

## SBRN ADULT EMPOWERMENT RETREAT



The Spina Bifida Resource Network's **Adult Empowerment Retreat** weekend was held at the Hyatt Regency in Morristown, NJ from August 25th - 27th for adults with disabilities.

The retreat started with a Meet & Greet Social and continued with interactive workshops on various topics throughout the weekend.

This first time end-of-summer conference was enjoyed by everyone!

## SOME UPCOMING EVENTS IN 2018

### MARCH

#### HOLLYDELL'S ICE SKATE SOCIAL

Hollydell Ice Arena, Sewell, NJ

### SUMMER

#### ADULT EMPOWERMENT RETREAT

Weekend Conference

### JUNE

#### SPRING WALK FOR EMPOWERMENT FOR SPINA BIFIDA

Roosevelt Park, Edison, NJ

### OCTOBER

#### HOWELL GIRLS SOFTBALL LEAGUE:

Spina Bifida Awareness Tournament



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# 2017 ANNUAL REPORT



*Empowering People*

*Enriching Lives*

*Educating the Community*

*Educating Ourselves*

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

## 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



The Spina Bifida Resource Network (SBRN) has roots in New Jersey as far back as the early 1970's. During these early years, parents of children with Spina Bifida in numerous communities throughout the state formed self-help groups in an effort to address the emotional strain and financial expense of caring for children with special needs. In 1982, the Spina Bifida Coalition was founded and in 1992, it was incorporated as the Spina Bifida Association of New Jersey.

In 2008, our name changed to the Spina Bifida Resource Network (SBRN) and our focus is primarily on families in New Jersey living with Spina Bifida, as well as other physical and developmental disabilities. Throughout these changes, our goal has remained the same: to provide comprehensive unduplicated supports and services to the individuals and their family members, as well as to related professionals in our community. Current project initiatives include the Family Support Program, which provides in-home nursing and social support coordination and education, innovative telegroups and teleconferences providing support and information in a format easily accessible from home, Nurse Delegation, 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.

### BOARD OF DIRECTORS 2017

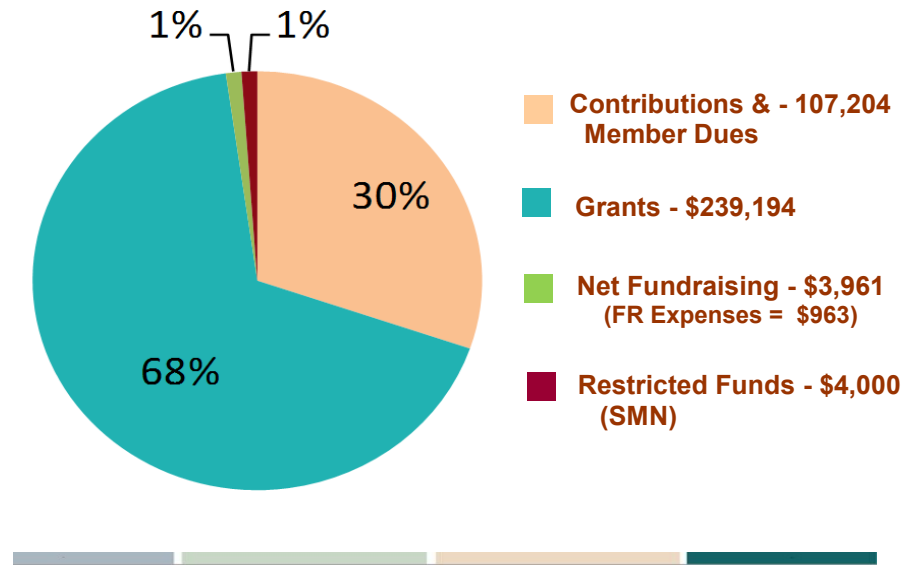
- Millie Gonzalez, *Chair*
- Armand Cucciniello, *Vice Chair*
- John Keith, *Treasurer*
- Eileen Creenan, RN, *Secretary*
- David Giannetto
- Roy Peterson
- Roberta Kestenbaum, *Executive Director*

### SBRN STAFF 2017

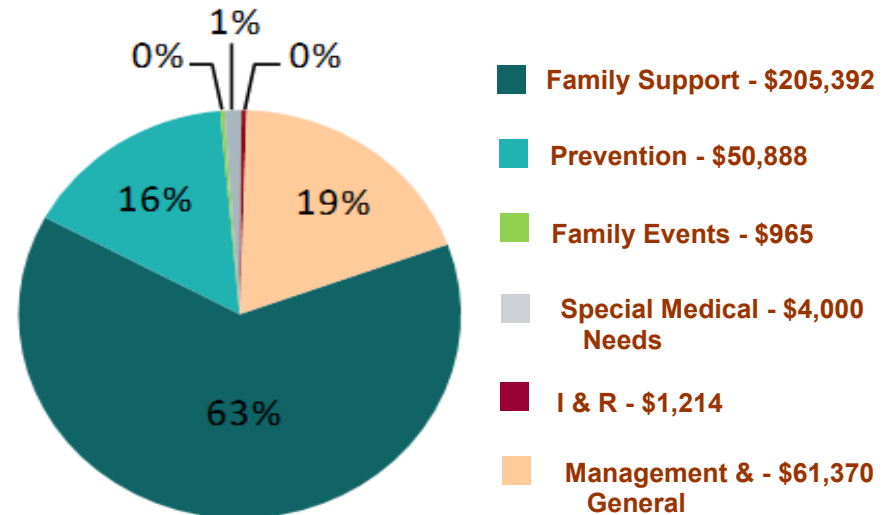
- Roberta Kestenbaum, *Executive Director*
- Jeremy Cantilina, *Business Administrator*
- Laura Larice, *Administrative Assistant*
- Michelle Tomaszewski, *Family Support Coordinator*
- Zara DeJesus, *Family Support Coordinator*
- Barbara Dombroff, RN, *Family Support Nurse*

## 2017 SBRN FINANCIAL HIGHLIGHTS

### 2017 Total Income



### 2017 Total Expenses



**Total End of Year Assets = \$623,665**

## 2017 SBRN EVENTS TO REMEMBER

### HOLLYDELL ICE SKATE SOCIAL



SBRN HELD ITS ANNUAL "Ice Skate Social" at Hollydell Ice Arena in Sewell, NJ on March 18th.

Participants enjoyed a fun day with songs and games on the ice!



### ANNUAL SPRING WALK FOR EMPOWERMENT

SPINA BIFIDA AWARENESS



Walk for Empowerment 2017

The Spring *Walk for Empowerment* held at Roosevelt Park, Edison NJ in June was a fun day with activities and a Tricky Tray Auction. The funds raised at this event help to support the nursing and social service coordination provided by SBRN and raise public awareness for Spina Bifida in the community.



### ANNUAL SOFTBALL TOURNAMENT



The **6th Annual Softball Tournament** in support of Spina Bifida was hosted by the **Matos Family** and the **Howell Girls Softball League** over multiple weekends in October to benefit SBRN's programs and services.



## MESSAGE FROM OUR EXECUTIVE DIRECTOR

Dear Friends and Supporters,

Our Annual Report provides a good opportunity for productive reflection: to look back at accomplishments and to look forward to new achievements and undertakings. In 2017, we continued with our successful programs, modifying and enriching them to meet the needs of the people we serve.

Our services focus on education and training – not formal schooling, but education in the real world that imparts usable, beneficial knowledge. We believe that:

**Knowledge -> Empowerment-> Action -> Success**

With the generous support of donors and volunteers in 2017, we delivered educational programs and activities that provide the tools needed to achieve independence and success.

In our **Family Support Program**, our nurses taught children how to catheterize themselves, which leads to greater independence. Our staff went into schools to educate about spina bifida and to provide support to students so they could teach their classmates about what they *can* do.

At our annual **Adult Empowerment Retreat**, adults with disabilities empowered themselves by teaching each other about their areas of expertise. In 2017, we also hosted several teleconferences, where experts shared their knowledge and engaged in stimulating discussions with participants.

We began a new prevention program, **Healthy NOW, Healthy LATER**, to educate the public about preventing birth defects such as Spina Bifida. In this program, we trained college students to educate their peers on how healthy living now can prevent birth defects later.

We are grateful to have so many community members who support us in many different ways. Some support us through financial contributions and raising pledges at our annual Walk for Empowerment. Some, like the Matos family and the Howell Girls Softball League, dedicate tremendous time and effort to hold a major event every year to raise funds and awareness of Spina Bifida. Many individuals collected books for our ongoing book donation fundraiser. And some dedicated their time and expertise through serving on our Board or by sharing their knowledge through presentations and conversations. We are thankful for every one of you and we look forward to continued collaboration!

Sincerely,

Roberta Kestenbaum, PhD, MSW



# 2017: The Year in Review

## FAMILY SUPPORT & ADVOCACY

Through our **Family Support Program**, we provided more than 1300 hours of services to more than 100 families in 2017. 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 & RECREATION

We hosted accessible recreational and educational events throughout the year for children, adults and families. For example, at our annual **Ice Skate Social** at Hollydell Ice Arena, children and adults of all abilities used skates, sleds, and wheelchairs to enjoy the activities on the ice. These types of events provide accessible, entertaining and challenging activities for everyone to enjoy.



At our annual weekend **Adult Empowerment Retreat**, 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.

## 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 pond 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.

## 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 2017, we distributed \$4,000 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 2017, we received funding from the NJ Office for the Prevention of Developmental Disabilities for our unique prevention program, **Healthy NOW, Healthy LATER**, 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. We also have extensive resources on many relevant topics on our website.

In 2017, we hosted several teleconferences and tele-support groups, which provide information in a format easily accessible from home. Our tele-support groups encourage peers to share advice and friendship, while our teleconferences offer insightful conversations hosted by experts in the field.