



# SPINA BIFIDA CLINIC NEWSLETTER

**Issue #2**

**Summer 2017**

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Mimi is in the office every  
Monday and Wednesday and  
every other Tuesday.

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If you have received this newsletter by mail and wish to receive it electronically, call or email Mimi, and she will add you to the Spina Bifida Clinic email list.

### **SEND US YOUR IDEAS FOR THE NEXT NEWSLETTER**

We encourage your comments and input. Please contact us to share your story or if you have a question or concern you feel should be addressed in an upcoming issue of the Spina Bifida Clinic Newsletter. We look forward to hearing from you!

### **Update from Mimi Ardis**

Spring has sprung. I'm always happy for sunny days and warmer weather. Once again, I hope this finds you happy and healthy.

My role as the SBC coordinator is ever-evolving as I try to complete and make new goals. I have accomplished many of my initial goals: the first SBC newsletter was distributed; teen clinics are being held in May, July and November; parent teaching packets are complete and being given to parents of newborns; and our first Adult/Transition Clinic will be held on July 31. There will be four adult clinics per year beginning in 2018.

My next project is to get a GoBabyGo workshop scheduled in conjunction with OSF HealthCare Children's Hospital of Illinois. GoBabyGo originated at the University of Delaware and has spread not only nationwide but worldwide. The project takes battery powered cars for toddlers and adapts them for children ages 2-4 with special needs, allowing them more independence and mobility. The cars are rewired allowing them to be hand driven instead of using foot pedals as well as adapted with trunk/upper extremity support for any physical impairments that may be present. You can search GoBabyGo online or find it on YouTube to watch a video for information. I will keep you informed as we get more definitive information in the future.

With the addition of Dr. Sue and Dr. Verda, clinic is much more involved and comprehensive. As a result, it is also more time consuming for all. Both doctors provide a welcome and much needed service to the spina bifida population. I sincerely appreciate your time and patience at clinic. It is a work in progress as I try to adjust and streamline the process for your day at clinic.

At our April clinic, we welcomed Eric Holman with Numotion and representatives from CPO-Comprehensive Prosthetics & Orthotics to the monthly clinics. See their bios later in the newsletter.

I've received input from many parents following the first newsletter. Parents of infants and toddlers have questions regarding what's available as far as networking-whether it's through Facebook, blogs or other social media channels and any tips that seasoned parents have about anything and everything that would make life easier, e.g., what are the best shoes to wear with braces? Your expertise and knowledge are boundless, and I would love for you to please share your tips you have learned along the way. My goal for the newsletter is to not only keep you informed of what we are doing collectively, but to keep you informed of what others are doing to make their lives easier. So please continue to give me feedback and share solutions to the issues that arise in your child's life.

### **Camp Independence**

Camp Independence is run by the YMCA of Metro Chicago in association with the Illinois Spina Bifida Association (ISBA). It is an overnight camp designed especially for people with spina bifida, age 7 through adult. Campers are encouraged to learn self-care skills, develop new friendships and try new adaptive sports. As part of the Camp Independence program, the ISBA supports independence programming and research conducted by the Chicago Healthy Adolescents Transition Study (CHATS). Dr. Grayson Holmbeck, a clinical psychologist and professor at Loyola University Chicago, is the principal investigator of this study. In research conducted by CHATS team members, parents and campers reported improvements in campers' goal attainment, management of health-related self-care and independence. There is a Facebook group for parents interested in Camp Independence.

**ISBA provides gas cards for families traveling from outside the Chicago area to Camp.**

Contact ISBA to obtain gas cards at [info@i-sba.org](mailto:info@i-sba.org) or call (773) 444-0305

### **Dr. Michelle Verda and Pediatric Neuropsychology**

The **Pediatric Neuropsychology Service** has recently joined the multidisciplinary Spina Bifida Clinic at OSF HealthCare Children's Hospital of Illinois. This service provides outpatient neuropsychological evaluations for children and adolescents with neurodevelopmental, neurodegenerative and acquired disorders of brain function.

Neuropsychology is the study of brain-behavior relationships. In pediatric neuropsychology, we work at understanding how a disorder like spina bifida, hydrocephalus, and/or a Chiari malformation affects a child's social, emotional and behavioral functioning and their learning skills.

Neuropsychological evaluation is an approach to testing based on 1) an understanding of what behaviors are carried out by different parts of the brain, e.g., functional neuroanatomy 2) normal brain development. This kind of assessment involves testing that is sensitive to problems in brain functioning, comparing how a child is functioning to expectations for that child's age level.

Unlike CT or MRI scans, which show what the structure of the brain looks like, neuropsychological testing examines how well the brain is working when it performs certain activities, e.g., remembering. The pattern of test results, interpreted in the context of neuroanatomy and the child's stage of cognitive development, is then used to define a plan for clinical and educational treatment.

For children with spina bifida, neuropsychological assessment can help:

- Establish a performance baseline that provides a means of assessing the functional effects of medical treatment, such as introduction of medications, changes in medications or neurosurgical procedures.
- Parents or teachers understand a child's cognitive strengths and weaknesses.
- Parents advocate for the most appropriate level of services in the school setting.
- Suggest interventions for the remedy of weaknesses or to compensate for weaknesses.
- Parents understand their child's developmental pattern, so that they may set appropriate expectations for their child.
- Parents understand what they need to do to help maximize their child's development.

### **Full Hearts Unique Child Care**

Are you looking for child care for your special child? Look no further!

Amber is more than qualified. She has a child with unique needs and has so much love to share with your child.

This is an in-home day care setting in Peoria. Amber currently has one infant with spina bifida and has three more openings for full or part time. If your child is in school and you only need summer care, she will provide that as well.

Please see her story and motivation on Facebook---search Full Hearts Unique Child Care.

*"If you think our hands are full, you should see our hearts!"*

**ABLE Illinois---Note from Kelly Tanney, Social Worker/ISBA**  
**SAVING FOR THE FUTURE**

The new Illinois Achieving a Better Life Experience (ABLE) program helps people with disabilities save, while preserving their SSI and Medicaid. The ABLE program, passed by Congress in 2014, allows people with disabilities and their families to put their money in an “ABLE” account without counting against their asset limits for federally means-tested benefits.

The accounts can be set up as FDIC-insured checking accounts with a debit card or tax-advantaged savings accounts with a range of investment options. Funds that people put in their accounts can be used for any expenses related to living with a disability and are intended to improve your quality of life, excluding alcohol and gambling.

To be eligible for these accounts, a person must have a disability, like spina bifida, that entitles them to SSI or SSDI, and the disability must be present before age 26. People of any age can have an account if they meet these criteria.

We strongly encourage people to check with their Medicaid, Social Security and any other caseworkers (DSCC, DHS, etc.) to confirm how putting funds in these accounts might affect their benefits. Since the ABLE program is new, every caseworker might not have the details on the program. If your caseworker is not familiar with ABLE, submit your questions in writing, so they can review. For more information, or to open an account, go to [www.illinoisABLE.com](http://www.illinoisABLE.com) or call (888) 609-8683.

**Illinois Spina Bifida Support Groups**

**Peoria Support Group—**

When: Second Monday of each month

Where: Hillcrest Medical Plaza (first floor), 420 NE Glen Oak Ave. in Peoria, IL

Next Meeting: Monday June 12 at noon & pizza lunch provided

Contact: (773) 444-0305 or [info@i-sba.org](mailto:info@i-sba.org)

**Bloomington/Normal Support Group—**

When: Third Thursday of each month, except in the summer

Where: OSF HealthCare Medical Group -College Avenue meeting room, 1701 E. College Ave., Bloomington, IL

Next Meeting: \*\*\*

Contact: [lynn.bradtk@comcast.net](mailto:lynn.bradtk@comcast.net) or call (773)444-0305

**Rockford Support Group—**

If you are interested in meeting other individuals and families living with spina bifida in the Rockford area, call (773) 444-0305 or email [info@i-sba.org](mailto:info@i-sba.org).

**Southern Illinois Support Group—**

If you are interested in meeting other individuals and families living with spina bifida in the southern Illinois area, call (773) 444-0305 or email [info@i-sba.org](mailto:info@i-sba.org).

**Western Illinois Support Group—**

If you are interested in meeting other individuals and families living with spina bifida in the western Illinois area, call (773) 444-0305 or email [nfo@i-sba.org](mailto:nfo@i-sba.org).

Always check the ISBA website for the most current information about support groups! [www.i-sba.org](http://www.i-sba.org)

### **Meet Eric Holman, ATP-Assistive Technology Professional**

Eric is an assistive technology professional, whose specialty is in seating, positioning and mobility. He is employed by Numotion. Numotion is the nation's leading provider of Complex Rehab Technology (CRT)-medically necessary, individually configured mobility products and services designed to meet the needs of individuals with disabilities and medical conditions to provide them with greater independence. Numotion's mission is to improve the lives of people with disabilities by enabling them to actively participate in everyday life.

Eric has been working with children and their families at the adaptive equipment clinic through Easter Seals for the past 25 years. Eric is based out of the Peoria/East Peoria office, but Numotion has numerous offices covering the entire state of Illinois.

Eric started coming to clinic in April. He will be working with Dr. Sue and Dr. Akeson to assist with wheelchair and adaptive equipment issues. We are extremely excited to have Eric join our team.



### **Meet the Professionals from CPO**

Another addition to Spina Bifida Clinic: CPO---Comprehensive Prosthetics & Orthotics. CPO will be coming to clinic monthly, and they started in April as well. CPO is a premier health care service that provides patients with the best in Prosthetic, Orthotic and Pedorthic care. The goal of CPO is to restore mobility and quality of life for their patients. CPO is home to a dedicated, talented and compassionate team of practitioners, who are committed to their patient's outcome.

In 2005, CPO opened its first office in Peoria. In 2016, CPO added its 25<sup>th</sup> office with regional offices in: Bloomington, Champaign, Decatur, Jacksonville, Peru, Moline, Rock Island, Rockford, Springfield and Quincy. CPO is an independent private practice accredited by the American Board for Certification in Orthotics, Prosthetics and Pedorthics.

Amit Bhanti, CPO and/or Alex Carter, MPO, an orthotic/prosthetic resident, who is doing his residency program with CPO, will be the new faces you'll be seeing in clinic. CPO will be working in conjunction with Dr. Sue in clinic.

## Upcoming Events

### **Summer Social Event & Wellness Fair Open House**

Date: Saturday June 24

Location: RiverPlex 600 NE Water St., Peoria

Time: 1-4 p.m.

Come join us for fun activities, food and friendship. Representatives from Heart of Illinois Special Recreation Association, Central Illinois Sled Hockey Association and Cat Ching Do Defensive Arts will be at the event. Basketball wheelchairs used by the Peoria Wildcats will be available to try out. Tim Kirk will have a hockey sled present, so you can check out what that fun activity entails. Jeremy Richards will do a martial arts demonstration. A dietician will be present to give us tips on healthy diet choices.

### **Concert on the Peoria Riverfront**

Date: Friday, July 28

Location: Peoria Riverfront

Time: To be determined

We will have a designated area cornered off that will be wheelchair accessible and paved so weather (specifically mud/mush) will not be a factor. Extra handicap parking spaces will be available close to the Gateway Building. More details to follow on the specific time and cost. The band will be KC & The Sunshine Band and Here Come the Mummies.

### **20<sup>th</sup> Annual Memorial Walk-and-Roll-a-Thon**

Date: Sunday, September 24

Location: Tipton Park in Bloomington

Time: Noon to 2:30 p.m.

The event is in Memory of Emma Kenny, Shannon Kolodzieski, Kaylin Rood and Sarah Whitted. Sign-in starts at noon and Walk & Roll starts at 12:30 p.m. Picnic lunch to follow for all registered participants. The event will raise funds for programs serving children, adults and families living with spina bifida. More info at [walkandrollathon.i-sba.org](http://walkandrollathon.i-sba.org)





### **Meet our Spina Bifida Clinic STAR patient-Lily Ann Kohtz**

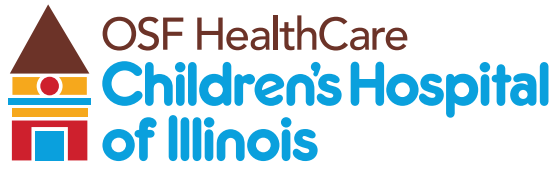
Lily was born at OSF HealthCare Children's Hospital of Illinois. She lives in Green Valley, Illinois. She will be going into the 8<sup>th</sup> grade at Midwest Central Middle School. Lily was born with myelomeningocele and borderline hydrocephalus. At 4 weeks old, Lily had a VP shunt placement for worsening hydrocephalus. Lily has had a total of 14+ surgeries. She gets around with the assistance of AFO braces, forearm crutches and a wheelchair. Lily enjoys many things, music being her favorite! She loves being on her phone and making musical.lys - follow her @kohtz\_16! She also enjoys hanging out with friends, watching Finding Bigfoot, camping and four wheeling! A couple of highlights of Lily's summer include: The Miss You Can Do It Pageant and Camp Independence! We are so grateful for the Illinois Spina Bifida Association for giving Lily the opportunity in her life to meet other kids with spina bifida. She set goals to become independent to care for herself. She is amazing. "Can't" is not an option, "you only know if you try" is! Lily tried out for cheerleading this year and made the school cheer team. She cheered from her wheelchair and proved the only limits that exist are the ones that you let get in the way. Her peers will tell her she can't, but she lets that be her drive to show them she can. Nothing gets in her way from trying.

#takethatspinabifida #beyondallimits



SPINA BIFIDA DOESN'T STOP ME! ~ LILY





530 NE Glen Oak Ave.  
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