates to meals, recreational games, other skill activities, and pure fun are important for learning. Athletes enjoy traditional camp and recreation activities, while they are improving daily living, sensory-motor-perceptual, strengthening, and hand-eye coordination skills.

As with any enterprise of this nature, there are costs involved. We project that the actual cost of participation for each athlete is \$800. This covers room, board, staff stipends, medical personnel, and some supplies. We ask each athlete to pay \$195, as most of the families involved are living on limited funds. Participants can apply for assistance through the Campship Program, part of the SBAI's Assistance Programs.



For more information on attending this camp, contact
Jack Eherenman
JEConstruction1@gmail.com
319-232-1911 or 319-493-0978

or

Dr. Nancy Hamilton
203 WRC
University of Northern Iowa
Cedar Falls, IA 50614-0241
Hamilton@uni.edu

Ames and Iowa State University Welcome the 2014 National Junior Disability Championships

The Ames Convention & Visitors Bureau and Adaptive Sports Iowa are excited to announce that the 2014 National Junior Disability Championships (NJDC) will be held at Iowa State University in Ames, Iowa from July 5-12, 2014.

The National Junior Disability Championships are an Olympic-style competition that provides the opportunity for physically disabled youth to compete in various athletic events. These talented athletes all have disabilities such as spinal injuries, cerebral palsy, visual impairments, blindness, limb deficiencies, limb amputations and other congenital anomalies. Athletes compete in sporting events such as swimming, archery, track and field, table tennis and weightlifting.

Those eligible for the National Junior Disability Championships must be between the ages of 7 and 21 and have met the appropriate Disabled Sports Organization (DSO) qualifying standards at a sanctioned regional qualifying competition.

For more information, go to <http://www.njdc2014.com/>.

Looking for information about SBAI Assistance Programs?
Looking for a New Member Form to share with a friend?
This information and more can be found under the membership tab on our website, sbaia.org.

Adapted Kindergym At UNI by Jess Dane

This past fall was the first session of Adapted Kindergym held at the University of Northern Iowa's Wellness and Recreation Center. The program was started by Heather Wiedemann, a physical therapist for AEA 267. Heather has been Brooklyn's Early Access physical therapist for the past couple of years and will continue to be her PT once she starts preschool this fall. We were very excited when Heather told us she was starting The Adapted Kindergym and got Brooklyn signed up right away. The kids meet on Wednesday mornings from 10am to 10:45am. The class is led by Professor Ripley Marston and the UNI Adapted PE class. Each session the UNI students take turns teaching the class and planning the different activities that the kids will be participating in. The kids all love going and playing with the college kids and one another. Each session begins with songs and dance and then they get to do three different sports or activities. Some of Brooklyn's favorite activities were t-ball, basketball, tag, racing around on the scooters, bean bag toss, and many more. The kids end each session with the parachute, and really enjoy bouncing the balls high with it. Adapted Kindergym at UNI has been such a wonderful experience for us and we are so glad that the second session just started this past week. It's great seeing the kids have so much fun and it was also great for the parents too. We were able to meet other local families from the Cedar Valley with children with special needs also, and have made some great friends through this experience. I hope to see the program continue to grow. For more information about the UNI Adapted Kindergym Program, contact Heather Wiedman, AEA 267 at hwiedman@aea267.k12.ia.us.



This newsletter is published by the Spina Bifida Association of Iowa, 8525 Douglas Avenue Suite 39, Urbandale, IA 50322.

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