

Spina Bifida Clinic Newsletter

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Clinic Staff

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 Dr. Michelle Verda
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Issue 1

January 2017

Spina Bifida Clinic Service Coordinator—Mimi Ardis, RN

Hope your holidays were happy and healthy. As of November 1st my job title changed to Spina Bifida Clinic Service Coordinator. I have functioned loosely in that capacity for many years, but now it is my sole responsibility. This position brings new responsibilities and goals for which I will have the time to achieve.

I am very excited to share a few of the goals...

1. Quarterly newsletter. We will include articles from our clinic staff, upcoming SB events, support groups, and new product info.

2. Teen clinics. My goal is to have 4 per year and am in the process of changing some of your child's clinic appointments to accommodate the new schedule.

3. Education. We will work to develop a comprehensive packet for new parents along with support groups that will be coordinated with other activities.

4. IEP/IQ/Development. We would like your child's IEP or any educational testing that has been done at school or any outside facility. Dr. Verda from neuropsychology will be at the "non-teen" clinics to meet with parents age 3-6. You will receive a survey with your reminder letter.

Please fill it out and bring with you to clinic. Dr. Verda will meet with any parent who has concerns about their child's learning, emotional, or social behaviors.

5. Transition program for teens to adults. Long term goal will to re-establish an adult Spina Bifida clinic.

These are a few of the wonderful and exciting things that will be happening.

If you have any ideas, suggestions, wants, or needs that you would like, please let me know.

Thank you!



Mimi Ardis, RN
 Spina Bifida Clinic
 Service Coordinator

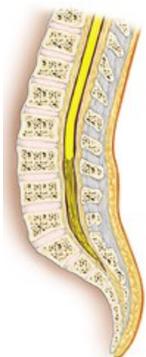
I am in the office on Monday and Wednesday and every other Tuesday.
 (309)624-4064

You can reach me by email at:
maureen.a.ardis@osfhealthcare.org

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.



Spina Bifida
literally means
“split spine”.
It is a very
general term that
can mean a lot of
different things to
different people.



Normal Spine



With Myelomeningocele

Dr. Julian Lin's Update—Spina Bifida General Overview

It is an honor and privilege to contribute to this newsletter. I am a pediatric neurosurgeon and have been seeing patients at our monthly spina bifida clinic for the past 15 years. My goals are to tell you what I think is important in taking care of children with spina bifida from my point of view in each newsletter.

Spina bifida literally means “split spine”. It is a very general term that can mean a lot of different things to different people. Technically, most of our children at the clinic have myelomeningocele. Obviously it is much easier to say “spina bifida” instead of “myelomeningocele”, hence Spina Bifida Clinic. Myelomeningocele is an open neural tube defect associated with “split spine” or spina bifida. In other words, all children born with myelomeningocele have their back open to the environment—their spinal cord is on the outside not covered by skin and the bony part of the spine has developed around the birth defect. Myelomeningocele can be very severe, if not the most severe, form of birth defects in babies that live. On the other hand, spina bifida could also mean a small cleft in the middle of the spine that does not cause any disability or abnormalities.

Myelomeningocele is associated with many abnormalities. These children can develop problems with their bowel and bladder function, orthopedic deformities, and issues with learning. That is why our clinic includes urology, orthopedics, neurosurgery, and neuropsychology. From a neurosurgical standpoint, myelomeningocele is associated with hydrocephalus (“water brain”) and Chiari 2 malformation (hindbrain herniation). This is due to the fact in the womb, the baby’s spinal cord is open to the environment and spinal fluid leaks and “drags down” the developing hindbrain causing blockages within the brain that lead to fluid buildup; hence hydrocephalus (“water brain”). Therefore, if there are no leakages of fluid in the womb from the open spinal cord defect, there would be no hydrocephalus theoretically. In fact, this is the basis of the MOMS (Management of Myelomeningocele Study) trial. This groundbreaking study published in 2011, showed a 50% reduction in the development of hydrocephalus in children with myelomeningocele who underwent repair of their birth defects in utero. The fetus undergoes repair at 24 weeks of gestation, is placed back into the mom’s uterus, then is delivered at 34 weeks provided that there are no preterm labor complications. For babies repaired postnatal, or the traditional way, the risk of developing hydrocephalus is approximately 80%.

The treatment of hydrocephalus in children with spina bifida can be quite complex. Shunt insertion remains the main treatment for infants and children with hydrocephalus regardless of the cause of hydrocephalus. However, with endoscopic techniques, there may be more options, but the jury is still out. We will save a more detailed discuss of the treatment of hydrocephalus for another day.

I hope you find the information useful and not too technical. If there are any other topics you would like us to discuss, please let Mimi know. In the meantime, per aspera ad astra or “through hardship to the stars”. All of you are our stars. Thank you for reading!

Illinois Spina Bifida Association—Community Clinic Connection

The Illinois Spina Bifida Association (ISBA) is proud to announce its new Community Clinic Connection program in partnership with OSF. Through the Community Clinic Connection, ISBA will provide individualized, home-based assistance by a professional social worker to children and adults living with spina bifida. The program is free and can help families access resources and social networks, as well as provide coaching on independence skills.

Kelly Tanney, ISBA’s social worker, is available to meet during weekdays, weeknights, or even weekends throughout the region served by the Spina Bifida Clinic. With permission, the social worker can coordinate with the clinic team to better meet the needs of the patients and families. In addition, ISBA will provide educational and social activities in the Peoria area in partnership with OSF, as well as support group activities in Bloomington/Normal and the Quad Cities.

The Community Clinic Connection program is made possible in part by generous funding from the Fritz and Doris S. Reuling Charitable Fund, the Fontaine Earle Fund, and the Pete and Mildred Donis Charitable Fund, via the Community Foundation of Central Illinois. Contact the ISBA to learn more about this great new program!



For more information about the Community Clinic Connection contact:

773-444-0305
— or —
info@i-sba.org

Michele Wawerski, LSW—Self-Care for Stress Management

As you move throughout your busy life, do you find that you are forgetting to take care of yourself? Whether you are a patient or caregiver, it is essential to take a moment for yourself every day.

Self-care is a stress relief tool for both body and mind. Practicing self-care gives us a chance to reflect and re-energize in order to be the best version of ourselves.

Some examples of self-care include taking a warm bath, reading a book, coloring, or meditation. It is important to pick a self-care activity that fits your specific needs and interests. In order to notice the benefits of self-care and form a habit, practice self-care every day. It may be important to set reminders for yourself when first starting the self-care technique. Your mind, body, and soul will thank you for this little bit of time you take each day to recharge and be your best self!

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February 2017

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Pediatric Spina Bifida Clinic

Our Spina Bifida Clinic is a multi-disciplinary service, which helps families in meeting the special challenges associated with Spina Bifida. Our clinic staff consists of a neurosurgeon, orthopedic surgeon, developmental pediatrician, neuropsychologist, advanced practice nurse, nurse clinic coordinator, and social work.

It also includes representatives from physical therapy and orthopedic supplies.

Our clinic is the second Monday afternoon every month at the Hillcrest Medical

Meet Dr. Verda—Pediatric Neuropsychology



Dr. Michele Verda received her doctorate in Clinical Psychology from Northern Illinois University in December 1999 with a specialty in child and adolescent psychology. As part of her training, Dr. Verda completed a clinical internship in child and adolescent psychology and pediatric neuropsychology at University of Minnesota Medical School. She was also a postdoctoral Fellow in Pediatric Neuropsychology at Kennedy Krieger Institute at Johns Hopkins School of Medicine in Baltimore. After working in the Northwest suburbs of Chicago for several years, Dr. Verda and her family moved back to Central Illinois at the end of 2005. In February of 2006 she started the Pediatric Neuropsychology service at the Children's Hospital of Illinois.

A neuropsychologist is a licensed psychologist specializing in the area of brain behavior relationships. Dr. Verda not only focuses on emotional and psychological problems, but is also educated in brain anatomy, function, injury and/or disease.

Dr. Verda will start coming to clinic in January. She will meet with all patients age 3-6 at clinic. If a parent/caregiver of a patient ages 7-11 has concerns with emotional, psychological, behavioral well-being or issues with learning/school, she will be available at clinic to meet with you as well. If she feels further workup is necessary, an appointment will be scheduled with her outside of the spina bifida clinic. At this time, she will not be going to the teen clinics. We are very excited to have her join our team.

Meet Dr. Caledcott-Johnson—Neurodevelopment & Rehabilitation



Dr. Sue (as she refers to herself) is a neurodevelopmental pediatrician and pediatric rehabilitation specialist. She attended medical school at University of Cincinnati and completed her residency programs in Pediatrics, as well as Physical Medicine and Rehabilitation, through Children's Hospital Medical Center and University of Cincinnati. She is board certified in General Pediatrics, Pediatric Rehabilitation Medicine, Neurodevelopmental Disabilities, and Physical Medicine and Rehabilitation. Her clinical interests include: spina bifida, pediatric stroke, cerebral palsy, spinal cord injuries, neuromuscular disease, spasticity treatment, motor delay, and prematurity.

A physiatrist specializes in brain, spinal cord nerves, bones, joints, muscles, ligaments, and tendons. A neurodevelopment physician specializes in and evaluates issues with learning and development.

Dr. Sue will also be starting at the January clinic. She has been involved in SB clinic in Texas in the past and loves having the privilege to do so again! With her expertise in physiatry and neurodevelopment, she is especially interested in orthotics as well as bowel management, to name a few, as these are integral to the development of independence and self-esteem. We are also very excited to have her join our team!

Meet Kelly Tanney—Licensed Social Worker for ISBA

Kelly Tanney is a Licensed Social Worker who has served children, adults, and families in the Central Illinois area for more than a decade. Kelly believes everyone should have the chance to live life as the best possible version of themselves. Ms. Tanny has worked in a variety of medical settings including addition/recovery, pediatric hematology, oncology, and hospice. She received her Bachelor's degree from Illinois State University and is currently obtaining her graduate degree from the University of Illinois School of Social Work. Kelly brings to our team strong case management skills and fashion advice. While Kelly's family is largely known for their sports accomplishments, she enjoys playing the alto saxophone. Kelly enjoys spending her time with family, friends, and her two purrrfect sidekicks Mr. Chloe and Coco Chanel. In no particular order she also enjoys candy, naps, and polka dots!



Meet Our SB Clinic STAR Patient—Cecilia Padilla

Cecilia, or Ceci, is a happy and energetic 11 year old girl that enjoys being a girl scout, cheerleader, volunteer, and big sister to her two little brothers—Aiden (5) and Nicholas (4). She is in 5th grade and really enjoys going to school each day and spending time with her family and friends.

Ceci has spina bifida (myelomeningocele), hydrocephalus with VP shunt and endoscopic third ventriculostomy, Arnold Chiari malformation type 2, neurogenic bowel and bladder with cecostomy and appendicovesicostomy, osteoporosis, scoliosis, and paralysis from her knees down. She uses a power wheelchair full time and has fought through 39 major surgeries, but she never lets anything stop her from doing what she wants and dreams about or lets it tarnish her ability to see the positive side of everything.

We call her our flower power gal because she frequently has a smile on her face and her passion for life shines in everything she does. She also enjoys doing beauty pageants (especially the Miss You Can Do It pageant), youth theatre, being a Children's Hospital of Illinois Champion Child and attending events to help support the hospital, going to Camp Independence, coloring, singing, and dancing.

Her favorite color is neon pink and her favorite food is taco in a bag. She loves binge watching episodes of Fuller House, Dancing with the Stars, and all the Disney Channel shows. She looks forward to family movie nights. She has a magnificent medical team at the Children's Hospital that consists of six wonderful specialists and they have helped inspire her to do what she wants to do when she grows up. If you ask her what she dreams of doing, her response would be to be a pediatric doctor to help care for kids just like her!



New Product—Peristeen Bowel Management

Within the spina bifida population, constipation and/or stool incontinence are unfortunate, but common occurrences due to a condition known as neurogenic bowel. Neurogenic bowel is caused from the spinal lesion and spinal nerve damage which results in the body's inability to store and remove stool.

Current first line treatment regimens to treat constipation and/or stool incontinence include: dietary modifications, water intake, laxatives, stool softeners, suppositories, mini enemas, digital stimulation, and/or manual evacuation.

Third line treatment regimens include: cecostomy tube placement, Malone procedure, sacral nerve stimulation, or creation of an ostomy.

There is now a second line form of treatment: Peristeen.

Peristeen is a bowel flushing (irrigation) system that is a fairly simple, much less time consuming process to flush out the lower bowel. Tap water is pumped into the bowel using a rectal catheter. The water stimulates the bowel and washes out the stool. The procedure is completed while sitting on the toilet. It takes an average of 15-45 minutes and is performed by the child or caregiver. It is done daily for 2 months and then every other day. There should be no stool leakage or constipation between irrigations. Peristeen has been used in Europe for many years and is now gaining popularity in the United States. It is not recommended in children under 3 years of age. Currently, we are waiting insurance approval for several of our patients and once we have that, we will be trained on the process and be a designated center for the Peristeen Bowel Management product.

If you are interested in Peristeen, please watch the YouTube video via Google or visit Coloplast's website at www.coloplast.us and search for Peristeen under "Products". You can also call Mimi at the SB clinic at 309-624-4064 or Linda at the Urology clinic at 309-624-5100 #2 for more information. A physician order is required and once approved by insurance you will be trained on the procedure. Currently the process to get Peristeen approved by insurance is 3-6 months so it is not a quick process.



Camp Independence

Camp Independence is run by the YMCA of Metro Chicago in association with the 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 or call 773-444-0305

Spina Bifida Support Groups in Illinois

Peoria Support Group—

When: Second Monday of each month

Where: Hillcrest Medical Plaza, 420 NE Glen Oak Ave., Suite 201, Peoria, IL

Next Meeting: February 13th at 12:00PM

Contact: 773-444-0305 or info@i-sba.org

Bloomington/Normal Support Group—

When: Third Thursday of each month in the fall, winter, and spring

Where: OSF-College Avenue meeting room, 1701 E. College Avenue, Bloomington, IL

Next Meeting: January 19th at 6:45PM

Contact: lynn.bradtke@comcast.net

Rockford Support Group—

If you are interested in meeting other individuals and families living with SB in the Rockford area...

Contact: 773-444-0305 or info@i-sba.org

Southern Illinois Support Group—

If you are interested in meeting other individuals and families living with SB in the Southern Illinois area...

Contact: 773-444-0305 or info@i-sba.org

Western Illinois Support Group—

If you are interested in meeting other individuals and families living with SB in the Western Illinois area...

Contact: 773-444-0305 or info@i-sba.org

Always check the ISBA Website for the most current information about support groups! www.i-sba.org



Play Dates in Chicago Area

Play Dates combine an informational and networking session for parents with structured play activities for children with Spina Bifida, their siblings, and their parents. Children have an opportunity to play in a safe and accessible environment while allowing parents to network with other parents, share information, learn about resources, and hear speakers on relevant topics.

Stay tuned for educational workshops in Central Illinois.

January 29th, 1:30-4PM, The Children's Museum in Oak Lawn

5100 Museum Drive Oak Lawn, IL

Speaker: Zoubida Pasha, Family Resource Center on Disabilities

Topic: Navigating the IEP Process

February 12th, 2-4:30PM, Kohl Children's Museum

2100 Patriot Boulevard Glenview, IL

Speaker: Cindy Housner, Executive Director

Founder of Great Lakes Adaptive Sports Association



Contact ISBA for more information: 773-444-0305 or info@i-sba.org

LOOK FORWARD TO FUTURE SPINA BIFIDA EVENTS

March 14—Access Family Night & Special Needs Information Fair at March Madness from 5-8:00PM. You are invited to join the Heart of Illinois Special Recreation Association staff and volunteers for an evening of fun at the March Madness Experience. Not only can you enjoy March Madness, but you can also meet a variety of vendors and support providers at the fair! There will be accessible restrooms and changing areas for your convenience. Request your free tickets and free parking passes by emailing jwahl@peoriaparks.org



March 25—Bowling Event for the Western Illinois Region. Location and time TBD. Save the date!

April 23—Bowling Event for the Peoria Area. Uncle Bucks Fishbowl and Grill, located inside Bass Pro Shop in East Peoria from 1-3:00PM. Please RSVP by April 15th to info@i-sba.org or by calling 773-444-0305.

September 24—20th Annual Memorial Walk-and-Roll-A-Thon at Tipton Park in Bloomington. More information to come in the next newsletter. The walk will raise funds for programs serving children, adults, and families living with spina bifida.

Anyone with Spina Bifida is welcome to attend any of these ISBA sponsored programming events.

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!

Mimi Ardis at 309-624-4064 or maureen.a.ardis@osfhealthcare.org