

Volume 26 Issue 1- WINTER 2026



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*Thank You*  
FOR YOUR SUPPORT

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From The Desk Of Nanette Forte-Gerst



Dear Friends,

As we enter the new year, I am filled with gratitude for the strength, compassion, and commitment of the community that surrounds the Spina Bifida Resource Network. Winter is often a season of reflection—and an opportunity to reaffirm what matters most: ensuring that individuals and families affected by spina bifida have access to trusted information, meaningful advocacy, and a strong network of support.

Like many nonprofit organizations, SBRN continues to adapt within a changing financial landscape. At the same time, the need for reliable resources, family connection, and advocacy continues to grow. These realities underscore the importance of our mission and the collective role we all play in sustaining it.

Thanks to your generosity and engagement, we have expanded our Empowerment Monthly Chats, strengthened advocacy efforts, and provided resources that encourage confidence, connection, and independence. Every contribution—whether through participation, advocacy, or financial support—helps ensure SBRN remains a trusted and responsive resource for our community.

Your continued involvement truly makes a difference. Whether you engage in our programs, attend events, share our mission, or support our work financially, you are an essential part of the SBRN community. Together, we are building a future rooted in empowerment, opportunity, and support for individuals and families affected by spina bifida.

As we look ahead, our focus remains on strengthening SBRN's foundation—deepening community partnerships, prioritizing long-term sustainability, and ensuring our programs remain accessible and responsive to evolving needs.

Thank you for standing with us and for believing in the importance of this work. Wishing you and your loved ones a healthy and hopeful winter season.

With gratitude,

*Nanette Forte-Gerst*

Nanette Forte-Gerst  
Executive Director





### Stay Informed and Take Action

Members are encouraged to stay informed about these developments and consider contacting their state legislators to express support for Senate Bill S4769. Advocacy from constituents plays a critical role in shaping disability policy and ensuring these protections remain strong.



A recent meeting of the New Jersey Legislative Disability Caucus featured remarks from Mr. Aronsohn reflecting on his tenure, as well as discussion of Senator Corrado's bill and Congressman Kean's federal efforts. We encourage members to view the recording for additional context.

### Helpful resources:

Recording of Meeting - <https://www.youtube.com/watch?v=RHz-zrSWr7A&t=1124s>

Senator Corrado's bill - <https://www.njleg.state.nj.us/bill-search/2024/S4769>

NJ Legislative Roster - <https://www.njleg.state.nj.us/legislative-roster>

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### 🔔 ACTION ALERT: Support READI for Disasters Act 🔔

The READI for Disasters Act has just been reintroduced in Congress — and we need your voice now. Disabled people and older adults are disproportionately harmed in disasters, not because of disability, but because emergency systems are inaccessible.

READI would change that by centering disabled voices, funding community-based and disability-led response, and building inclusive preparedness before the next disaster hits.

🔔 Take action today! Contact your members of Congress (<https://www.congress.gov/members/find-your-member>) and ask them to co-sponsor the READI for Disasters Act and support disability-led disaster work year-round. \*You do not have to be disabled to advocate for this important piece of legislation.

### Disaster equity can't wait.

Thanks to our friends at The Partnership for Inclusive Disaster Strategies (<https://disasterstrategies.org/>) for their leadership on this.



## “Your Voice Matters” Take Action Now - Join SBRN Advocacy”

Policy decisions are being made right now that directly affect individuals with spina bifida and the broader disability community. These decisions need informed, committed voices at the table—and that means you.

SBRN is actively building its advocacy network and committee to respond to policy changes, leadership transitions, and legislative opportunities at both the state and federal levels. Whether you can give a little time or are ready to step into a leadership role, your participation matters.

We invite you to take part in SBRN’s advocacy efforts and help elevate the voices of individuals with spina bifida and other disabilities. Our **Advocacy Interest Form** allows you to choose the level of engagement that best fits your interest and availability.

**Before completing the form, please note that you will be asked to select one of the following advocacy roles:**

- **Learn More / Stay Informed**

Receive advocacy updates, action alerts, and invitations to educational opportunities. No time commitment required.

- **Occasional Advocacy Support**

Participate in advocacy activities as opportunities arise, such as campaigns, outreach, or events, with flexible involvement.

- ⇒ **Advocacy Committee Member**

Express interest in a formal leadership role supporting SBRN’s advocacy strategy and outreach. Committee membership requires an application and Board approval. **The committee is being formed this quarter.**

This role requires an application and Board approval. Individuals selecting this option will be contacted by an SBRN team member to discuss next steps.

- ⇒ **Complete the Advocacy Interest Form – [Advocacy Interest Form](#)**

*SBRN respects your privacy. Information collected through this form will be used solely to share advocacy updates, action alerts, and related communications.*

## Updated Billing Codes for Catheters

The Centers for Medicare & Medicaid Services (CMS), effective January 1, 2026, made updates to insurance billing codes for hydrophilic catheters. These updates help better identify catheters with a hydrophilic coating, which can reduce friction, improve comfort, and lower the risk of infection.

What does this mean for you? If you currently use a hydrophilic-coated catheter, your healthcare provider may need to issue a new prescription that clearly specifies a hydrophilic-coated catheter, so it can be billed appropriately.

CMS has also made it easier for people with certain conditions—including spina bifida, spinal cord injury, or multiple sclerosis—to continue accessing medically necessary catheter supplies. Talk with your healthcare provider about what options are right for you.

## SBRN Welcomes Chris Rosati to the Board of Directors

SBRN is pleased to announce the election of **Chris Rosati** to its Board of Directors. Chris officially began his first term on **January 1, 2026**, and we are excited to welcome his perspective and commitment to advocacy.

Chris is currently pursuing a **Master's degree in Public Policy**, bringing both academic training and hands-on experience in government and advocacy work to the Board. He has expressed a strong interest in strengthening SBRN's advocacy efforts and supporting policies that positively impact the spina bifida community.

*"I'm honored to join the SBRN Board and contribute to advocacy efforts that strengthen policies impacting people with spina bifida and other disabilities." said Rosati.*

Through his education and experience, Chris brings a thoughtful understanding of public policy and regulatory issues, along with a passion for effective, mission-driven advocacy. He is particularly interested in helping SBRN advocate efficiently for policies that advance access, equity, and support for individuals and families affected by spina bifida.

We are grateful for Chris's willingness to serve and look forward to his contributions as SBRN continues to expand its advocacy and policy impact.



Save the Date: Sunday, May 31, 2026  
Roosevelt Park, Edison, NJ

SBRN's  
WALK FOR  
EMPOWERMENT



Activities, Tricky Tray  
and Refreshments



Registration and sponsorship is on our website

[www.theSBRN.org](http://www.theSBRN.org)  
[info@thesbrn.org](mailto:info@thesbrn.org)

## Volunteer Spotlight: Ernie Mathews



The Spina Bifida Resource Network is pleased to shine a spotlight on Ernie Mathews, a dedicated volunteer who has been part of the Spina Bifida Resource Network (SBRN) community since 2021. From the start, Ernie was drawn to the “vibrant, welcoming energy of SBRN and the way the community supports one another” – an environment he credits, in part, to the inspiration and leadership of SBRN board chair, Millie Gonzalez, a fellow disabled advocate who coordinates the adult programming.

For Ernie, volunteering with SBRN has been both meaningful and personal. It has offered him an opportunity to continue his cognitive recovery while putting his skills and experience to good use in a supportive and understanding space. What he values most is the chance to be part of a regular social setting “with my kind of people,” where connection, empathy, and shared experiences matter.



Outside of SBRN, Ernie remains committed to helping others. He supports individuals and groups—both online and in person—who are navigating chronic illness, connective tissue disorders, and related conditions. Professionally, Ernie spent 20 years working in software, database, and website development. Today, he continues to challenge his brain by coding for fun and self-education, proving that curiosity and learning don’t stop with a career change.

A few fun facts round out Ernie’s story: his daughter is currently a freshman at the University of Vermont, studying Environmental Science. He also has a musical background—he sang for several years with a professional choir The Princeton Singers <https://princetonsingers.org> and even served as the office producer and liaison for the reissue of one of their most popular recordings, [Welcome Yule](#).

We are grateful for Ernie’s time, talents, and heart that help make SBRN an incredible community.

## A Winter Message from Spina Bifida Resource Network (SBRN)

As winter settles in, all of us at **SBRN** want you to know how deeply we value our community. Whether you are a parent, an adult living with **Spina Bifida**, or a caregiver, your resilience, advocacy, and daily care make a meaningful difference.

We know winter can bring added challenges—colder temperatures, seasonal illness, changes in routine, and weather that may affect mobility or access to care. At the same time, winter can also be a season to slow down, focus on comfort, and lean into connection and support.

At SBRN, our mission is to support individuals and families across every stage of life. We hope the winter wellness checklist below serves as a gentle guide and a reassuring reminder that small, thoughtful steps can help protect health, comfort, and peace of mind during the colder months.

Please remember that **you are not alone**. SBRN is here to provide resources, education, and community support whenever you need it.

Wishing you warmth, wellness, and peace this winter season.

— *The SBRN Team*



### SBRN Winter Wellness Checklist

#### For Individuals with Spina Bifida, Parents & Caregivers

##### Stay Warm & Comfortable

- \* Dress in warm layers and weather-appropriate clothing
- \* Wear insulated, well-fitting footwear
- \* Limit time outdoors in extreme cold or wet conditions
- \* Check skin daily, especially feet, legs, and pressure points

##### Prevent Seasonal Illness

- \* Practice regular handwashing
- \* Stay up to date on recommended vaccinations
- \* Avoid close contact with people who are sick
- \* Watch for early signs of cold, flu, or respiratory illness

##### Keep Moving Indoors

- \* Continue physical therapy or home exercise routines
- \* Stretch daily to reduce stiffness
- \* Use adaptive or chair-based exercises as needed
- \* Change positions regularly to support circulation

##### Support Skin, Bladder & Bowel Health

- \* Moisturize skin daily to prevent dryness and breakdown
- \* Use gentle soaps and skincare products
- \* Maintain consistent bladder and bowel routines
- \* Stay hydrated, even when thirst feels reduced

##### Care for Emotional Well-Being

- \* Keep daily routines when possible
- \* Stay connected with friends, family, or support groups
- \* Make time for enjoyable indoor activities
- \* Reach out for support when feeling overwhelmed

##### Plan Ahead for Winter Weather

- \* Refill medications before storms or cold spells
- \* Check and maintain assistive devices and equipment
- \* Keep emergency contact information up to date
- \* Plan ahead for transportation and appointments

## Healthy Foods to Keep You Warm and Energized this Winter

Oats are one of the best winter breakfast ingredients. They contain soluble fiber that slows digestion and keeps you warm for hours. Enjoy a piping hot bowl of protein **OATMEAL** for a delicious and energized way to start your day!



### HOMEMADE CHICKEN NOODLE SOUP

#### Ingredients:

- 1 tablespoon butter
- ½ cup chopped onion and ½ cup chopped celery
- 4 (14.5 ounce) cans chicken broth
- 1 (14.5 ounce) can vegetable broth
- ½ pound chopped cooked chicken breast
- 1 ½ cups egg noodles
- 1 cup sliced carrots
- ½ teaspoon dried basil and ½ teaspoon dried oregano
- salt and ground black pepper to taste



#### Directions:

- Melt butter in a large pot over medium heat. Add onion and celery and cook until just tender, about 5 minutes.
- Add chicken broth, vegetable broth, chicken, egg noodles, carrots, basil, oregano, salt, and pepper. Stir to combine and bring to a boil then reduce heat and simmer for 20 minutes.

### CLASSIC STOVETOP BEEF STEW

#### Ingredients:

- 2 Tablespoons of Vegetable Oil
- 1 pound beef stew meat, cut in cubes
- 1/4 teaspoon salt
- 4 cups assorted cut-up fresh vegetables (potatoes, carrots, celery, and onions)
- 1 (14.5 ounce) can low sodium beef broth
- 1 can (8 oz each) Hunt's® Tomato Sauce with Basil, Garlic and Oregano



#### Directions:

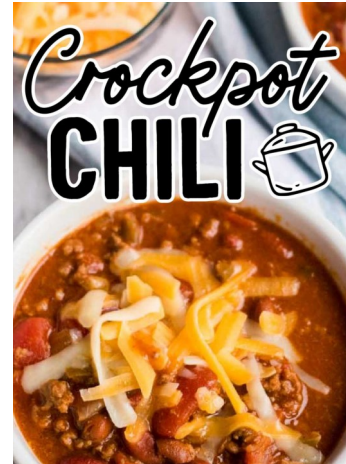
- Over medium-high heat add 1 tablespoon oil in large skillet and brown meat for about 5 minutes. Remove from skillet; keep warm.
- Add 1 tablespoon oil and vegetables to skillet. Cook 5 minutes until tender, stirring occasionally. Return meat to skillet; stir in broth. Bring to a boil. Reduce heat to medium-low; simmer 15 minutes, stirring occasionally.
- Stir in tomato sauce; simmer 15 minutes more or until meat and vegetables are tender, stirring occasionally.

## Healthy Foods to Keep You Warm and Energized this Winter *(continued)*

### EASY CROCKPOT CHILI

#### Ingredients:

- 1 lb ground beef browned
- 2 15 oz cans dark kidney beans, drained
- 1 14.5 oz can of tomato sauce
- 1 14.5 oz can tomatoes
- 1 packet of chili seasoning
- 2 cups water



#### Directions:

- After beef is browned and grease drained place in crockpot . Add in kidney beans, tomato sauce, tomatoes, chili seasoning and water. Stir until well combined.
- Cook on LOW for 6-7 hours or HIGH for 4 hours.

Serve with your favorite chili toppings, such as cheese, sour cream or corn chips!

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### BEST SLOW COOKER HOT COCOA

#### INGREDIENTS NEEDED:

- **Six Cups whole milk** – this is a homemade hot chocolate so therefore it is rich and creamy. Whole milk is going to give you the absolute best result here for the best hot chocolate.
- **2 Cups semi-sweet chocolate chips** – we don't want this overly sweet which is why I went with semi sweet chocolate chips. You could use milk or dark chocolate but keep in mind how that will really change the flavor profile.
- **1 ½ cups whipping cream**
- **1 (14 oz.) can sweetened condensed milk** – it needs to be sweetened condensed milk here.
- **1 tsp. vanilla extract**

Combine milk, chocolate chips, cream, condensed milk, and vanilla in a 4-6 qt. slow cooker. Cover and cook on Low, stirring occasionally, until chocolate chips are melted and mixture is smooth, about 2 hours. Turn to warm setting and hold cocoa up to 2 hours.

Ladle into mugs and top with some mini marshmallows or whipped cream and a mini candy cane.

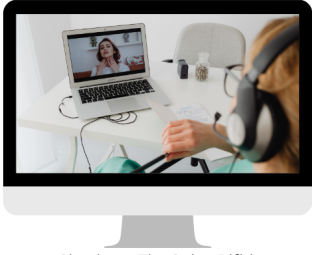


The Spina Bifida Resource Network

# Empowered Conversations

Virtual Speaker Series by/for Disabled Adults <sup>2026</sup>

**A Different Topic Each Time**  
**2nd and 4th Wednesdays of the month**  
**at 7pm ET on Zoom with auto-captioning**



Check out The Spina Bifida Resource Network Facebook page for speaker info.

REGISTER: [bit.ly/sbrn-empoweredconvos26](https://bit.ly/sbrn-empoweredconvos26)

SBRN offers individuals with spina bifida and other disabilities a convenient, enjoyable way to learn and network online. We offer peer-led support groups as well as interactive workshops and seminars on a wide range of topics presented by disabled experts in a variety of fields. There is no need to travel - simply join in from the comfort of your phone, tablet or computer.

Sessions are free and usually last about an hour. Registration is required. Groups are open to adults with disabilities only.

The Spina Bifida Resource Network

## Crafty Corner

A creative, hands-on social space to relax, create and connect while working on hobbies, crafts or creative projects together.

1st, 3rd and 5th Thursdays of each month at 4pm ET via Zoom with auto-captioning

REGISTER: [bit.ly/sbrn-crafty26](https://bit.ly/sbrn-crafty26)




The Spina Bifida Resource Network

## MONDAY Chat

A welcoming, open conversation space for adults with disabilities 21+ to connect, share updates and experiences, and support one another.

1st, 3rd and 5th Mondays of each month at 3pm ET via Zoom with auto-captioning

REGISTER: [bit.ly/sbrn-monchat26](https://bit.ly/sbrn-monchat26)



The Spina Bifida Resource Network

## Men's Chat

A supportive virtual space for disabled men 21+ to connect, talk openly, share resources, and support one another in a relaxed, judgment-free environment.

1st Thursday of the Month at 7pm ET via Zoom with auto-captioning

REGISTER: [bit.ly/sbrn-menschat26](https://bit.ly/sbrn-menschat26)



The Spina Bifida Resource Network

## Golden Girls

A supportive virtual space for disabled women 21+ to discuss life and celebrate wisdom, resilience and shared stories in a relaxed, judgment-free environment.

1st Wednesday of each month at 5pm ET via Zoom with auto-captioning

REGISTER: [bit.ly/sbrn-womenschat26](https://bit.ly/sbrn-womenschat26)




The Spina Bifida Resource Network

## Disability Book Club

Explore disability-related books that spark insight, reflection and conversation through shared lived experience and collective learning.

Quarterly (March, June, Sept., Dec.) on the last Tuesday of the month at 7:30pm ET via Zoom with auto-captioning

REGISTER: [bit.ly/sbrn-bookclub26](https://bit.ly/sbrn-bookclub26)



*The Spina Bifida Resource Network prioritizes providing safe and open environments for participation and discussion in all of our programs. By registering to participate in SBRN programs, you agree to behave respectfully, maintain appropriate boundaries and participate in open discussion. SBRN reserves the right, at our discretion, to deny a person who does not act accordingly from participating in any program.*