



## SPINA BIFIDA CLINIC NEWSLETTER

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(309) 624-4064

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**

Oh my, did summer go by in the blink of an eye! I hope this finds you all healthy. I guess novel coronavirus (COVID-19) should serve as a reminder that we are all infallible, and that cleanliness really is next to Godliness. Hand washing always has been and always will be the best defense against germs. With school starting in many ways, shapes and forms, please, please, please keep your children and yourselves safe by practicing social distancing, masking and good hand hygiene. Let's weather this storm and stay as healthy as possible.

Some good news for pediatric urology: Dr. Pankaj Dangle has signed a letter of intent to be head of the Pediatric Urology department at OSF Children's Hospital. Dr. Dangle (pronounced Dong-lay) comes from Children's of Alabama in Birmingham. He did his urology residency at University of Chicago and pediatric fellowship at Children's Hospital of Pittsburgh. He most likely will not be starting until early to mid-2021. Dr. David Vandersteen, locum from Gillette Children's Hospital in Minneapolis, started in August and may be covering some clinics. Dr. Julius Teague, locum from Greenville, South Carolina, will be starting in October. Dr. Steckler has accepted a position at another facility so his last day at OSF will be October 9. OSF continues to recruit another full time pediatric urologist, and after doing so will no longer need locum coverage.

More good news! Pediatric orthopedics will be welcoming another physician: Dr. Andy Michalowicz. His previous practice was in Mount Clemens, Michigan. He joined the OSF Children's Hospital team on September 9. Dr. Michelle Prince will be the main orthopedic physician in clinic, but Dr. Michalowicz may be covering if she is unavailable. Dr. Akesson will continue his association with OSF Children's Hospital as well. The pediatric orthopedic practice has moved their main office to the OSF Center for Health on Route 91 in Peoria. New orthopedic phone number is (309) 655-7668.

I encourage you all to join the Facebook group: Spina Bifida Support of Central Illinois. Here is the link: <https://www.facebook.com/groups/2583258388573318/?ref=share>.

**Check this out!** The Spina Bifida Association has launched its first mobile app. It's free and available on Apple and Google Play- search "Spina Bifida Association" and download. The app features both the *Guidelines for the Care of People with Spina Bifida* and a symptom tracker. The symptom tracker gives you the ability to: a) track health markers such as skin integrity (allows you to take photos) and activity; b) keep track of symptoms like pain and problems with sleep; c) follow your medications, bowel management plan and catheterization routine; d) add notes. You can share this information with your physicians at visits.

In keeping with the education theme and with school starting soon, this newsletter article will give a general overview of IEPs and 504 plans.

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

## **Differences between an IEP and 504 Plan**

**IEP stands for *individualized education plan*.** An IEP is a written plan. Schools and parents use it to meet a child's special needs for education. It will go into much detail. Descriptions and instructions will be written out. The IEP is used to help the child improve skills. It lists services the child may need. These can be things like therapy or other help. All children who get special education services need an IEP. The federal government requires this. The law talking about IEPs is called The Individuals with Disabilities Education Act (IDEA). IDEA lists out 13 types of disabilities. A child needs to have at least one of these to have an IEP. This disability is one that gets in the way of the child's classwork. It stops them from learning well in a general education class. An IEP is a legal document, so things listed on it must be done. The goal of an IEP is simple. The IEP lets a "team" decide what your child needs to succeed in school. It outlines how and where to get the help they need.

### ***The IEP team must have:***

- Parent(s)
- General education teacher
- Special education teacher
- School administrator
- Evaluation staff (ex: school psychologist or therapist)
- Any other person with "knowledge or special expertise about the student." This can be a person the parent asks, or someone the school asks. Knowledge or special expertise is determined by the parent.

### ***What is included in an IEP:***

1. How your child is doing in school now. Both their strengths and weaknesses will be listed.
2. Goals. The IEP sets measurable, short-term goals. These short-term goals will help them reach long-term goals.
3. How performance and progress toward goals will be measured.
4. Needed services. A child may need physical, occupational or speech therapy. They may need other services. The IEP will list how often, how long and where the services will be held. It also will list who will provide them. The family will not pay for the services.
5. What aides the child needs. A child may need assistive technology or computers. They may need to have modified assignments. They may need more study breaks. They may need a personal aides. The family will not pay for any of these.
6. How the child can fit into a general education class.
7. Modifications or accommodations the child needs. This can be both in and out of the classroom. It can include transportation.
8. Training and/or support the student, parent or staff may need.
9. An Individual Transition Plan (ITP) will be put in place at age 14.

The IEP “team” decides on where the child will be put in the school. The child should be put in the Least Restrictive Environment (LRE) with children in general education. This will be done to the “maximum extent that is appropriate.” A child should be in the general education setting as much as possible.

*Parents must give written consent before school can provide any services in the IEP.*

The team will review the IEP at least once a year. Children are retested every 3 years.

### **Tips for Parents:**

#### Before the IEP:

1. Bring support. If you want, bring a family member. You can also bring an educational advocate.
2. Make sure you know what services and accommodations your child gets now. Think about any you would like to add.
3. Write down your questions. Ask as many questions as you need. You have that right.
4. Write down *your* goals for your child. You know your child best.

#### During the IEP:

1. Bring all the medical documents you have. This includes medication and diagnosis changes. Also bring any recommendations from your child’s doctor.
2. Be prepared to be uncomfortable. It isn’t easy to listen to your child’s weaknesses.
3. Stay calm. Your demeanor reflects back on you.
4. Be respectful. Be cooperative. Do not attack.
5. Be positive. Focus on your child’s positives.
6. Share what works for your child at home.
7. Ask your questions. There are **no** stupid questions!
8. Take notes.
9. It’s ok to cry. You are human. You have emotions.

#### After the IEP:

1. Review the IEP. Make sure goals and accommodations are correct.
2. File your copy in one place.
3. Go over the IEP through the year.
4. Explain the changes to your child. Tell them the reasons for the changes.
5. Continue any therapy goals at home.
6. Help your child focus on progress of goals. Try not to focus on grades.
7. Find activities that show off your child’s strengths.

## 504 Plan

Section 504 of the Rehabilitation Act of 1973 is a federal law. It says that any person or agency that gets federal funds needs to have policies that protect disabled people from discrimination.

A 504 plan comes out of that law. This plan is a blue print. It will help a disabled child learn at school. It takes away barriers to learning. A child with disabilities will have the same education other children do.

### **Who can get a 504 plan? Anyone between the ages of 3 and 22 who:**

- Has a disability that gets in the way or limits a major life activity.
- Can't walk, see, speak, breathe, work, care for themselves, do manual tasks or learn.
- Has physical, intellectual or attention issues.
- Or has a disability that gets in the way of their learning in a general education class.

*Either a parent or school can ask for a 504 plan. They must ask in writing. A parent must give consent before the child can be evaluated to see if they qualify.*

A 504 plan team may include parents, general and special education teachers, and the school principal.

### **504 plans will say:**

1. What help the child will need. This can be accommodations, services or supports. There are many ways a child can be helped. What your child needs will be in the 504 plan.
2. Who provides services
3. Who will make sure the plan is put into place

Unlike the IEP, the 504 plan doesn't need to be written. Your school should have a written plan on how they administer 504 plan services. The school also needs to tell you about a "significant change" in your child's services. That also doesn't need to be written. Some schools will write these changes, but some will not. The plan should be reviewed once a year. All services on a 504 plan are free to the student. States don't get extra funds for 504 plan students. However, they can lose funds if they don't comply with the law. The school will implement the 504 plan. If you think the school is not following the law, you can contact The Office of Civil Rights (OCR) of the Department of Education for help.

### **To learn more:**

Illinois State Board of Education (ISBE): [isbe.net](http://isbe.net)

U.S. Department of Education, Office for Civil Rights  
phone: (312) 730-1560 | email: [OCR.Chicago@ed.gov](mailto:OCR.Chicago@ed.gov)

Understood: [understood.org](http://understood.org)

### **Meet Dr. Andy Michalowitz**

Dr. Michalowitz is a fellowship-trained pediatric orthopedic surgeon who joins the OSF Children's Hospital team. He graduated from Des Moines University College of Osteopathic Medicine, completed his residency at McLaren Macomb Hospital in Detroit, Michigan, and his fellowship at New York University Langone Health in New York City, New York. His areas of expertise are pediatric sports medicine and hip preservation. He may be covering some spina bifida clinics along with Dr. Michelle Prince.



### **Meet Dr. David Vandersteen**

Dr. Vandersteen is one of the newest pediatric urology locums. He graduated from Stanford University School of Medicine, completed an internship in general surgery and residency in general surgery and urology at Oregon Health Sciences University in Portland, Oregon, and completed his pediatric urology fellowship at Mayo Clinic in Rochester, Minnesota. He currently practices in St. Paul, Minnesota, and is affiliated with Gillette Children's Health Care Hospital. He is very familiar with spina bifida, as he is seeing patients with spina bifida every Monday afternoon and in a multidisciplinary clinic once a month currently in Minnesota.



## **STAR Patient—Makenna**

Makenna is 15 (almost 16) years old. Some of her favorite things include swimming, floating and boating. She enjoys watching movies, You Tube videos and TikTok. She loves fires and s'mores! She has been participating in remote learning her sophomore year and is missing spending time with her friends.



## **Illinois Spina Bifida Association Support Groups**

Illinois Spina Bifida Association offers support groups in the following areas:  
Peoria, Bloomington/Normal, Rockford, Southern Illinois and Western Illinois  
For information contact (773) 444-0305 or [info@i-sba.org](mailto:info@i-sba.org)

## **Funds Available through the Illinois Spina Bifida Association**

*Did you know that ISBA offers funds for equipment and emergency assistance?*

**Equipment Fund:** Families may request up to \$250 toward out-of-pocket costs for orthotic or other mobility equipment. To qualify, the equipment must be utilized by an Illinois resident with spina bifida. The 2018 ISBA Equipment Fund was made possible by generous gifts from “A Helping Hand” and Kiwanis Clubs. Funds will be available for 2020, check the ISBA website soon!

**Emergency Assistance Fund:** Illinois residents with spina bifida can apply for emergency financial assistance up to \$500. Money is paid directly to the vendor/supplier and documentation of need is required. Call ISBA at (773) 444-0305 for more information.

Information about ISBA funds is available on their website: [i-sba.org](http://i-sba.org)



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