



# **SPINA BIFIDA CLINIC NEWSLETTER**

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(309) 624-4064

Mimi is in the office every  
Monday and Wednesday.

[maureen.a.ardis@osfhealthcare.org](mailto:maureen.a.ardis@osfhealthcare.org)

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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**

As we welcome summer, I'm hoping you all are staying happy and healthy through the ever evolving changes due to COVID 19.

There is good news on the horizon for Spina Bifida Clinic. I am very excited to announce that we have two new physicians coming to clinic. Dr. Robert Steckler, a pediatric urology locum from New Jersey, will be at the July and September clinics. OSF Children's Hospital also now has a part-time pediatric orthopedic physician: Dr. Michelle Prince. She will be commuting from her home in Maine two weeks each month. She will be working in conjunction with Dr. Akeson, and she will be the main orthopedic physician in clinic.

Read more about Dr. Steckler and Dr. Prince in the pages following in this newsletter.

We also welcome: Dr. Paul Noh, pediatric urology locum from Ohio, who began seeing patients in May; and Dr. David Vandersteen, pediatric urology locum from Minnesota, who should be here mid-August. With the addition of Drs. Noh and Vandersteen, I am hopeful that we will have 100% urology coverage for clinic sometime this fall. Let's keep our fingers crossed that this comes to fruition. It's been a long year, and I personally thank you all for your patience with all of the uncertainty.

In other news, we are working on our sixth GoBabyGo build. We had it scheduled for April but the novel coronavirus forced our hand, and it was rescheduled to July 18. We will be providing seven children with mobility and smiles. We plan on getting more creative with our "blinging" of cars. I already have two more kids who need cars, so we may have another build this either late this summer or fall. If your child would like one, please contact me. There is absolutely no cost to you, and the only requirement is that your child is at least 18 months of age.

Peristeen anal irrigation system update: I now have 30 kids using Peristeen with success. The great news is that Medicaid is now covering Peristeen, so it is available to most children. It is a simple approval process that I am more than happy to assist with if you are interested.

Don't forget to join the Facebook group: Spina Bifida Support of Central Illinois. It is a closed group. To maintain privacy of the group, you will need to request to join the group, then answer questions: who referred you to this page, and is it a child or yourself with spina bifida. Its intention is to network with other families, share ideas and get advice on solving issues.

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

Call me anytime you have any needs: (309) 624-4064

Mimi

## **Neuropsychology: Help Your Child with their R's—Reading and 'Rithmetic**

In the last newsletter, we talked about learning issues. Some of them were: motor skills, perception, language, reading, math and attention/hyperactivity. This article will give helpful hints and suggestions to help your child with these issues.

**Most importantly, be your child's advocate.** Meet with school administrators and teachers. Schools have to provide for your child's needs. IEPs and 504 plans are your child's right. They are a guide for their learning and physical needs. Your child's teacher may be the first to notice changes. A good relationship with the teacher is very important. Keep lines of communication open and honest.

**Preschool:** These are very formative learning years for your child. Interactions are the building blocks to language and listening skills. Interactions start at birth with parents. They extend through preschool as your child plays with other children. These are the beginning, necessary skills for reading comprehension and math.

Ways to help build reading and comprehension skills:

1. **READ, READ, READ** to your child! Start as an infant. It is *never* too early to read to your child.
2. Engage your child's curiosity. Ask and answer questions when reading books, watching TV, coloring or doing other activities.
3. Ask "why" questions throughout the day. This teaches cause and effect relationships.
4. Ask your child to look at pictures and describe what he or she sees.
5. Teach them the meaning of new words.

Ways to help build math skills:

1. Count throughout the day all day! Count the stairs they go up or down. Count the grapes they eat. Count their toys. Count fingers. You get the idea. Practice counting!
2. Play fun counting games such as Candyland or Trouble.
3. Teach them to name and recognize shapes: circle, triangle, square, etc.
4. Help them to learn to sort items: by color, size, shape, type of toy, etc.
5. Help them learn concepts like more and less. Place the same items (like blocks) in two piles. Have them pick which has more and which has less. Confirm their answer by counting piles.

Preschool children often benefit and do well in a structured preschool classroom environment. They respond well to step-by-step instructions and teacher prompting. Children with spina bifida should be evaluated by Early Intervention and qualify to start a preschool program at age 3.

**Kindergarten/Early-Mid Elementary School:** Children with spina bifida generally have success with reading. They often have trouble understanding what they read (comprehension). Help your child become more interactive when reading. Don't let them read on cruise control not understanding what they are reading or have read.

Visual spatial difficulties (ability to tell where objects are) may become more noticeable as your child gets older. They need to know the difference between certain shapes for reading: m & w or 6 & 9.

**Ways to help build reading/comprehension skills.** Approach a book in this fashion:

1. Talk about the book: the cover, the title, the pictures, the difficulty of the words, etc.
2. If there are unknown words in the book, have your child look them up to build their vocabulary.
3. Help the child identify a purpose for reading the book. Is it to answer comprehensive questions? For entertainment?
4. If it is being read to answer comprehensive questions, teach your child to review the questions before reading the book. Help your child to decide what information will be needed to answer the questions. Do they need a name or date or do they need to come to a conclusion from the information.
5. Teach your child how to highlight. They should highlight important details as they read. They can then re-read the highlights. This improves comprehension.
6. When you read with or to your child, ask questions about the story. This will help you monitor their comprehension of the story. Watch your child while reading to make sure they don't lose focus. Stop and re-read as needed. This also improves understanding and comprehension. Talk about parts of the story that may be confusing to your child.
7. Discuss the book. Ask questions that are easily answered: Who? What? and Where? Other questions like Why? How? or What if? are not as easily answered and may need your help. Answering these types of questions help your child learn to summarize what they have read.
8. Again, encourage your child to re-read what they have read and highlighted. It may help to get a "text to read" program that will read the story to your child. This can be helpful if your child gets tired of re-reading stories.

Early screening to evaluate reading and listening comprehension is recommended around second or third grade. The evaluation can give direction to parents and teachers with more specific focus geared toward your child's strengths and weaknesses.

Number sense should be the math focus at this age. This is the ability to understand the actual size of a number (10 is bigger than 5; 5 is bigger than 1). Number sense is a building block for other areas of math. Many children with spina bifida struggle with this concept.

### Ways to help with math skills:

1. Have your child draw a number line. Help them figure out problems such as which number is closer to 5, 2 or 9 by using the number line.
2. Learning math combinations (addition, subtraction) is essential for higher math learning. Practice this with a deck of cards or flash cards. Go through the deck using ace through 10. Have your child add 0 to all of the cards, then add 1, then 2, etc. Do the same with subtraction. This helps them get a better understanding of number sense.
3. Have your child do their math out loud. You can better understand their thought process and make corrections if needed.
4. Help your child with math by using “word pictures.” Instead of saying subtract 70 from 100, say take the smaller number (70) out of the larger number (100).

About 30% of children with spina bifida have attention deficit hyperactivity disorder (ADHD), mainly the inattentive type. Struggles with planning, organizing and starting tasks are common. You may notice more struggles as the child’s school work becomes more demanding.

### Ways to help with organization and planning:

1. Make sure that his or her teacher is aware of struggles.
2. Get your child a planner with large spaces for writing. Make sure that all assignments are written in the planner. Make sure the planner gets home nightly. Use the planner as a checklist.
3. Use color-coded book covers, notebooks, folders, binders and dividers. Each school subject has its own color. Have a filing system at home with the same color coding as used at school. Your child can easily find assignments or work for a certain subject that may be due at a later date.
4. Establish daily routines for homework. Have an organized work space for them with all they need to complete their work.
5. Help your child with the concepts of time and sequence. Give them direction: first, last, before, after, etc. First, you need to do your homework. After your homework is done, you can get a snack and watch TV. Or: Before you watch TV, you need to do your homework. After your homework is done, you can get a snack then watch TV.
6. Do weekly cleanouts of backpacks, binders and folders. This will help prevent an overload of unneeded papers and make sure that no assignments are missed.
7. Help your child think and prepare ahead of time. Lay out clothes for school the night before. A master calendar may a helpful visual reminder of upcoming events and needs.
8. **BE PATIENT! *Your child is not lazy. There is a medical issue playing a role in this.***

**Later Elementary School/High School:** Reading comprehension can become more of a problem as reading difficulty and paragraph length increase.

Problems with math also become more noticeable as subjects like geometry are introduced. It is common that people with spina bifida have difficulty with memory. This plays a part with advanced math problem solving.

As your child becomes more independent, he or she will have more things to remember. Most children will need to be or will catheterize themselves or use the restroom every two hours. These add more “tasks” to remember and complete. In younger years, a teacher or school nurse may have reminded your child of these needs. In middle school, your child should begin to assume or be aware of their needs. A watch with a timer is a good way to reinforce this. They may still need help with performing the task but can and should start taking responsibility for knowing what the task is and when to perform it.

### **College/Young Adulthood:**

Sometimes, reading skills are satisfactory, but reading comprehension is still below average.

Math difficulties may also continue. They may be a lifelong struggle. Problems with accuracy, speed and sequencing can lead to problems with banking, budgeting, price comparisons and coin values.

Here are some resources provided by Dr. Verda

#### **Reading Websites:**

<http://www.interdys.org>

**International Dyslexia Association** – Information and resources to help with reading and writing difficulties

<https://www.readingrockets.org/audience/parents>

**Reading Rockets** - Provides reading resources to help parents, teachers, and other educators to help struggling readers build fluency, vocabulary, and comprehension skills

#### **Math Websites:**

[http://tech.aph.org/mf\\_info.htm](http://tech.aph.org/mf_info.htm)

**Math Flash** – Helps children learn math facts

[www.SingaporeMath.com](http://www.SingaporeMath.com)

**Singapore Math** - Shifts from concrete to pictorial to abstract concepts

[www.khanacademy.org](http://www.khanacademy.org)

**Khan Academy** - Web-based instruction on all levels of math

<https://learn.khanacademy.org/khan-academy-kids/>

**Khan Academy Kids** app for 2- to 7- year-olds available for via Apple, Google, and Amazon app stores

**Meet Dr. Michelle Prince**

Dr. Prince joins Dr. Akeson and the pediatric orthopedics team. She graduated from Loyola University Stritch School of Medicine, completed her residency in orthopedic surgery at University of Massachusetts Medical Center, and pediatric orthopedic surgery fellowship at Children's Healthcare of Atlanta. She is board certified from the American Board of Orthopedic Surgery. She has 17 years of experience treating pediatric patients with musculoskeletal problems: trauma, angular deformities, non-operative management of pediatric spine disorders, hip dysplasia and clubfoot.

**Meet Dr. Robert Steckler**

Dr. Steckler is one of the locums who is covering in pediatric urology. He graduated from Albany Medical College, completed his residency at New York Hospital-Cornell Medical Center, and pediatric urology fellowship at Hospital for Sick Children in Toronto, Canada. He is board certified in pediatric urology.

**STAR Patient — Connor**

Connor is a 12-year-old complete with all of the typical tween interests. In his spare time, he loves to play video games and can commonly be found playing Minecraft with his twin sister, Shannon. He loves dogs and has two Welsh Corgis and a French Bulldog that he loves to take for walks. When not gaming, Connor also enjoys swimming all summer, playing board games with his family and puzzling through escape rooms. Connor hopes to attend Camp Independence again this summer and has fond memories of his camp attendance two years ago. Nothing gets him down, and he is always there for family and friends with a big hug just when you need one.

