Happy Holidays from our SBRN family to yours!

As we finish up this year of celebrating our 40th anniversary, we are very grateful for our amazing supporters, volunteers and participants, who enrich our community in so many ways. We are so appreciative of the leaders and coordinators of our vibrant virtual programs: Millie Gonzalez, Colleen Roche, Sonya Burroughs and Steve Nguyen. Our weekly Empowered Conversations and Afternoon Chats, as well as our monthly Golden Girls and Men’s Chat are vibrant virtual groups that bring people from all over the country together to engage in conversation, share ideas and build community. We say thank you to these leaders and to the talented presenters and eager participants. We are also grateful to the Reeve Foundation, who generously supported our Empowered Conversations program through a Quality of Life grant.

In addition, this fall Millie and Colleen coordinated and led our first hybrid Empowerment Retreat weekend, which included numerous virtual work-shops as well as an opportunity to get together in person (finally!) for one of the days. We’d also like to give a special thank you to our Board members who make all of this possible!

For October’s Spina Bifida Awareness Month, we provided info each day to be shared on social media to raise awareness. We also joined with the SBA and its chapters to launch two new Book Clubs for adults with spina bifida and for caregivers. In addition, we held another online Empowerment Auction, which raised over $1,100.

For those in need, we continue to offer financial assistance through our Community Fund, and the opportunity to talk with our Nurse about your health concerns through our Health Conversations program. And for those who are able, please consider supporting SBRN’s programs and services. Your support really makes a difference in our community!
Scoliosis and Spina Bifida

Approximately half of people with myelomeningocele (the most common subtype of spina bifida) develop scoliosis. Because of the high prevalence of this orthopedic condition, it is important to know the symptoms and treatment options available.

What is Scoliosis?

The spine naturally curves in three places (near the neck, chest and lower back), which creates a flattened S-shape, but sometimes it can curve in ways that it should not. This curvature, usually in the thoracic spine, can create the condition of scoliosis, which is characterized by abnormal sideways curves in the spine, often S-shaped or C-shaped. Scoliosis rarely develops before adolescence and is more prevalent and serious in females than males. Scoliosis can be caused by muscle, nerve and bone abnormalities present at birth such as spina bifida or cerebral palsy, but often the cause is unknown.

Symptoms and Complications of Scoliosis

Early signs of scoliosis can sometimes be seen in children. Warning signs that a child may have scoliosis include uneven shoulders or hips (one side looks higher), leaning to one side and protruding blades. Later signs might include pressure sores, decreased mobility and back flexibility, as well as changes in the way the child sits. Children may experience changes in muscle weakness and spasms. Scoliosis can also affect bowel and bladder management.

Scoliosis is often diagnosed during regular screenings in schools. Exams and x-rays can determine the type and severity of scoliosis. Clinical exams will look at spinal asymmetry and differences in the height and shape of the shoulders, back and hips. X-rays are used to determine the extent of the curvature of the spine. The curvature of the spine is measured by the Cobb angle, which helps determine what type of treatment may be necessary.

If the curvature is very pronounced, it can cause additional serious health problems. For example, if the curvature is greater than 70 degrees, the rib cage may press against the lungs and heart and cause shortness of breath and chest pain. This is particularly true when the curvature is in the thoracic spine. For some people, particularly children, scoliosis does not cause back pain; however, others may experience lower back pain or shooting pains in their arms or legs. Every case is different and the size of the curve doesn’t necessarily determine the amount or type of pain.
Scoliosis is seen in about 50% of individuals with spina bifida. Scoliosis may progress more quickly and to a larger curve in people with spina bifida. Curves tend to worsen more during growth spurts so it is important to monitor these changes throughout childhood and adolescence.

Research has also found that individuals with spina bifida who have scoliosis are more likely to experience bladder/bowel incontinence, decreased ambulation and more pressure injuries than those without scoliosis.

Treatment Options

In general, the majority of children with scoliosis do not have enough of a curvature to require surgery. If the curve does progress over 20 degrees, braces may be used to provide some correction of the curve and keep it from worsening. This is best done early when there is still time for the bones to grow and mature.

Most braces are worn between 13-16 hours per day. They are usually made of plastic and designed to conform to the body. They fit under the arms and wrap around the rib cage, lower back and hip. It is important to check the skin often for pressure sores or skin breakdown. The use of a brace is generally stopped when the child stops growing. Bracing is not always a permanent solution, and the spine may begin to curve again after the brace is removed.

With mild scoliosis, exercises may help reduce pain, strengthen core muscles, and improve posture. As always, patients should consult with their doctors to make sure the exercises are okay for them, and if the exercise is painful, they should stop.

If the curve is over 40-50 degrees, or there are other concerns such as pain or difficulty breathing, surgery may be recommended. There are many different types of scoliosis surgery. Spinal fusion is the most common type, but there are other options as well.

The Mayo Clinic describes several options as follows:

- **Spinal fusion.** In this procedure, surgeons connect two or more of the bones in the spine (vertebrae) together so they can’t move independently. Pieces of bone or a bone-like material are placed between the vertebrae. Metal rods, hooks, screws or wires typically hold that part of the spine straight and still while the old and new bone material fuses together.
Scoliosis and Spina Bifida (continued)

- **Expanding rod.** If the scoliosis is progressing rapidly at a young age, surgeons can attach one or two expandable rods along the spine that can adjust in length as the child grows. The rods are lengthened every 3 to 6 months either with surgery or in the clinic using a remote control.

- **Vertebral body tethering.** This procedure can be performed through small incisions. Screws are placed along the outside edge of the abnormal spinal curve and a strong, flexible cord is threaded through the screws. When the cord is tightened, the spine straightens. As the child grows, the spine may straighten even more.

(https://www.mayoclinic.org/diseases-conditions/scoliosis/diagnosis-treatment/drc-20350721)

Some research suggests that while surgery for scoliosis for adolescents and adults with sb can stop curve progression, it does not appear to provide significant benefits for functional improvement (such as walking capacity or sitting balance) or health-related quality of life issues. Patients should discuss with their doctors what the risks of surgery are compared to the benefits they might attain.

In general, treatment plans for scoliosis should be individualized for each person based on their conditions, symptoms and growth and development.

This information is presented for the purpose of education and is not meant as a substitute for medical advice or care from a physician or other healthcare providers. Contact your healthcare provider with questions about care.

### Additional References:


The New Year is often a time to reflect upon what we want to achieve in the upcoming year. Developing self-empowerment can help you to achieve your goals and feel good about yourself. But what is self-empowerment? Loosely defined, it’s the practice of intentionally choosing to take charge of your life and to be in control of your own destiny. It isn’t just about speaking up for yourself: there are many other aspects to consider. Self-empowerment can help you with making decisions, developing skills, and keeping your spirits up when things go awry.

Self-empowerment is different for everyone. We all have different goals so your journey to self-empowerment may not look like someone else’s. As you get started, be sure to go at your own pace – don’t try to change everything all at once. Instead, decide what’s most important to you and start to build on that:

Here are some tips to help guide you through the different facets of self-empowerment:

1. Self-Reflection- Get to Know Yourself:

   - Think about what makes you unique and what your individual skills are.
   - Think about what your passions are and what you enjoy. Reflect on your values and beliefs.
   - Think about what you are thankful for every day.
   - Ask your friends and family about how they see you to learn more about yourself.
   - Recognize your limitations.
   - Think about what thoughts or beliefs are holding you back.
   - Get to know your triggers and reactions.
   - Realize that you are not perfect and don’t need to be – nobody is perfect!
   - Embrace the failures or obstacles – Recognize that they teach and shape us into who we are.
   - Learn from the past but continue to look forward.
   - Keep reminding yourself to think positively – make it a habit!
How to Build Self-Empowerment (continued)

2. Set Goals:
Create a vision for the future: you don’t have to identify all steps right away but reflect on what you want out of life.

- Set short-term achievable goals.
- Break long-term goals into shorter steps.
- Write down your goals and self-affirmations.
- Find a mentor to help you define your goals.
- Find an accountability partner to keep you on track.
- Reflect on your goals and progress through journaling.

3. Take Control:

- Remind yourself that you control your own destiny.
- Recognize what you can control and understand what you can’t.
- Gain control by holding yourself accountable for your successes and failures – this puts you in the driver’s seat.
- Slowly expand your “circle of influence” or what you have control of in your life.
- Use positive self-talk: Tell yourself you can and use positive affirmations like “I am strong enough to reach my best potential.”
- Instead of trying to ignore negative thoughts, challenge and reframe them.
- Be open to different possibilities. Be flexible.

4. Take Action:

- Create a to-do list. It can be for the upcoming day, week, month, year or the future.
- Take action, no matter how small, instead of waiting for things to happen.
- Form small positive everyday habits and build on them over time.
- Ask for help when you need it so you can continue moving forward.
- Don’t over-promise: recognize that everyone has limits.
- Practice expressing your thoughts, needs and ideas.
- Ask for feedback. If you work or volunteer, get clarity on how you are doing and what is expected of you.
- Take the high road when people are naysayers or nasty – you will be proud of yourself and seen as a leader.
How to Build Self-Empowerment *(continued)*

5. Embrace Community and Interdependence:

- Identify your support system.
- Recognize that you can’t always do it alone and find a supportive interdependent community.
- Surround yourself with positive people. Have a laugh with friends!
- Network! Find inspiration from those around you anywhere you are.
- Listen and learn from others and share with them your thoughts and dreams.
- Work with others to mutually empower one another.

**Don’t Forget about Self-Care!**

Self-care is key for optimizing your mental and physical health. Check in with yourself: Take time for yourself every day to focus on calmness and less stress. Pay attention to your body, your health and your needs and don’t overextend yourself. In the long run, tending to self-care will help you be more productive and will nourish you to be your best self.

JOIN A SPINA BIFIDA BOOK CLUB!

SBRN is joining with the network of Spina Bifida organizations across the country to launch two book clubs:

One for adults living with spina bifida and one for family/caregivers of someone living with spina bifida.

[Click here for more info and to register](#)
In October-November, we held our annual online *Empowerment Auction*. We had over 30 items donated by generous diversified businesses. For several weeks, participants made their bids until the close of the auction determined the lucky winners! Over $1,100 were raised for SBRN’s programs!

*Thank You* to our Donors who made the event a success!