



2019 Annual Report



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MISSION

The mission of the Spina Bifida Resource Network (SBRN) is to empower the lives of people with Spina Bifida and promote the prevention of Spina Bifida through advocacy, education, collaboration, public awareness, research and programs.

HISTORY



For over 30 years, the Spina Bifida Resource Network (SBRN) has been serving children and adults with spina bifida and other disabilities throughout NJ. We provide unique, personalized services in the home and community, including care coordination, trainings by nurses, advocacy in the schools, financial assistance, and educational and social events. Our goal is to empower the lives of people living with spina bifida and other disabilities.

SBRN began in the 1970s, when parents of children with spina bifida formed self-help groups to address the emotional strain and financial expense of caring for children with special needs. The Spina Bifida Coalition was founded in 1982, was recognized as exempt under 501(c)(3) in 1987 and 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 focus is on individuals, caregivers, and families in NJ living with spina bifida and other disabilities. Our services are geared towards increasing knowledge, self-care, capabilities, independence and the ability to participate in school, employment and community activities.

Current project initiatives include our Family Support Program that provides nursing and social support coordination and education, innovative Telegroups and Teleconferences providing support and information in a format easily accessible from home, new parent and early childhood support, IEP advocacy and assistance, financial assistance through our Special Medical Needs Fund, and an educational campaign on the prevention of Spina Bifida and other neural tube defects. In addition, SBRN provides schools and medical personnel with educational trainings and materials about living with disabilities.

MESSAGE FROM OUR EXECUTIVE DIRECTOR

Dear Friends & Supporters,

It is my pleasure to share what we have accomplished in 2019. This past year was a challenging but ultimately successful year for the SBRN. Due to changes at the State level in how they fund and provide disability services, we lost a significant funding source that we had had for many years. Nonetheless, we rose to the occasion, and through updating, streamlining and coordinating resources, we continued to provide the quality services and programs we have always delivered for over 30 years.

As always, our services were focused on empowering people living with disabilities to embrace self-care and live as independently as possible. To achieve this, we used a variety of systems, procedures and communication platforms to reach as many people as we could. For example:

- * We updated and improved our Family Support Program by increasing phone calls, emails and texts while still providing in-home visits and trainings when needed. This cut travel time and expenses, while other modes of communication allowed us to stay more continuously connected with our consumers and provide more stability.
- * For our annual Adult Empowerment Retreat, we received a Quality of Life Grant from the Reeve Foundation, which allowed us to bring in a variety of new speakers and also expand our workshops to include comedy, art and movement. In addition, we were able to provide scholarships for those who needed assistance.
- * We revamped our website, making it more user-friendly and providing many more updated resources. Information and referral is an important part of our mission. Our internal needs assessments indicated what information people seek out and we then provided it in an easily accessible format.

These are some examples of how we have continued to provide our services with a focus on the needs of our consumers. We are proud to serve, collaborate with, and be a part of the disability community. Thanks to generous donors, sponsors, fundraisers, volunteers and participants, our community is empowered to achieve great things!

Thank you for your support!

Sincerely,



Roberta Kestenbaum, PhD, MSW



2019: THE YEAR IN REVIEW

FAMILY SUPPORT & ADVOCACY

Through our Family Support Program, we provided more than 800 hours of services to more than 90 families in 2019. Our nurses provided trainings on common issues such as bowel and bladder management and wound care, and assisted with medical coordination. Our family support coordinators connected families to community resources and addressed social, emotional, and financial issues. Additionally, our staff provided in-services at schools across NJ to educate staff on the unique presentation of Spina Bifida.

Our nursing staff continued to provide assistance at the Adult Spina Bifida Clinic at the Kessler Institute for Rehabilitation in West Orange, NJ. We provided support and care coordination during and after the visits to ensure that patients understood follow-up procedures and received community support.

EDUCATION & PEER SUPPORT

We hosted accessible educational events and support groups throughout the year. At our annual weekend **Adult Empowerment Retreat** in Edison, NJ, adults with disabilities participated in interactive, peer-led seminars, recreational activities and social events. These weekends provide a sense of community and camaraderie in a fun, educational environment. This year, the Reeve Foundation provided funding for speaker stipends, participant scholarships and conference facilities and supplies.



In 2019, we hosted tele-support groups, which provide information in a format easily accessible from home. For example, our longstanding Golden Girls group, which met once a month, encouraged peers to share advice and friendship.

SPREADING AWARENESS



Throughout the year, we are always working to educate the public about Spina Bifida and living with disabilities. At our annual **Spring Walk for Empowerment**, participants strolled and rolled around the lake in Roosevelt Park, Edison, NJ, to show solidarity and raise awareness of living with Spina Bifida. We educated health professionals, school personnel and service providers about how to support people with Spina Bifida. We also presented information about Spina Bifida at conferences, health fairs and other venues throughout the State.

2019: THE YEAR IN REVIEW *(continued)*

FINANCIAL ASSISTANCE

Children born with Spina Bifida often require dozens of surgeries and other medical procedures throughout their childhoods and into adulthood. The costs can be astronomical over time and insurance rarely covers all of the expenses. In 2019, we distributed \$2,930 through our ***Jane Horowitz Special Medical Needs Fund*** to provide relief to families and individuals struggling with excessive non-reimbursed medical expenses related to Spina Bifida.

PREVENTION

As part of our mission, we continued to educate the public about folic acid's role in reducing the risk of Spina Bifida. In 2019, we continued our unique prevention program, ***Healthy NOW, Healthy LATER***, with partial funding from the NJ Office for the Prevention of Developmental Disabilities, in which we trained college students to educate others about the importance of good health now and the role of folic acid in the prevention of birth defects later. Our outcome measures indicate that through this program, students gain knowledge about the need for folic acid and healthy living, and are motivated to make changes in their diets.



INFORMATION & RESOURCES

We continue to be a major resource for the community on issues related to Spina Bifida and living with disabilities. Our newsletter, the *Empowerment Zone*, which is widely distributed through mail, email and social media, includes information regarding health topics, legislative news, educational issues and advocacy efforts, along with community and agency news.

In early 2019, we did a complete overhaul of our website, making it more accessible, readable and functional. We reorganized and added additional resources to create an extensive library of information related to living with Spina Bifida. We also increased our social media presence and have thousands of followers on Facebook

2019 SBRN EVENTS TO REMEMBER

ANNUAL SPRING WALK FOR EMPOWERMENT



SBRN's 11th annual spring "Walk for Empowerment" was held on June 2nd at Roosevelt Park, Edison NJ and was well attended by families and friends. It was a beautiful day to stroll and roll around the lake at the park to raise awareness of Spina Bifida!

Attendees enjoyed breakfast and lunch provided by donations from local supermarkets. The popular Tricky Tray raffle baskets and certificates were generously donated by many businesses around the state. In addition, several groups formed teams and raised funds to support SBRN. The funds raised support our services for children, teens and adults with spina bifida and other disabilities.



SBRN ADULT EMPOWERMENT RETREAT

Over 30 adults with disabilities gathered at our *Adult Empowerment Retreat* from September 20 - 22 at the Crowne Plaza in Edison. This year's theme was: *#LiveFiercely through Self-Care*. The retreat is a weekend-long event with workshops on topics related to living with disabilities, as well as social opportunities. The focus is on increasing independence, socialization, self-esteem and overall growth.

This year, workshop topics included: self-care, advocacy and civic engagement, sex and body image, resilience, depression and stages of independence. Participants had time to laugh with comedy routines, time to move with workout sessions and time to paint at an art workshop.

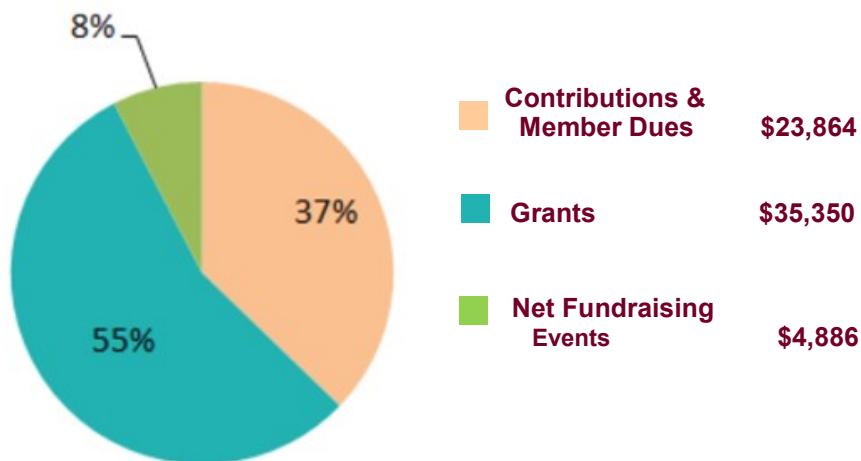


In the words of one repeat retreat participant: "Something I really like is that we choose to eat together and have real, meaningful discussions where things are shared, and nothing can replace that. It's important to have these connections."

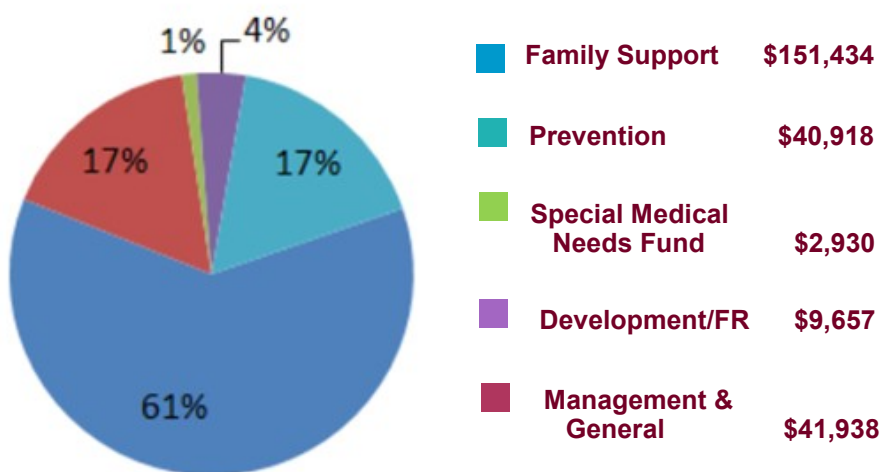
This year, the Christopher and Dana Reeve Foundation provided us with a Quality of Life Grant to help fund the retreat. This allowed us to offer scholarships for those who would not otherwise have been able to attend.

2019 SBRN FINANCIAL HIGHLIGHTS

2019 Total Income - \$64,100



2019 Total Expenses - \$246,877



Total End of Year Assets = \$471,528

BOARD OF DIRECTORS 2019

- Millie Gonzalez, *Chair*
- Armand Cucciniello, *Vice Chair*
- John Keith, *Treasurer*
- Eileen Creenan, RN, *Secretary*
- Roberta Kestenbaum, *Executive Director*

SBRN STAFF 2019

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

SOME UPCOMING EVENTS IN 2020



JUNE

WALK FOR EMPOWERMENT FOR SPINA BIFIDA

Sunday - June 14th

Roosevelt Park, Edison, NJ



SEPTEMBER

EMPOWERMENT RETREAT

for Adults with Disabilities

Crowne Plaza, Edison, NJ



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