



# SPINA BIFIDA CLINIC NEWSLETTER

**Issue #19  
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Mimi is in the office every  
Monday and Wednesday.

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## **Want to receive this newsletter by email?**

If you 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**

The times they are a changing! There are many new and exciting changes happening at OSF HealthCare Children's Hospital of Illinois, Pediatric Urology in particular. We will be welcoming Dr. Ali El Ghazzaoui in January 2023. He will relocate to central Illinois from Toronto, Canada. I will provide more in-depth info on Dr. El Ghazzaoui in a future issue. Tentative plans are for him to attend spina bifida clinic starting in January. Until then, we have several new pediatric urologist locums: Dr. Charles Gerry Henderson from Pensacola, Florida, and Drs. Stanley Kogan and Jordan Gitlin from New York. They may be assisting with spina bifida clinic if their schedules coincide with clinic dates. Dr. Paul Noh will continue conducting video visits post-clinic as well.

### **BASC questionnaire**

Prior to your child's clinic appointment, I will email you a link to Q Global's BASC (neuropsych) questionnaire. The BASC questionnaire provides useful information regarding your child's/teen's behavior. It assesses problem behaviors, such as aggression, anxiety, attention issues, hyperactivity and learning issues. It also assesses adaptive skills, such as communication, study and social skills. Other assessed areas include anger control, bullying, emotional self-control, executive function and resiliency. The questionnaire takes approximately 10-15 minutes to complete. If your child is 8 or older, you'll receive two emails: one for your child to fill out about themselves and one for you (parent or guardian) to fill out about your child. Tessa Day, a licensed social worker, will review and discuss the results and recommendations with you at clinic. I truly appreciate your time and attention to the BASC because it gives us so much useful information about your child.

### **About this edition**

This edition will continue with age-specific issues for teens. I'll describe the process of getting your teen ready to drive, and I'll provide general information regarding where to get evaluations, vehicle modifications and lots of other helpful tips.

### **Facebook support group**

The Facebook group for Spina Bifida Support of Central Illinois is located at the following link and can also be found by searching for "Spina Bifida Support of Central Illinois" in Facebook: <https://www.facebook.com/groups/2583258388573318/?ref=share>. This is a private group, so you'll be asked confirmation questions prior to being accepted into the group.

Anytime you have needs, feel free to call me at (309) 624-4064.

Stay safe and stay healthy!

- Mimi

## The ins and outs of getting your teen ready to drive



Driving is one of life's greatest "rites of passage." It allows us independence and freedom. We should all have the opportunity to learn to drive, and people with disabilities are no exception as there are laws that protect the privilege of driving.

Safety is the number one factor to take into consideration regarding driving and your teen. People with spina bifida may have numerous obstacles that will need to be addressed prior to driving. There may be physical issues, such as limited/no use of their legs or weakness/limited range of motion in their arms. There may also be issues with vision, perception and learning. Other factors that should be considered are your teen's ability to process and react in a complex or stressful situation.

Adaptive (or assisted) driving uses modifications in a vehicle that are specific to your child's needs to safely follow the "rules of the road." Modifications can include hand controls or joysticks; wheelchair lifts and/or ramps; accessible doors and handles.

Illinois high schools must provide driver's education to all students, even those with disabilities like spina bifida. This includes driving with hand controls, if needed. If your high school student is interested in learning to drive, the first step is to request that driver's education be included in their IEP and/or 504 Plan. For more information on driving with spina bifida and driver's education, please contact Robert "BT" Trierweiler, vocational rehabilitation counselor at the Illinois Spina Bifida Association, at [bt@i-sba.org](mailto:bt@i-sba.org) or (773) 444-0305.

### How and where do you start the process of obtaining a license?

1. First and foremost, your teen will need to be evaluated by one of their physicians. If the physician believes your teen is capable of driving, they'll need to write a prescription and refer your teen for a driving evaluation. The prescription must include a diagnosis and specifically state "OT Driver Evaluation and Treatment." This will prevent delays in getting the evaluation scheduled. The evaluation can be done at the facility of your choice.
2. The driving evaluation is performed by a certified driver rehabilitation specialist (CDRS) and will include: muscle strength, range of motion, reaction time, cognition, vision, dexterity and a possible driving simulation. The CDRS will assess and determine your teen's strengths and weaknesses. They will also determine what, if any, vehicle modifications need to be utilized. Their goal is to make your teen an independent and safe driver.

### **Locations of driving evaluation and training facilities:**

- OSF Rehabilitation  
6501 N. Sheridan Road  
Peoria, IL 61614  
(309) 621-4111  
Fax: (309) 621-4148
- Marianjoy Rehabilitation Hospital  
26W171 Roosevelt Road  
Wheaton, IL 60187  
(630) 909-6080
- Loyola University Medical Center  
1219 W. Roosevelt Road  
Maywood, IL 60153  
(888) 584-7888
- Strive For Independence  
919 S. Highland Ave., Building C, Ste. 119  
Lombard, IL 60148  
(630) 984-1919
- Rush University Driving Rehab Program  
1725 W. Harrison St., Ste. 440  
Chicago, IL 60612  
(312) 563-2454
- AMITA Health (with Shirley Ryan Ability Lab)  
935 Beisner Road  
Elk Grove Village, IL 60007  
(847) 640-3119

For more information and locations of driver rehabilitation specialists, contact:

ADED (The Association for Driver Rehabilitation Specialists)

200 First Ave. NW, Ste. 505

Hickory, NC 28601

(866) 672-9466

[info@aded.net](mailto:info@aded.net)

[www.aded.net](http://www.aded.net)

3. Once the evaluation is complete and your teen is approved to drive, they will need to take driver's education. As stated previously, make sure that driver's education is included in your teen's IEP or 504 Plan. Driver's education is provided by your teen's high school, and they'll be required to drive the same number of hours as a person without a disability.

**\*\*They will need to drive a car with appropriate modifications.\*\***

4. Your teen is now ready to obtain a driver's license! Per Illinois law:

- The requirements to get a driver's license include: being 16 years of age, successfully completing driver's education, getting the required behind-the-wheel driving hours, passing a written test, passing a road test and passing a vision test.

- Be aware that in the state of Illinois, you **must** disclose any condition that can impair your driving ability. You may be required to get a medical report from one of your teen’s physicians.
- Your teen may be issued a “restricted” license if they have any of the following:
  - A car equipped with hand brakes or other modifications
  - If they use prosthetics or adaptive devices while driving
  - If they wear prescription glasses or cannot drive at night

If your teen receives a restricted license, they may be required to carry a “Medical Restriction Card,” which would have detailed information about their restriction.

## How to obtain a disability license plate or placard

Visit the Illinois Secretary of State website at [ilsos.gov](http://ilsos.gov). You’ll need to fill out the “Persons with Disabilities Certification for Parking Placard (VSD 62)” form. This form can be used for either the disabled driver or a parent with a child with a disability. You or your teen need to have a valid driver’s license to obtain a specialty plate/placard.

- Part 1: Filled out by the driver applying for the plate/placard (or with the minor child’s information)
- Part 2: Filled out by the parent if getting the plate/placard for their child
- Part 3: Filled out by a physician or APN
- Part 4: Filled out by a physician if the person is eligible for meter-exempt parking

Important things to know when filling out the form:

- There are two sides/pages that need to be filled out.
- Any part of the form that is filled out needs to be dated and signed by either the teen, parent and/or physician, depending on what part it is.
- If the disability is temporary, the form can be taken directly to a driver’s license facility or mailed to the Illinois Secretary of State. A temporary placard may be good for up to six months depending on the diagnosis.
- If the disability is permanent, **this form MUST be mailed to:**  
 Secretary of State  
 Persons with Disabilities Placard Unit  
 501 S. 2<sup>nd</sup> St.  
 Springfield, IL 62756

It can take 45-60 days for the permanent plate/placard to be approved.

Most states honor other states’ disability plates/placards, so you can safely park in handicapped spaces when traveling out of state.

## Vehicle modifications

### Primary driving controls

1. **Hand controls** do exactly what their name implies: allow drivers to steer and brake with their hands. These are perfect for people who have little to no lower extremity function. The most common styles include: push/pull (push lever forward to brake, pull back to

accelerate); push/twist (push forward to brake, twist to accelerate); push/right angle (push up to brake, pull down at right angle to accelerate), push/rock (push forward to brake, rock back to accelerate).

2. **Steering ring accelerator:** Placed directly on the steering wheel, the driver pushes the ring forward to accelerate. A hand brake can be placed on either side of the steering wheel and pushed down to brake. This allows the driver to have both hands on the wheel while driving.
3. **Spinner nobs:** This is attached to the steering wheel with numerous buttons that can be programmed to utilize as turn signals, windshield wiper controls, etc. It's designed for people who have use of one hand but can't grasp the steering wheel. It can be mounted on either side of the steering wheel.
4. **Adaptive electronic controls** include direction/signal extension levers and remote horn, wind shield wiper and headlight controls. These are ideal for people who have limited strength in an extremity.
5. **Steering wheel and pedal extensions:** These are easy to install and bring the pedals closer to the driver. They're ideal for people who have limited range of motion or mobility issues.

### **Wheelchair lifts and ramps**

1. **Platform lifts:** There are internal-occupied and external-unoccupied platform lifts. The mobility device is driven onto the lift and secured. If occupied, it lifts the driver into the cabin of the vehicle. If unoccupied, it will be secured outside the vehicle.
2. **Wheelchair ramps include:**
  - **In-floor ramps:** These ramps are stowed in the floor of the vehicle.
  - **Fold-out ramps:** These ramps come in power and manual modes. They fold out of the vehicle and are stored upright by the door or on the floor of the vehicle.
  - **Manual ramps:** These ramps can only be used by another person. They need to be physically folded out of and into the vehicle so they can't be used by the person with a disability.

### **Financial assistance**

Adaptive equipment can be expensive, so look for discounts or rebates. Private insurance companies may cover some of the equipment expenses. Medicare Part B and Illinois Medicaid may also cover some costs. Insurance and IDPA plans are all different, so you'll need to check to see what is covered.

There are a few other options that may offer assistance:

- Grants may be available. Check out [Illinois Disability Grants - The Mobility Resource](#). This website is full of useful information regarding sources for grants, rebates, different types of equipment, vehicle types and their accessibility, and a blog with many informative articles on a wide variety of topics.
- DSCC (Division of Specialized Care for Children): If you qualify for DSCC, they can help with costs for lifts but not modifications.
- The Elks of Illinois: Your local chapter may assist with costs.

### **Where to get modifications done:**

1. Personal Mobility: Offices in Peoria, Springfield and Champaign, Illinois
2. Mobility Works: Offices in Plainfield and Villa Park, Illinois
3. United Access: Office in St. Louis, Missouri
4. Siebert Mobility of Iowa LLC: Office in Iowa City, Iowa

These sites also have vehicles and equipment for sale and other useful information on driving with a disability.

### **Car insurance**

The Americans with Disabilities Act ensures that insurance companies cannot deny car insurance to a person with a disability or to a driver that requires adaptive equipment. You have the right to fair and affordable insurance. Be aware that some vehicle modifications (lifts and ramps) may increase your premiums. Some handicaps (vision, hearing impairments, seizures, etc.) may also increase your premiums. It's important to ensure that all of your modifications/special equipment are covered in your policy. If you're involved in an accident, these tools should be covered if they're damaged. Modifications include lifts and ramps. Special equipment includes:

- Attached: Vehicle conversion - lockdown system, kneeling systems, etc.
- Unattached: Wheelchairs, motorized scooter, walkers, etc.

Getting your teen ready to drive is a daunting task, but this information should be helpful in guiding you through the process.

### **ISBA offers free executive functioning coaching**

The Illinois Spina Bifida Association (ISBA) offers free executive functioning coaching for Illinois adults and high school students with spina bifida who want to work toward personal goals and develop plans and strategies to achieve them. The training consists of four sessions over a month, one hour per week by phone or video chat. If you're interested, contact the ISBA at (773) 444-0305 or [info@i-sba.org](mailto:info@i-sba.org).

ISBA offers free education advocacy services to Illinois families living with spina bifida for:

- Individualized Education Programs (IEP)
- Individualized Family Service Plans (IFSP)
- 504 Plans
- ISBA has a trained parent advocate who can offer assistance and advice in navigating the complex world of special education. They can support you by:
  - Attending meetings with you and your child's educational team
  - Reviewing educational plans
  - Advocating for the rights of your child

If you have any questions or concerns regarding your child's education, please contact ISBA at (773) 444-0305 or [info@i-sba.org](mailto:info@i-sba.org) to be connected with a trained parent advocate.



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