



# 2024 ANNUAL REPORT



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# HISTORY



For more than 40 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.



# MESSAGE FROM OUR EXECUTIVE DIRECTOR

Dear Friends,

With the help of our supporters and volunteers in 2024, we continued our mission to empower people with disabilities to live their best lives. Through informative resources and programs such as our *Health Conversations* program, we provided education on health-related concerns and options to optimize health and well-being. Through our online peer-led support groups and workshops, as well as our unique hybrid *Empowerment Retreat*, we continued to build a thriving community where people obtained knowledge and new skills, heard new perspectives and created strong connections.

We held several fundraisers throughout the year to support our programs and events, including an online auction, a popcorn fundraiser and our annual *Walk for Empowerment*. We also received much appreciated support from event sponsors and foundation grants.

Sincerely,



Roberta Kestenbaum, PhD, MSW  
SBRN Executive Director

We are grateful for the incredible assistance from our community. Our collaborative efforts enrich and empower our community to thrive.

*Thank you for your support!*

## OUR MISSION

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.



## OUR VISION

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

# 2024: THE YEAR IN REVIEW

## HEALTH & WELLNESS SUPPORT

In 2024, our **Health Conversations with Nurse Barbara** program continued 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.

## VIRTUAL PEER SUPPORT & EDUCATION

Our online community continued to thrive. We hosted our well-received peer-led video chats, support groups and virtual workshops for adults with disabilities from all over the country, including our weekly **Afternoon Chats**, **Crafty Corners** and **Get Fit with SBRN** as well as our monthly **Men's Chat** and **Golden Girls** groups. And through our unique **Empowered Conversations: Virtual Speaker Series (EC)**, we offered weekly peer-led informational and interactive workshops and activities on a variety of topics led by guest speakers with disabilities. The EC program was supported in part by a generous **Quality of Life Grant** from the Reeve Foundation. Together, these programs offer adults with disabilities a safe and open space to share their thoughts, concerns and dreams while fostering friendships and community and gaining valuable resources.

## EMPOWERMENT RETREAT

Our popular weekend adult **Empowerment Retreat**, which was coordinated, led and attended by people with disabilities, was held from November 1-3 as a hybrid event. The weekend-long virtual program included participants from across the country, while the in-person event welcomed local participants to gather together to socialize and engage in workshops. The Retreat was sponsored in part by the Dircks Foundation. All attendees participated in interactive seminars on topics such as: *The Ability to be Authentic Strong You*, *The Art of Gratitude*, *Defining Wellness on Our*

*Own Terms*, *End-of-Life Planning* and *Out of the Shadows*. 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.



# 2024: THE YEAR IN REVIEW *(continued)*

## ADVOCACY & AWARENESS



In 2024, we held our annual *Walk for Empowerment* to raise awareness of spina bifida and funds for our programs. We joined together in-person to walk and roll around the lake at Roosevelt Park in Edison. We also raised awareness of spina bifida and the needs of people with disabilities at events such as the widely attended Abilities Expo in May. In addition, during October's Spina Bifida Awareness Month, we posted "facts about spina bifida that people might not know" to be shared on social media.

We continued to advocate for the rights of people with disabilities at the federal, state and local levels on issues such as the rights and needs of people with disabilities during disasters, funding for services, access to Medicaid and increased asset limits for SSI.

## FINANCIAL ASSISTANCE

Our **SBRN Community Fund** provided assistance for a variety of healthcare and day-to-day needs to help support those living in NJ with spina bifida. In 2024, we disseminated \$760 through the **Community Fund** to help cover one-time emergent needs to help our community optimize their wellness and live their best lives.

## INFORMATION & RESOURCES

We continued to be a major resource for the community on issues related to spina bifida and living with disabilities. We updated the resources on our website and responded to email and phone inquiries about living with spina bifida. Our newsletter, the **Empowerment Zone**, which is widely distributed through email and social media, included information regarding health topics, legislative news, educational issues and advocacy efforts, along with community and agency news. We also continued to increase our social media presence, where we raised awareness of resources and opportunities.

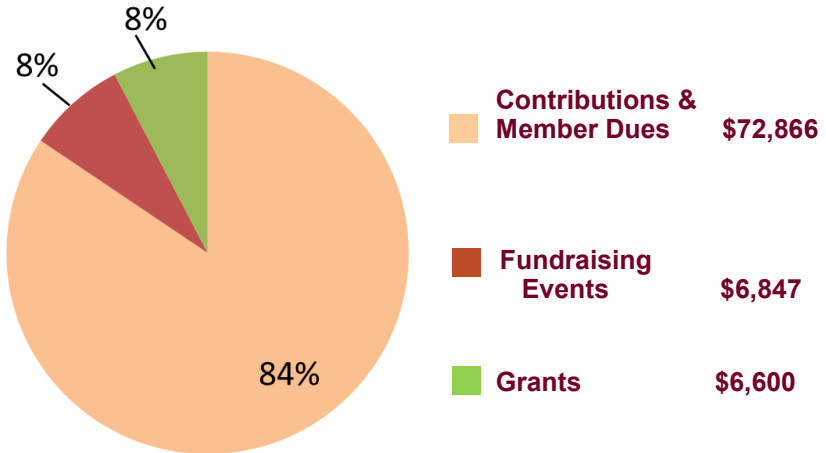
# 2024 WALK FOR EMPOWERMENT

Sunday June 8th at Roosevelt Park, Edison, NJ

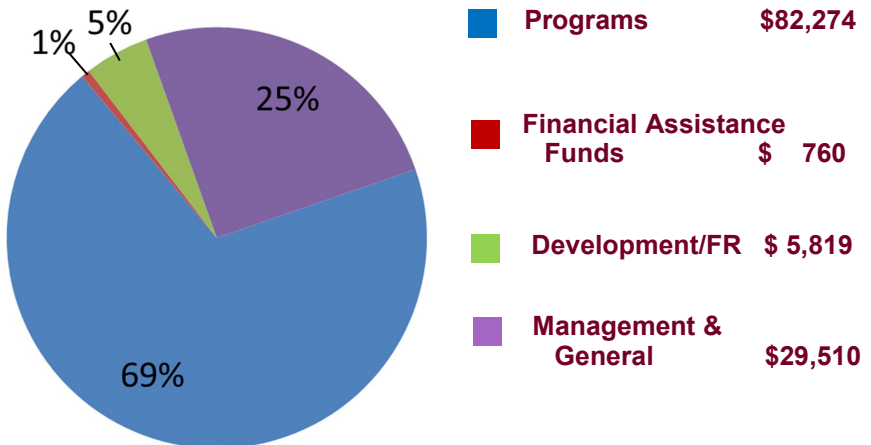


# 2024 SBRN FINANCIAL SUMMARY

## 2024 Total Income - \$86,313



## 2024 Total Expenses - \$118,363



**Total End of Year Assets = \$84,440**

## BOARD OF DIRECTORS 2024

- Millie Gonzalez, *Chair*
- John Keith, *Treasurer*
- Eileen Creenan, RN
- Gregory Morganoff
- Amanda Sloan
  
- Roberta Kestenbaum, *Executive Director*

## SBRN STAFF 2024

- Roberta Kestenbaum, *Executive Director*
  
- Jeremy Cantilina, *Business Administrator*
  
- Laura Larice, *Administrative Assistant*
  
- Barbara Dombroff, RN, *Family Support Nurse*

## SOME UPCOMING EVENTS IN 2025



### WALK FOR EMPOWERMENT

Sunday - June 8th

Roosevelt Park, Edison, NJ



### SBRN EMPOWERMENT RETREAT

*for Adults with Disabilities*

Fall 2025

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### ONLINE DISABILITY EMPOWERMENT AUCTION

Fall 2025

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Flemington, NJ 08822

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