



**SPINA BIFIDA
CLINIC
NEWSLETTER**

Issue #9

Winter 2020

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Mimi is in the office every
Monday and Wednesday.

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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

What the heck happened to fall? Fall is and has always been my favorite time of the year. I love the beauty of fall: hues of yellow, red, orange; crystal clear skies with cool, crisp nights; windows open; smell of wood fires; s'mores; apples and pumpkins; football; Halloween candy, candy and more candy! I could go on forever.

I am hopeful we will have pediatric urology coverage for Spina Bifida Clinic figured out in the next few months. Although nothing is confirmed, OSF Children's Hospital should have full urology physician coverage after the first of the year and will be working on coverage for clinic. The physician's coverage will be with locums – pediatric urologists who travel from another area. OSF Children's Hospital has not yet hired a full-time pediatric urologist but is diligently working on doing so. Thank you again for your loyalty and patience during this transition process!

I am pleased to announce that there is now a Facebook group for our patients and families: Spina Bifida Support of Central Illinois. It will be a closed group with Nichole, one of my beautiful patient's mom, as the administrator. To maintain privacy of the group, you will need to request to join the group, then answer a couple of questions: who referred you to this page, is it a child or yourself with spina bifida. Its intention is to network with other families, share ideas, and get other's advice on solutions to problems. There will be no involvement from OSF, or me with the group to allow your privacy and freedom of expression.

Here is the link: <https://www.facebook.com/groups/2583258388573318/?ref=share>.

In keeping with the education theme of the newsletter, this newsletter will contain information about the study of neuropsychology and difficulties children with spina bifida encounter with learning.

In future newsletters, I will discuss ways to help you and your child with learning difficulties. I will also explain the differences in IEP's and 504 Plans. As always, if there is a certain subject you would like learn more about, please do not hesitate to let me know.

Happy 2020!

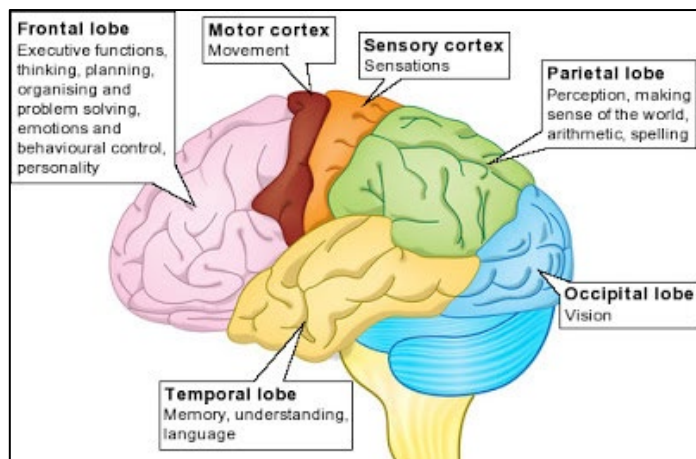
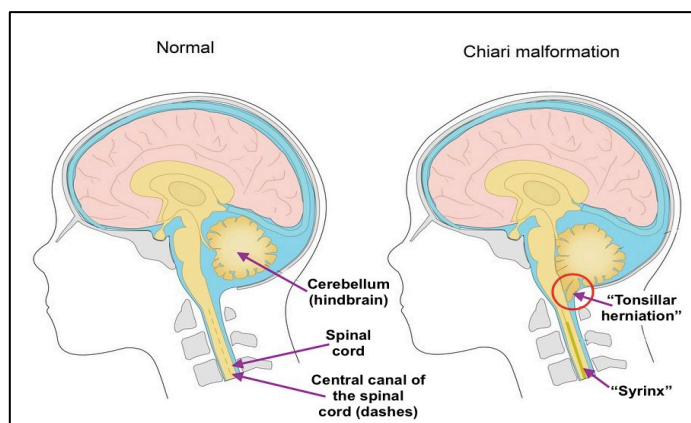
Mimi

Dr. Michele Verda does the evaluations. It is a long process. It is worth it because the results will give us a guide for your child's learning. This guide will be specific to them. It will be used in your child's IEP. The school will be able to use the guide to create the best learning environment for your child.

Children with spina bifida may be strong in one way, and weak in another. A child may have motor issues. Things like movement and activity are problems. The child may have cognitive issues. They may have trouble thinking, remembering and reasoning. They may have academic problems. A child's issues may reflect the level of spina bifida they have. Some forms of spina bifida cause more problems than others.

What are the strengths and weaknesses in a child with spina bifida myelomeningocele (open lesion)? **Strengths** include learning and doing tasks that are rule-based. Examples are vocabulary and math fact retrieval. **Weaknesses** include reading comprehension, math problem solving and memory. The strengths and weaknesses stay the same over the person's life.

What does the brain look like with and without chiari? The pictures below will give you an idea. Note the chiari or "tonsillar herniation" of the cerebellum in the second picture. This can affect motor function. Hydrocephalus affects the parietal lobe. This will affect reading comprehension, math, and spelling.



Motor function: Children with spina bifida and chiari malformation have poor eye-hand coordination. This can affect reading, writing and use of tools. Motor skills can improve. This is done with repetition and correcting errors.

Perception: Children with spina bifida can identify faces and read words. They do have trouble making sense of letters and numbers. In math, they need to know where numbers are in an equation. They need to learn that if the numbers are changed then the answer will change. $3 + 5 - 2$ is not the same as $3 + 2 - 5$. Reading is the same challenge. The child will have to learn that letters form a word, but the same letters can make different words. Read and dear have the same letters but are different words. Pot and top is another example.

Language: Strengths are grammar and vocabulary. Challenges come with expressing thoughts, comprehension (understanding concepts) and use of language in social settings.

Reading: Word recognition is a strength. Challenges are reading comprehension, understanding concepts and memory. Children can understand what they see or read, but they may not remember it. They can tell a story but can't write it down. This is because they have trouble organizing ideas.

Mathematics: Children with spina bifida can learn math facts. Complex problems with multiple steps can be a challenge. They may have trouble estimating amounts and in problem-solving. Sequencing, like telling time or counting change, is hard. Problems with math are common in adults and children with SBM.

Attention/Hyperactivity: Many children with spina bifida may have Attention Deficit Disorder. They may not be able to focus or make decisions. They may finish work slowly or miss assignments. They can be impulsive and disorganized. They often do tasks too fast and can be careless. They may lose or misplace things.

Some of the information in this article is from the Spina Bifida Association.

To learn more you can go to their website and look for this:

Spina Bifida Association. Guidelines for the Care of People with Spina Bifida. 2018.

<https://www.spinabifidaassociation.org/guidelines/>

We don't want this article to discourage you. We think knowing more will help you better understand your child. When you know why they have problems learning, it will help you to help them! In the next newsletter, we'll talk about how you can best help your child.

Meet Tessa Day



Tessa Day, MSW, LCSW. Tessa received a Master of Social Work from the University of Illinois and obtained her clinical social work license. She worked in Chicago in child welfare for 10 years. Along with her family, she moved home to Peoria, and has worked at OSF Children's Hospital for 7 years. She enjoys working with families, helping them navigate the challenges of their child's medical needs, while building relationships with them and seeing their children grow. Outside of work she enjoys spending my time with her husband and three kids. Tessa will be at each spina bifida clinic and will stop by to meet you and your child.

Meet Kara Marriott

Kara Marriott, MSW, LCSW. Kara is a Licensed Clinical Social Worker (LCSW) for Illinois Spina Bifida Association in the Community-Clinic Connection Program. She also works at the OSF Children's Hospital where she is the Congenital Heart Neurodevelopment Coordinator. Kara received her bachelor's degree in social work from St. Cloud State University in St. Cloud, Minnesota, and her master's degree in social work from University of Wisconsin, Milwaukee. Kara completed a two-year certification program in infant and early childhood mental health from the University of Minnesota. Kara has worked in pediatric and adult health care settings throughout her career and has a passion for working with adults and children with complex medical conditions and their families. She has provided clinical and psychosocial care, counseling, case management, referral to resources and support for patients and families experiencing hospitalization and long-term medical management of congenital health concerns. Kara lives with her husband, Brandon, three children and two dogs in Dunlap.



Illinois Spina Bifida Association Support Groups

Illinois Spina Bifida Association offers support groups in the following areas/regions:

Peoria, Bloomington/Normal, Rockford, Southern Illinois and Western Illinois

For more information, contact (773) 444-0305 or info@i-sba.org

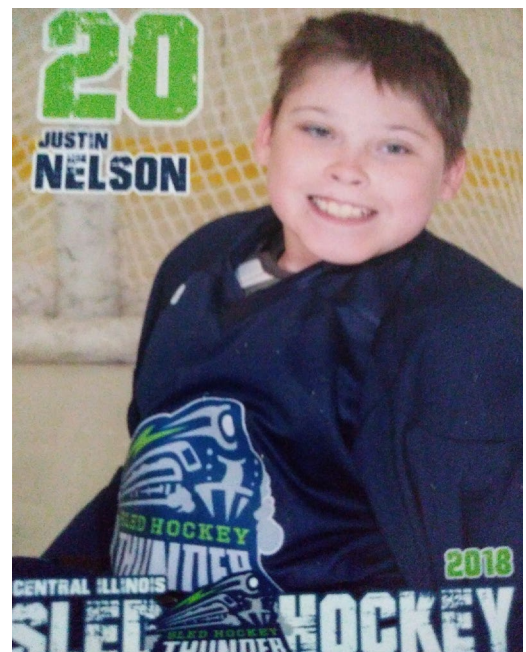
STAR Patient—Teagan



Teagan is an 8-year-old typical girl with the exception of having spina bifida. She loves all things fashion but will also hunt for toads in the summer. She loves to draw, sing, dance and hang out with friends. Teagan doesn't let her "different ability" slow her down. If she is told she can't – she is going to figure out how she can! She has a heart of gold, always there to pick anyone up when they are down. She is one of only two who received the cool and kind award at school! She also has sass for days! She loves to boss her little brother around, teach him new things and snuggle! Oh, and she loves all things '80s

STAR Patient—Justin

Justin loves playing sled hockey and video games on his tablet or his play station. He has always been fascinated with firemen and fire trucks. He loves school and learning new things. He is a very special boy with a heart of gold who wants to see everyone smile. He never lets his disability define who he is!





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