

ANNUAL REPORT 2022



SPINA BIFIDA ASSOCIATION
OF NEW YORK STATE



Presented By:



From the Chair

Wow! I want to report to you that 2022 was a transformative year for us. We officially became the Spina Bifida Association of New York State (SBANYS), moved into our new office and substantially increased the number of consumers who benefited from our services.

We are pleased to tell you that in the past year SBANYS has responded to nearly 2,000 requests for assistance from consumers and providers, and we've welcomed 21 new individuals impacted by Spina Bifida into our family. During 2022 we hosted over 30 programs, many in collaboration with other Spina Bifida Chapters, reaching individuals across the state and at various points in their lifespan.

With your help and support we look forward to continuing to pursue our mission and increasing those that we impact in 2023. Please take a look at this Annual Report for ways that you can continue to or perhaps increase your support. It has been an honor to Chair the SBANYS Board of Directors in 2022, thanks to what we all have accomplished.

Jim Dunham, Board Chair, 2022



Chapter Highlights



The organization officially changed its service area from Northeast New York to all of New York State. In addition to a name change, the organization moved to a larger office in June, 2022 to aid expanded services and staffing.

Spina Bifida Association of New York State (SBANYS) received The Capital Region Chamber Nonprofit Award for Excellence in Local Impact. This award was created to recognize local and affiliate chapters of a national association for making an impact in their service area.



2022 Program Calendar

- ♦ Over 35 programs hosted throughout the year
- ♦ 66% of SBANYS programs were new initiatives
- ♦ Total program attendance was 1,300+ in 2022



Winter

Legislative Advocacy
Strut & Stroll: Virtual Adaptive Fashion Show
Paralympic Watch Parties

Spring

100 Mile Challenge
Virtual Education Day
Abilities Expo

Summer

Open House
Spina Bifida Day at Citi Field

Fall

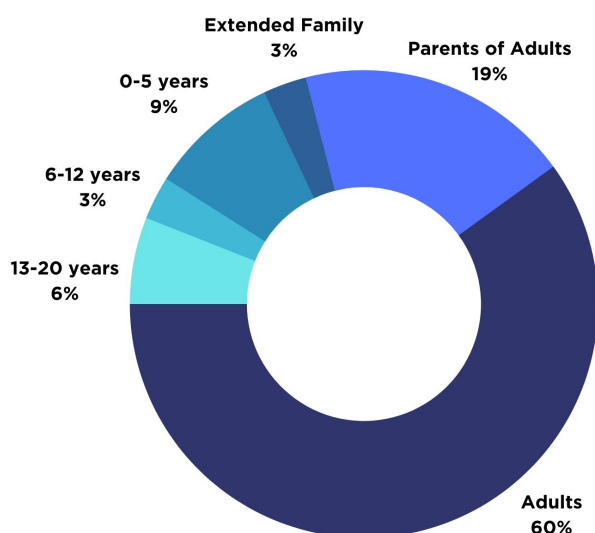
Financial Planning Series
Fall Family Weekend at Double H Ranch
Leadership Academy



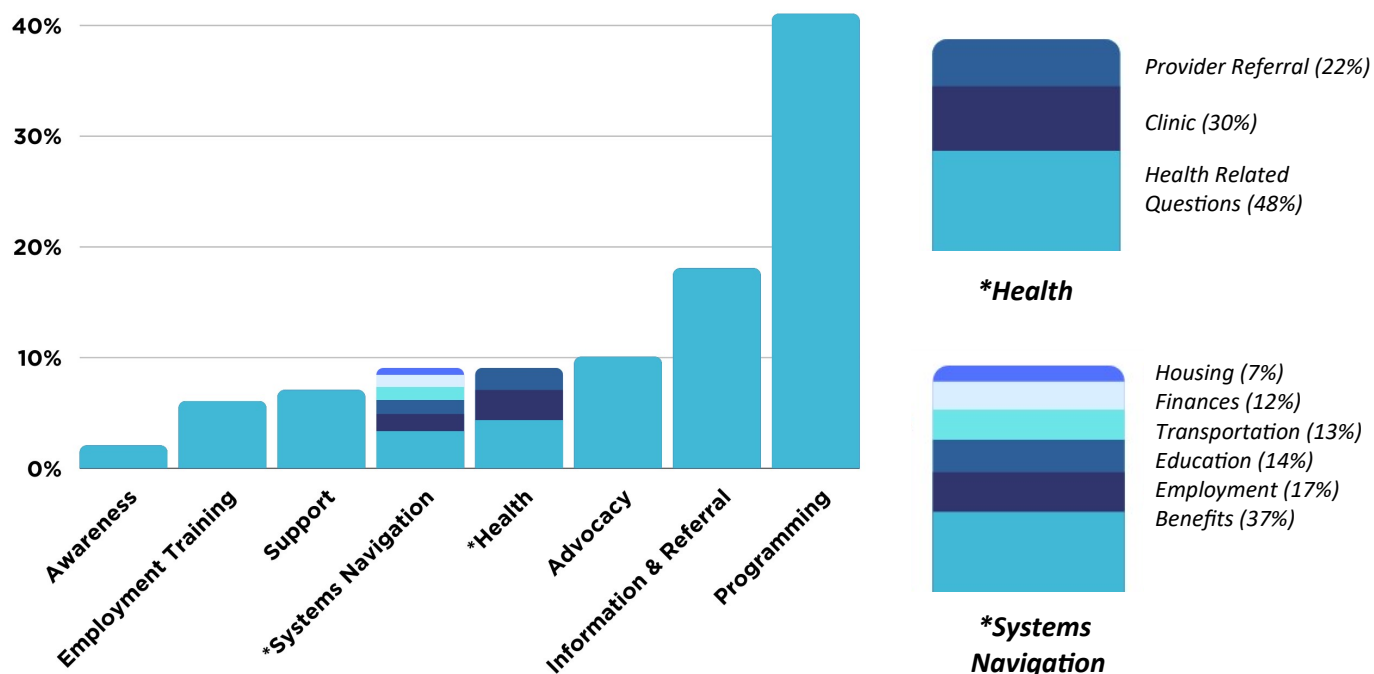
SBANYS Services

- ♦ An average of 5 individuals were served by SBANYS daily
- ♦ SBANYS served 11% of the estimated Spina Bifida population in NYS
- ♦ SBANYS consumer base grew by another 5% in 2022

Consumer Age Breakdown



Type of Service Breakdown



*See enlarged version

Service Highlights



SBANYS launched 2 new consumer training programs; a 4-session training on finances and 12-week training on becoming a leader of your own life.

SBANYS presented to over 400 professionals working with the Spina Bifida community.

SBANYS created a healthcare provider database including 10 specialties that serve the Spina Bifida community by distributing a survey to over 350 consumers (pediatric and adults) and providers across NYS.



SBANYS awarded 4 financial scholarships to individuals living with Spina Bifida to support their attendance at the 2022 NY Metro Abilities Expo providing exposure to hundreds of vendors serving the disability community.

SBANYS saw our 3rd graduate exit the Employment Training Program, a paid internship for individuals with Spina Bifida at the SBANYS office.

Consumer Testimonials

Leadership Academy

"I think everyone should be a part of this program, whether you can pinpoint what you want to learn from it right away or not. You will come away with tools to look at and handle life in a more positive way. You'll see that you are not alone in the struggles of life/life with a disability, and you'll get to know great people in the process." - *Anonymous*

Abilities Expo

"Throughout the beginning of COVID 19 I relied a lot on my Spina Bifida community virtually. One of the happy side effects of that was meeting people from across the country on Zoom and other platforms. Being able to attend the Abilities Expo in 2022 gave me the opportunity to meet those people in person. Also, learning about new technologies gave me hope for the future." - *Lyndsi Holmes-Wickert*

Internship Program

"This experience gave me the opportunity to learn valuable job skills in a safe space that helped prepare me on my career path." - *Bryan Darby*



2022 Financial Report

Balance – December 31, 2021 **\$ 198,784**

Revenue

Fundraising	102,673
Donations	4,257
Grants	109,812
Interest and dividends	5,204
Other Income	1,233

Total Revenue **223,179**

Expenses

Programs	115,959
Fundraising	24,595
Administration	13,866
Insurance	4,473
Professional Fees - Accounting	2,200
Depreciation	0

Total Expenses **161,093**

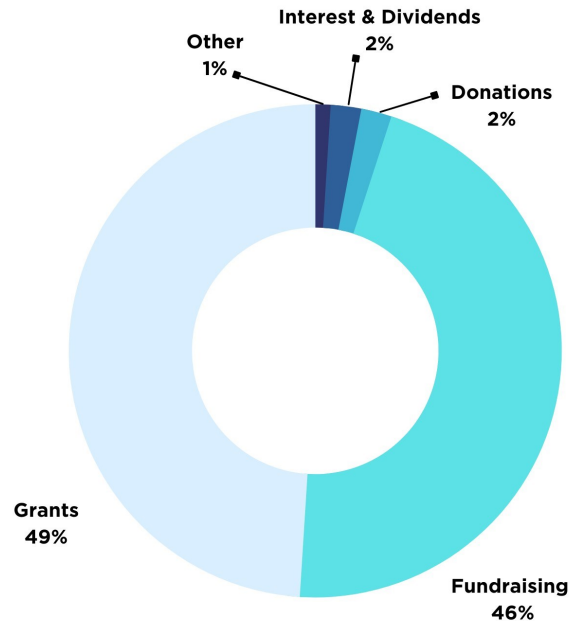
Investment Performance

Gain (loss) from sale of investments	(2,708)
Unrealized gain (loss) on investments	(26,099)

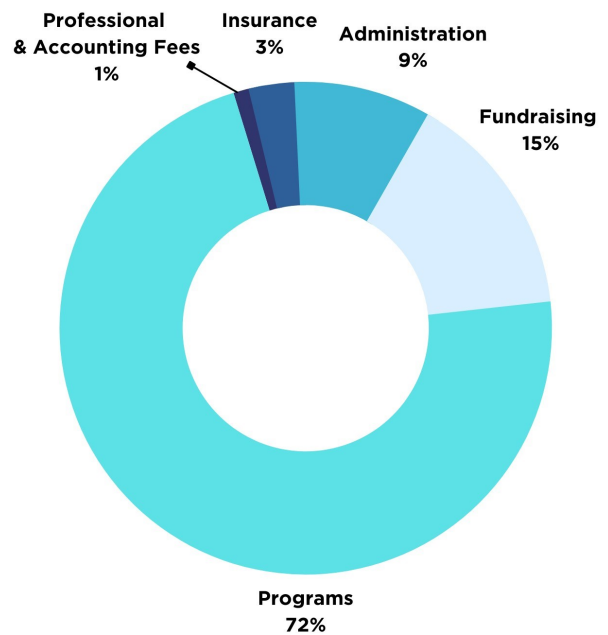
Net Investment Gain (Loss) **(28,807)**

Balance – December 31, 2022 **\$232,063**

Revenue



Expenses



Recognitions



You Make a Difference Award

SUNY Albany School of
Social Welfare (SSW)

Every year SBANYS recognizes an individual or business who has made a significant difference in the lives of those we serve. In 2022, SBANYS recognized the SUNY Albany School of Social Welfare (SSW). In 2019, SBANYS began utilizing SSW interns to supplement our individual and family services. Our interns have advocated with state departments, Assemblymembers and Senators, provided trainings to local schools and professional organizations, implemented virtual conferences and webinars, helped launch new programs, and worked with individuals and families to navigate life's challenges. Thank you to the SSW and all the interns who have worked with us through this program!

Volunteer of the Year Award

In Memory of Orlo Hulett, Sr.



Orlo Hulett, Sr. was a long time volunteer for SBANYS. He was an integral part of the SBANYS Walk-N-Roll team since its early years. He volunteered on the planning committee and the day of the event, soon volunteering to take on the role of managing the event catering, in addition to whatever else was needed! Orlo always had a smile on his face and was ready with a joke, regardless of how busy he was at the event. Very sadly, Orlo passed away in 2021. We are grateful for all that he did to support the Spina Bifida community through his leadership and to help make the Walk-N-Roll run successfully over the years. He is greatly missed. Thank you Orlo!

Volunteers

36 volunteers completed 1,800 hours of service in 2022!

Thank you for your volunteerism!

Committee
Members
(9%)

Office
Volunteers
(11%)

Interns (24%)

Board of Directors (56%)

Get involved!

Give

**SIGN UP AS A
MONTHLY
DONOR**

DONATE

**CELEBRATE
YOUR
BIRTHDAY ON
FACEBOOK**

**RECYCLE WITH
CLYNK**

Committees

**DEVELOPMENT
WALK-N-ROLL**

**DARE TO
DREAM**

**DIRECT MAIL
CAMPAIGN**

Volunteer

**EVENT
COMMITTEES**

**BOARD OF
DIRECTORS**

**REMOTE
SUPPORT**

**OFFICE
PROJECTS**

Sponsor

**ANNUAL
FUNDRAISER**

WALK-N-ROLL

**CHAPTER
PROGRAM**

**AWARENESS
MONTH**

SBANYS

Our Mission: To build a better and brighter future for all those impacted by Spina Bifida

Our Vision: We envision a world where everyone impacted by Spina Bifida is accepted and thrives

Our Values: *Our purpose is* Support, Health & Wellness, Awareness, Respect & Dignity, Empowerment

Our History: SBANYS was formed in 1993 by a small group of local parents whose children were born with Spina Bifida. This core group of parents met through a local Spina Bifida clinic and volunteered to support a handful of local families in the Capital District before hiring their first part-time Executive Director in 2001. Twenty years later, the organization has grown, with one full-time staff, three part-time staff, and multiple interns now serving over 400 families, including adults with Spina Bifida, young children and their parents, siblings and service providers.

2022 Board of Directors

James Dunham, **Chair**, Michelle Miller, **Chair Elect**, Margaret Smith, **Immediate Past Chair**, Dave Wentworth, **Treasurer**, Jessica Ryder, **Secretary**, Kevin Chamberlain, Chris Darby-King, Robert Derrick, Crystal Hoey, Paul Lukasiewicz III, Diane Skibinski, Joe Slaninka, Andrew White

Julia Duff, LMSW
Executive Director

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