



**SPINA BIFIDA
CLINIC
NEWSLETTER**

**Issue #16
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Mimi Ardis is in the office every
Monday and Wednesday.

(309)624-4064
maureen.a.ardis@osfhealthcare.org

In this issue:

2: Update from Mimi

3-7: Guidelines for children
ages 3-8

Want to receive this newsletter by email?

If you have received this newsletter by mail and wish to receive it electronically, please call or email Mimi at the information above, and she'll add you to the Spina Bifida Clinic email list.

Send us your topic and story ideas!

We encourage your comments and input. Please contact us to share your story or any questions or concerns 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

Wow! We survived another winter! I can't tell you how many times I walked outside and said, "I can't wait for warmer weather." I hate to wish my life away, but the damp, windy, cold weather was way too much this past winter. But spring is here, and that always makes me smile.

This newsletter will concentrate on preschool and middle childhood (ages 3-8) and will give some tips and recommendations system by system regarding spina bifida.

News and Notes

1) I'm trying to be proactive and get all of my patients signed up for OSF MyChart. This will allow us to conduct video visits in the future if COVID-19 continues trending up and we need to limit physical, face-to-face appointments. There are so many positive benefits to having you or your child signed up in OSF MyChart. To name a few, you can make, change or cancel appointments; review lab and test results; get after-visit summaries; review physician notes; send pictures of wounds; request medication refills; and most importantly, contact your physician's office without waiting on hold on the phone.

To use OSF MyChart, you must have an active email account. If your child is under age 12, you'll need to sign up, have an active account and then "add" your child to link them to your account. If your child is between the ages of 12-17, they'll need to give you permission to be on their MyChart account, and a form will need to be filled out in the office. Go to ***OSFMyChart.org*** and follow the prompts. There is also a mobile app in both the Apple Store for iPhone users and Google Play for Android users.

2) GOOD NEWS!!! Camp Independence will be doing in-person camps this summer. But don't wait! Slots fill up quickly, so get your applications in. For more information or to schedule a camp tour, call (847) 546-8086 or contact the Illinois Spina Bifida Association at (773) 444-0305. Another way to ease your fears and get answers to questions is by joining the Facebook group [Camp Independence Parents Facebook Group](#).

3) Mark your calendars for the **2022 Chicago Abilities Expo**, which will be held June 24-26 at the Renaissance Schaumburg Convention Center. It's free! The Expo brings life-changing opportunities, including products and tech, workshops and connections with others in the disability community, as well as a chance to participate in sports. For a full schedule and to register, visit abilities.com/chicago.

4) ISBA will be sponsoring another night at a Peoria Chiefs game this summer. The date and more information will be announced later this spring.

5) The Facebook group for Central Illinois spina bifida is located at: <https://www.facebook.com/groups/2583258388573318/?ref=share>. This is a private group, and you'll be asked confirmation questions prior to being accepted into the group.

Stay safe and stay healthy! Call me anytime you have any needs at (309) 624-4064.

- Mimi



Your child's preschool and early school years (ages 3-8) are so very important. These years can and should be exciting and rewarding. Your child will be introduced to many new activities and situations. Many children struggle with new things, and your child is no different. They will do some things well but may have difficulties with other things. This is normal.

Remember: *Be* supportive. *Be* positive. *Be* loving. *Be* encouraging. *Be* helpful. And most of all, *be* patient. *Do not* smother. *Do not* rush. *Do not* be overbearing.

This is an important time to teach and encourage your child to be independent and responsible. If there's a task your child can do, allow them to do it. If it's a new task, let them try to do it. Offer assistance only when needed. Don't jump in and do the task because it's faster for you to do it. Foster independence.

Mental health guidelines

- Encourage socialization and developing friendships with peers. For younger children: participate in preschool educational programs, attend library reading programs and sign up for local activities. For older children: encourage participation in camps, adaptive sports, Boy/Girl Scouts, church youth groups, etc.
- Make and keep regular schedules. Allow your child to make age-appropriate choices and decisions. Be a good role model.
- For preschoolers: Contact your local school district to begin the process of requesting special education or support.
- For school age children: Assess them for depression, anxiety and bullying.
- Be your child's advocate in school.
- If your child is having behavioral or emotional difficulties, get a referral for counseling or psychological help.

Neuropsychology guidelines

- Preschoolers can show early issues with attention, language and math. These can impact learning as they age. Early/special education preschool is highly recommended.
- Watch for language comprehension problems. Early interventions may help with the development of vocabulary and conversational speech. These are essential for reading comprehension later in school.
- Watch your child for attention problems. These are often described as a lack of or inability to focus and stay on task and/or difficulty beginning a task. They are not hyperactivity or impulsivity. Attention problems are related to Chiari malformation or abnormalities of the corpus callosum.
- Be your child's advocate for high-quality education. Know your child's rights to services that are mandated by the state of Illinois. All children can and should be evaluated for eligibility for special education services. Be active in your child's IEP/504 Planning.
- Over 25% of children with spina bifida myelomeningocele have significant language and reading comprehension problems.
- Over 50% of children with spina bifida myelomeningocele develop math difficulties.
- Interventions for deficits should be included in your child's IEP/504 Plan.

Neurosurgery guidelines

- If your child has a shunt, be aware of signs and symptoms of malfunction. Notify your neurosurgeon's office if you have any concerns regarding your child's shunt.
 1. **Infant:** Full soft spot; being too irritable or too sleepy; raspy breathing; rapid head growth; crossed eyes or inability to look up; vomiting; headache; periods of slow breathing or when a baby stops breathing; worsening motor skills
 2. **Children/adults:** Headache; vision changes; persistent vomiting/nausea; excessive irritability and/or tiredness; worsening memory; new onset or worsening seizures; speech or swallowing difficulties; neck pain; sudden personality changes; worsening sensory or motor skills
- Monitor your child for tethered spinal cord (TSC). Symptoms include back pain, pain going down the back of one leg, changes in gait (becoming clumsy or tripping), and changes in bladder or bowel function (worsening incontinence/accidents). Tethered cord symptoms can worsen or be more prominent after growth spurts.

Mobility guidelines

- Mobility is of the utmost importance. Your child learns through exploration.
- If your child can't pull themselves up or stand, consider a stander. Weight bearing is important for bone health.
- Range of motion and strengthening exercises will help maintain joint and general mobility.
- Braces may be necessary to optimize gait. Teach your child how to take their braces on and off. Teach your child to look for pressure areas that may be caused by their braces.
- This is a great age to introduce your child to adaptive sports. We have wheelchair basketball, sled hockey and hand bicycling in the Tri-county area. Contacts:
 - Basketball: Visit hisra.org or contact Katie at (309) 691-1929.
 - Thunder hockey and bicycling: Visit cisledhockey.org.

Orthopedic guidelines

- Common orthopedic problems in children with spina bifida include club foot; dislocated hip/hips; contractures of knee, hip or ankle; and spinal curvatures (scoliosis).
- Surgery may be necessary to correct foot abnormalities.
- Growth spurts can worsen orthopedic deformities, especially scoliosis.
- Yearly scoliosis and pelvic/hip x-rays should be done if problems are identified.
- Scoliosis treatments include monitoring, bracing and surgery if it is severe or progressive in severity.
- Fractures can occur, especially in non-ambulatory cases. Be aware of some symptoms of fractures: swelling; bruising; any deformity, skin or tissue injury or pain.
- Be aware that many children with spina bifida may walk during early school years, but as they age, they may choose to use a wheelchair. This uses less of their energy, allows them to keep up with peers, and frees up their hands.

Activity guidelines

- Stress to your child the importance of being social and staying physically active.
- Encourage independence with activities.
- Adaptive PE should be available through your child's IEP or 504 Plan.
- Activity recommendations are: 60 minutes of physical activity daily, three days per week of muscle strengthening and three days per week of bone strengthening.
- Muscle strengthening exercises include running; walking; skipping; swimming; riding a bike; wheeling a wheel chair; leg, abdominal and arm exercises. Good muscle strength helps with balance and coordination.
- Bone strengthening exercises include running, walking, skipping, dancing and any weight-bearing exercise. Swimming and biking are not good bone-strengthening exercise. Strollers for younger children are essential for bone health. Bone strengthening builds bone mass, which makes bones stronger.

Urology guidelines

- Yearly kidney and bladder sonograms are recommended to make sure kidneys are growing (or stable) and to look at bladder wall thickness.
- Urodynamic study (UDS) may/may not be done. UDS will show bladder pressures. If bladder pressures are high, it can cause damage to the kidneys. The physician may order intermittent catheterization and/or anticholinergic medication (oxybutynin) to keep the bladder from being too full, which decreases bladder pressure. It is *very important* that bladder pressures are kept low to prevent kidney damage.
- If your child has not started a clean intermittent catheterization (CIC), they may very likely be started on one. The main goal of CIC is to empty the bladder. This not only keeps bladder pressures low, it helps decrease the incidence of urine incontinence and also keeps urine from sitting in the bladder. Stagnant urine can cause bladder stones to form.
- Anticholinergic medications, such as oxybutynin, tolterodine and myrbetrique may be prescribed. The bladder is a smooth muscle. These medications decrease bladder spasms and relax the bladder, allowing the bladder to hold more urine. Side effects can be significant. The most common being constipation, heat intolerance and high blood pressure, specifically with myrbetrique. Always monitor for urinary retention, which can occur as well. Notify your physician's office for urinary retention issues.

- Monitor for urinary tract infections (UTI). Signs and symptoms include fever and chills; low abdominal or flank pain; pain with urination/catheterization; foul smelling or dark urine; increased incontinence; increased mucus and increased tiredness/lethargy. Some children have UTIs without any symptoms. If your child has a fever or is not acting “normal” but has no other symptoms, always consider calling your child’s provider to check a urine culture to rule out a UTI.

Bowel guidelines

- Constipation, constipation, constipation: This is what you don’t want! Is it easier to let your child have it? Yes. Is it good for your child to have it? No. I hear all the time that there aren’t the worries of bowel accidents when a person is constipated, but it’s so unhealthy in so many ways.
- Start a bowel diary. Note when they go: Bristol stool scale type, time and how much. Note if certain foods are triggers for constipation or diarrhea.
- This is an ideal time to get your child on a good bowel program. Place your child on the toilet 30 minutes after meals. Focus on getting your child enough fiber, water and exercise. These are as much a part of a bowel program as toileting.
- Fiber recommendations: ages 1-3=19 grams; ages 4-8=25 grams. Increase fiber slowly. Increasing it too much too fast can cause constipation. Fiber absorbs water, so adequate water intake is necessary, or the fiber may cause hard stools.
- Oral medications for constipation include lactulose, MiraLAX®, Colace®, senna, etc.
- Suppositories for constipation include Dulcolax®, glycerin and The Magic Bullet™.
- Enema systems for constipation include Peristeen®, cone enema, cecostomy and MACE.

Endocrine guidelines

- Hormones made in the brain control how and when puberty starts. Children with hydrocephalus are more likely to have early puberty.
- Normal puberty begins in girls between ages 8-12 and in boys between ages 9-14.
- African American girls usually start puberty up to one year earlier than Caucasian girls.
- Precocious puberty is a term that means early puberty. In girls, the most common change is significant breast development before age 8. In boys, it would entail penile and scrotal enlargement with growth spurt before age 9.
- It is important to address precocious puberty early. Once puberty starts, bone growth will slow and eventually stop. This can cause your child to be shorter than they may have been otherwise.
- If your child truly has precocious puberty, they should be referred to a pediatric endocrinologist (a physician who specializes in hormones) for an evaluation.

Skin guidelines

- Check your child’s skin daily and teach them to do the same. Especially watch weight bearing areas and areas with little to no sensation. Pressure that can’t be felt can cause sores. Sores are often hard to treat and extremely costly.
- Be mindful of temperature. Again, teach your child to be aware of temperature. Things like bath water that’s too hot, car seats that become extremely hot in the sun, and extremely cold weather can cause unintentional burns or frost bite.
- Use skin barriers to prevent maceration of skin due to extended exposure to urine or stool.

- Children who will be swimming and scooting over cement at a pool should wear coverings on their legs and feet to prevent abrasions. Swimming pools are not clean, and any abrasion can result in an infection.

Latex guidelines

- Natural rubber latex is a milky substance from a tropical rubber tree. The substance can be heated and either molded or dipped to make items, such as tires, rubber bands and gloves.
- People with a latex allergy react to the proteins in natural rubber.
- People with spina bifida have a higher risk of developing a latex allergy, so they're placed on a latex precaution. This means that exposure to latex will be limited or nonexistent.
- Common products that contain latex include balloons; rubber bands; balls in ball pits; gym mats; many art supplies; crutch hand grips and tips; handles on tools and bikes; and tooth brushes.
- Some fruits and vegetables have proteins similar to latex proteins that may cause an allergic reaction. Foods with high likelihood include avocados, bananas, kiwis and chestnuts. Moderate likelihood: Apples, carrots, celery, melons, papayas, potatoes and tomatoes. Low likelihood: Apricots, grapes, pineapple, soybeans, walnuts, citrus fruits, peaches, plums, strawberries, mangos, pears, cherries, figs, nectarines, peanuts and shellfish.
- Some products that are latex-free include Elmer's® glue, Crayola® products, Mylar balloons, NERF™ balls, PlastiBands®, Oral B® products and 100 % silicone products.
- Always read labels to check for latex.

Nutrition guidelines

- Encourage healthy eating and physical activity. Drink water and other noncaffeinated, noncarbonated, low-calorie drinks.
- Most children with spina bifida follow “normal” growth patterns until age 4. Then they have an increase in fat mass. Height may be slower due to lower extremity paresis.
- Due to an increased risk for fractures, diets should be high in calcium and vitamin D3 and limited in soda.
- Calcium-rich foods include cheese (American, Swiss, cheddar, ricotta); fortified cereals; fruit juice with added calcium; low-fat or fat-free yogurt; low-fat or fat-free milk; soy or other non-lactose milks with calcium; ice cream and frozen yogurt.
- Foods high in vitamin D3 include fish; fish oil; cheese; fortified, low-fat or fat-free and lactose-free milks; fortified yogurt; butter; eggs; fortified cereal; fortified orange juice; chicken; pork; beef and mushrooms.
- People with spina bifida can battle obesity. Obesity is a double-edged sword. It's easy to get but hard to get rid of. It places extra stress on skin and bones, which, in turn, can cause pressure sores and fractures. It makes it hard to walk, get dressed, bathe and do many daily activities. It can cause blood pressure to soar, lipids to elevate, and push a person into diabetes. Incidences of stroke, gall bladder disease, and sleep and breathing issues increase as well.
- Bottom line: Be proactive! Give you and your child a well-balanced diet rich in fruits and vegetables and low in junk food.

It's important to get your child involved in their own care. The earlier you start, the more attentive they will be. So, start early! Be supportive! Be patient!