For more than 30 years, the Spina Bifida Resource Network (SBRN) has been serving children, adults and families living with spina bifida and other disabilities throughout New Jersey and beyond. We provide healthcare and other informational resources, financial assistance, and peer-led retreats, virtual support groups and educational sessions.

SBRN began in the 1970's, when parents of children with spina bifida formed self-help groups to address the emotional strain and financial expense of caring for children with disabilities. The Spina Bifida Coalition was founded in 1982 and was recognized as exempt under 501(c)(3) in 1987. We became the Spina Bifida Association of NJ in 1992. In 2008, we restructured to become an independent nonprofit organization and our name changed to the Spina Bifida Resource Network. Our services and programs are geared towards increasing knowledge, self-care, capabilities and independence, along with building supportive communities.

Providing resources for our consumers and offering peer support have always been major goals. We provide information about the medical, cognitive, social and psychological aspects of living with spina bifida and other disabilities. This information helps prevent complications, optimizes care and increases independence and productivity. We have also emphasized peer support and building supportive communities as a means of empowering individuals to achieve their greatest goals.
Dear Friends & Supporters,

In 2021, the isolation and uncertainty from the enduring pandemic continued to affect how we all live and work. In response, we adapted our programs to provide for the growing emotional and financial needs of individuals and families living with disabilities. Working collectively with our community, we were able to offer special, unique programs to reduce loneliness, build relationships and optimize health, such as our:

♦ Online “Chats” and Virtual Speaker Series
♦ Health Conversations with Nurse Barbara
♦ Financial Assistance Funds
♦ Annual Empowerment Retreat

We also put our creative minds to work to implement some new and old fundraisers, including an online Empowerment Auction. Additionally, we collaborated with Subaru’s Share the Love Program, HundredX Causes, and Rita’s and Popcorn Nation to bring in thousands of dollars to support our programs.

This year also marked a dramatic change in how we will approach the future. After evaluating the changing needs of our community, we developed new Mission and Vision Statements to guide and inspire us in the coming years. We look forward to collaborating with our growing numbers of invested supporters and partners to achieve our goals and realize our vision of a thriving community where people with disabilities realize their unlimited potential!

Thank you for your support!

Sincerely,

Roberta Kestenbaum, PhD, MSW
2021: THE YEAR IN REVIEW

HEALTH & WELLNESS SUPPORT

In 2021, we initiated a new program, *Health Conversations with Nurse Barbara*, to provide enhanced healthcare resources and support. Individuals and family members engaged in one-on-one personalized chats with our RN about health issues related to living with spina bifida, such as bladder and bowel management, wound care, shunt function or upcoming surgeries or procedures. Consumers had the opportunity to prioritize their health, ask questions, discuss options and talk through concerns.

In addition, we emphasized empowerment through self-care by offering self-care tips through social media for the 31 days of October’s Spina Bifida Awareness Month.

VIRTUAL PEER SUPPORT & EDUCATION

Based on the success of our virtual programs, as well as the continued pandemic, we continued our well-received peer-led video chats and teleconferences. We held *Afternoon Conversations* each week which helped adults with disabilities from all over reduce loneliness and stay connected and supported. Through our *Virtual Empowerment Speaker Series*, we offered weekly peer-led informational and interactive workshops and activities on a variety of topics led by guest speakers who identified as having a disability. These programs offer adults with disabilities a safe and open space to share their thoughts, concerns and dreams while fostering friendships and community.

EMPOWERMENT RETREAT

Our unique popular weekend *Empowerment Retreat*, which was coordinated, led and attended by people with disabilities, was held virtually from September 17-19, 2021, which allowed us to include people from across the country. Attendees participated in interactive seminars on topics such as body positivity, sexuality, health concerns, and disability rights. They also engaged in fitness and dance activities as well as social events. This annual weekend event provides a sense of community and camaraderie in a fun and educational environment.
FINANCIAL ASSISTANCE

Our two Financial Needs Funds provided assistance for a wide variety of healthcare and day-to-day needs to help our community optimize their wellness and live their best lives. In 2021, we disseminated $1,990 through our Jane Horowitz Special Medical Needs Fund to provide relief to families and individuals struggling with excessive healthcare costs related to spina bifida.

We also distributed $1,000 through our Disaster/Emergency Rapid Assistance (DERA) Fund to help cover one-time emergent needs for medical supplies, adaptive equipment and other basic needs.

ADVOCACY

To protect the rights of people with disabilities during the pandemic and beyond, we continued our advocacy efforts at the federal, state and local levels on issues such as the rights and needs of people with disabilities during disasters, funding for Home & Community Based Services and requesting that Medicare cover Complex Rehab Technology.

INFORMATION & RESOURCES

We continued to be a major resource for the community on issues related to spina bifida and living with disabilities. We continuously updated the resources on our website and responded to many email and phone inquiries about living with spina bifida. Our newsletter, the Empowerment Zone, which is widely distributed through email and social media, includes information regarding health topics, legislative news, educational issues and advocacy efforts, along with community and agency news. We continued to increase our social media presence and have thousands of followers on Facebook, where we raised awareness of resources and opportunities.
In 2021, in response to the changes created by the pandemic, we turned our sights to the future and reflected on what our agency should look like and how we could best serve our community. Our staff and committed volunteers came together and evaluated how we could effectively address current needs. We considered how needs have changed, what people are looking for, and what we are looking to be/do NOW and in the future. From this, we developed a new mission statement that reflects who we are and what we do as an organization and we created a new vision statement for what we strive to achieve.

To provide educational resources, social events and advocacy programs that empower people with disabilities and their allies to challenge perceptions, embrace interdependence and live their best lives.

A thriving community where people with disabilities have equitable access to resources and opportunities to optimize their wellness and realize their unlimited potential.

SBRN Empowerment Retreat for Adults with Disabilities

SBRN’s annual Empowerment Retreat was held virtually from September 17-19, 2021. This year’s theme was Challenge Perceptions, Embrace Interdependence and Live Your Best Life. Over 40 participants from around the country engaged in an exploration of healthcare, sexuality and relationships, body positivity, gender-based violence, disability rights, fitness and dance workshops and social events.

SBRN’s annual Empowerment Retreat is designed to foster essential self-acceptance and community building in adults with disabilities. Coordinated and facilitated by disabled adults, this unique, peer-led, fun and interactive three-day event promotes interdependence, socialization and self-empowerment.
2021 Total Income - $30,168

- Contributions & Member Dues: $25,118 (83%)
- Net Fundraising Events: $5,050 (17%)

Total End of Year Assets = $192,431

2021 Total Expenses - $148,161

- Programs: $105,742 (71%)
- Financial Assistance Funds: $2,990 (2%)
- Development/FR: $6,001 (4%)
- Management & General: $33,418 (23%)

Total End of Year Assets = $192,431
SOME UPCOMING EVENTS IN 2022

Introducing our new weekly interactive

Supported in part by the Christopher & Dana Reeve Foundation

SBRN EMPOWERMENT RETREAT
for Adults with Disabilities
September 16 - 18, 2022

ONLINE DISABILITY EMPOWERMENT AUCTION
October 2022