



SPINA BIFIDA ASSOCIATION OF NEW YORK STATE



Fall Greetings,

What an exciting season for fall colors and the Spina Bifida Association of New York State (SBANYS). October is [Spina Bifida Awareness Month](#) and we've had a variety of programs, as well as efforts in awareness and fundraising. Please look and possibly participate. I really loved the collaboration with National SBA to kick off the month with a Virtual Education Day for Adults 30+ on October 1st and all of the Financial Planning Awareness programs that were offered throughout this month. These highlight our goals of education and empowerment. To request a recording of any of the abovementioned programs and events, email admin@sbany.org.

Stay tuned for our next 3 Year Strategic Plan. Various stakeholders were surveyed last month about our current Strategic Plan's Goals. The SBANYS Board of Directors will be taking all of this information into consideration as we develop the next 3 Year Plan (2023-2025). We are fortunate to have Ryan Ben, National Director of Field Relations for Spina Bifida Association facilitating our discussions and process.

Our 10th Annual [Dare to Dream Gala](#) is planned for November 19th at Wolfert's Roost Country Club again. Please check it out and join us either in person or virtually if you can. We are recognizing The School of Social Welfare at SUNY Albany with our "You Make a Difference Award" and Orlo Hulett with the "Volunteer of the Year Award" posthumously. Our thanks to the Dare to Dream Planning Committee for all their efforts and talents that went into this upcoming event.

We are extremely proud and humbled to be recognized by the Capital Region Chamber. SBANYS will receive the Excellence in Local Impact Award at their upcoming 2022 Nonprofit Business Awards Luncheon on November 18th. We greatly appreciate the individuals who nominated us, wrote letters in support of our nomination and the Chamber for selecting us for this award.

How would you like to help such a vibrant and impactful organization as SBANYS? There are a variety of ways. In addition to the opportunities mentioned above, we are always looking for new volunteers to help us plan our various events and guide us as we grow in serving those impacted by Spina Bifida throughout New York State. We would also ask that you consider SBANYS when you are planning your end of year giving. Please go to our website (<http://sbany.org/>) for information on volunteering, contributing and all of our upcoming events.

Thank you so very much,

Jim Dunham

Disclaimer: Spina Bifida Association of New York State does not endorse or recommend products, services or manufacturers and assumes no liability whatsoever for the use or contents of any product or service mentioned herein. The information provided in this newsletter is for informational, educational and entertainment purposes only. It is not intended as medical or professional advice.

ISSUE #91 OCTOBER 2022

WELCOME LETTER

SPINA BIFIDA
AWARENESS MONTH

DARE TO DREAM

SBANYS UPDATES

SPONSORS

NEWS TO USE

GET INVOLVED

SBANYS BOARD

Chair: Jim Dunham

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OCTOBER IS SPINA BIFIDA AWARENESS MONTH



Thank you to all who helped celebrate Spina Bifida Awareness Month this October!



SBANYS's 30-Year Anniversary Calendars are available for \$30 starting this October! The calendar features individuals and families living with Spina Bifida. All proceeds (after shipping) will help raise funds for SBANYS programs and services.

October is ALSO Financial Planning Awareness Month!

We partnered with the Association of Financial Educators to cover four important topics about financial planning and living with Spina Bifida.

Recordings: [Budgeting Basics](#), [Financial Planning Basics](#), [Wills, Trusts and Power of Attorneys](#)

Upcoming:

- **SSI, SSDI & ABLE Accounts, Date & Time TBD:** Learn about setting goals and planning ahead, creating and executing transition, legal, and financial plans, understanding government benefits, types of supplemental needs trusts and ABLE accounts. Save the date!

The Spina Bifida Association of New York State
presents the 10th Annual:

DARE TO DREAM GALA

*All proceeds benefit the programs and services of
the Spina Bifida Association of New York State*

This year's fundraiser is available in-person and online!

Both formats include an auction, virtual wine-tasting/cash bar, and recognition ceremonies.

Online auction opens for bidding Friday, November 4 at 9:00am.

Join us in person Saturday, November 19, 2022 at 6:00pm

Wolferts Roost Country Club

120 Van Rensselaer Blvd, Albany, NY 12204

Honorary Chair:

Edward V. Wilcenski, Esq.

You Make a Difference Award:

The School of Social Welfare, SUNY Albany

To purchase a ticket, sponsor,
or donate, visit www.sbanys.org
or contact the office at
admin@sbanys.org / 518-399-9151.





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SBANYS Updates

Spina Bifida Association of New York State wins Nonprofit Award for Excellence in Local Impact!

This award was created to recognize local and affiliate chapters of a National association making an impact in their service area. SBANYS is absolutely honored and looking forward to the luncheon taking place at the Hilton Garden Inn Troy (235 Hoosick St, Troy, NY 12180) from 11:30am-1:30pm on Friday, 11/18/22. For more details and to register, click [HERE](#).



DREAM Symposium

SBANYS tabled at the Disability Rights & Employment Awareness Month (DREAM) Symposium with dozens of agencies providing disability and employment services. The event included vendor visit, recognition ceremonies, and webinars on important topics such as ABLE accounts, Ticket to Work and Benefits Advisement. **One exciting result of this event, is SBANYS is currently working in conjunction with the New York Employment Services System (NYESS) to create a Job-Seekers Guide for People with Disabilities. In the future, we will be recruiting consumers to participate in a focus group to provide input, feedback and suggestions for the final product. If you are interested, contact the office at 518-399-9151 or admin@sbanys.org.**



New York State Independent Living Council (NYSILC) Sponsorship Ambassador Program

NYSILC developed an Ambassador Sponsorship Initiative to reach out and establish collaborative relationships via their Board members. Cliff Perez, a NYSILC Board member, serving as Ambassador, awarded the Ambassador Sponsorship Award, in the amount of \$1,200, to SBANYS. The Award was presented to Julia Duff, Executive Director and her interns at the Independent Living Center of the Hudson Valley (ILCHV) on September 22. To kick-off this partnership, SBANYS is recognizing the award as part of our upcoming Dare to Dream Gala. Members from NYSILC will be attending as guests and receive acknowledgments on the stage that evening, on our website, and in the program. Dare to Dream is SBANYS' major annual fundraiser raising critical funds for services including support/counseling, referrals, systems navigation, education, advocacy, awareness and outreach. Additionally, our fundraisers support our programs including webinars, support groups, trainings, scholarships, peer support networks, equipment exchange, and more! ***We are looking forward to our continued partnership with NYSILC!***

SBANYS Executive Director had the chance to talk with School of Social Welfare University at Albany on The Social Workers Radio Talk Show this past month

Check it out to hear about SBANYS becoming a statewide organization, Spina Bifida Awareness Month plans, our Social Welfare Interns and Dare to Dream Gala! Listen [HERE](#).

SBANYS Updates

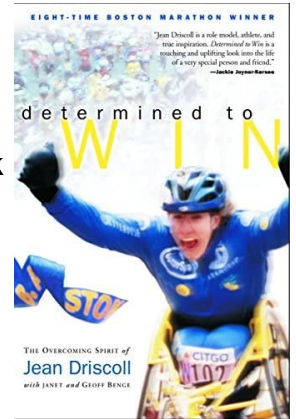
Spina Bifida Provider Survey

This winter, we developed a survey requesting information from our consumers about the generalist and specialty providers they see in order to better respond to requests from our community about finding experts in the field. **SBANYS responded to over 50 requests for a provider referral last year—that is near once a week!** With your feedback, we can better respond to consumers statewide looking for providers who have treated a person living with Spina Bifida. Help us build our provider database by completing the survey [HERE](#)!

Book Club

This October SBANYS and chapters across the country launched two separate book clubs for adults living with Spina Bifida and parents/caregivers of individuals with Spina Bifida. Book clubs will take place via Zoom every other month on Thursday evenings at 4:30pm PDT/7:30pm EDT. Sign up and find the upcoming dates and authors for book club [HERE](#).

We are kicking off our first meeting with *Determined to Win* by Jean Driscoll who is joining us on 11/10/22! You can purchase the book in the format of your choice. Chapter leaders will facilitate the book club virtual session each month and moderate a Q&A.



Adult Group

Join our adult group at one or more of the meetings taking place at 5:30pm EST throughout the rest of the year :10/25 (World Spina Bifida Day!), 11/22, 12/27. Register to attend [HERE](#).

Join a committee!

SBANYS is actively recruiting for 2 committees for 2022-2023. **Want to spend more time with a fun group of dedicated volunteers and SBANYS friends!? Contact the office to get involved!**

Walk-N-Roll for Spina Bifida taking place May 13, 2023! Joining the committee includes:

- ⇒ Virtual meetings in the evenings 1 time a month November-June
- ⇒ Assisting with the preparation and implementation of the event including determining the venue, website, fundraising goals, marketing, corporate and nonprofit partnerships, recruitment, and catering. Further, assisting with the day of the event during set up, registration, manning tables- sales, raffles, and clean up.



SBANYS Conference Committee, date TBD. Joining the committee includes:

- ⇒ Virtual meetings in the evenings 1 time a month
- ⇒ Assisting with the preparation and implementation of the event including determining the venue, speakers and topics, theme, cost, catering, day of volunteering in sessions or at registration, evaluations, conducting outreach and recruitment.



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The **Albany Med Health System** is proud to provide a single, unified source for health care, scientific discovery, and medical education in our communities.

Albany Medical Center is honored to continue its partnership with the **Spina Bifida Association** to provide unique, coordinated, and multi-disciplinary care to children and adults affected by spina bifida.



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News to Use

Health

The New York State Department of Health Disability and Health Program is offering a **14-week exercise and nutrition program** for people with I/DD. You can receive this program virtually or in-person. If you are interested in receiving the toolkit please email DHP@health.ny.gov.

Bowel Management Protocol: Individuals living with Spina Bifida are at risk for bowel incontinence. The Lifespan Bowel Management Protocol was developed to support those living with Spina Bifida and healthcare professionals to better understand Spina Bifida and its risks. The protocol can be found [HERE](#).

Social Security

If you need to obtain your social security card, update your name, or make any other changes, you can visit <https://www.ssa.gov/ssnumber/> to start or complete an application online. This process can be started online and finished at your local social security office.

Social Security and Supplemental Security Income (SSI) benefits will increase 8.7% in the 2023 year. This will begin with payable benefits to over 65 million beneficiaries in January 2023. You can access your new benefit amount by logging into your personal [mySocialSecurity](#) account.

Education Days

Spina Bifida Association of Greater New England is hosting an Education Day, November 4 @ 6:30 PM EDT to 11/5 @ 4:30 PM EDT. This Education Day will be held at the DoubleTree Hotel (2 Somerset Parkway Nashua NH 03063). To register, click [HERE](#).

Children's Hospital of Philadelphia is hosting a Spina Bifida Education Day for parents and caregivers to learn about IEP's, transition, healthy nutrition, mental health, activities of daily living, neurocognition, ambulation and more. This event is on November 5th from 8:30am-5:00pm at the Roberts Center for Pediatric Research. Register [HERE](#).

SBANYS Frank Bucino Jr. Memorial Scholarship can assist with costs including registration, travel and lodge to attend Education Days like the opportunities above! Apply for financial assistance [HERE](#).

Employment

The Job Accommodation Network focused on assistive technology in their September newsletter which contains resources to help employers, individuals with disabilities, and service providers regarding assistive technology. Learn more [HERE](#).

National Spina Bifida Association

Project ECHO: Extension for Community Healthcare Outcomes, ECHO, offers the opportunity to healthcare professionals to gain knowledge and deepen their understanding of Spina Bifida. Learn through short lectures from top Spina Bifida specialists and join in case-based discussions through Zoom. This program starts October 6, 2022 and ends April 20, 2023. Click [HERE](#) to learn more.

Individuals diagnosed with Spina Bifida Occulta, SBO, struggle due to the lack of resources, information and awareness. SBA is offering an information session led by three well-known physicians and the opportunity to ask any questions you may have. This session will be held on 11/17/2022 at 7pm ET via Zoom. Register to attend [HERE](#).

The Spanish Language Education Series, hosted by SBA in the summer months, Charla y Cafecito Acerca de la Espina Bifida, was recorded and is available on the SBA website. You can find links to educational videos on the topics of physical activity, self-care and independence, and mental health and well being [HERE](#).

Teal on the Hill 2023: Join other members of the Spina Bifida community to meet virtually with members of Congress. You will receive guidance through advocacy training in preparation for a powerful and fun experience. Topics that will be covered include; continued funding for Spina Bifida programs at the Centers for Disease Control & Prevention, disability rights, affordable and accessible health care, medical supplies, and technology. Save the dates February 28-28, 2023 and register to attend [HERE](#).

Voting

Voting is a powerful way to advocate for disability rights, and every vote matters! Elections can affect who decides how vital programs for people with disabilities get funded and work, including Social Security, and Medicaid. So, it's important to vote and to consider how the candidates do or do not address issues that are important to YOU! Here are five easy things you can do to get ready for Election Day:

- [Sign the pledge to vote](#) and encourage others to vote
- Make sure you're registered – [check your status](#)
- [Get informed – access free resources](#) to learn more about voting, critical issues for people with disabilities, their families, and the direct support workforce
- [Find your candidates](#) – see who's running for office where you live and learn more about their positions on key issues
- Make a plan for how you will get to your polling place to cast your ballot!



SPINA BIFIDA ASSOCIATION
OF NEW YORK STATE

ABOUT SBANYS

Contact: admin@sbany.org / 518-399-9151 / 133 Saratoga Road, Suite 4, Scotia, NY 12302

Mission: *To build a better and bright future for all those impacted by Spina Bifida.*

Our purpose is

Support

Health & Wellness

Awareness

Respect & Dignity

Empowerment

UPCOMING EVENTS!

Adult Group

10/25/2022

SSI/SSDI Webinar

10/27/2022

Dare to Dream

11/19/2022



JOIN THE TEAM!

If you are interested in offering your support and expertise to the Spina Bifida community, contact the Spina Bifida Association of New York State to learn more about our Board of Directors, Professional Advisory Council, or one of our volunteer committees!

COMMITTEE MEETINGS

Development —November 2, 2022

Dare to Dream —November 7, 2022

Governance— November 9, 2022

Board of Directors— November 12, 2022

COMMITTEES TO JOIN

Conference

Development

Dare to Dream

Direct Mail Campaign

Walk-N-Roll

ESTATE PLANNING, MEMORIALS & HONORARIUMS

Have you considered including SBANYS in your estate plans?

You may also want to consider honoring or memorializing a friend or a loved one with a gift to SBANYS. Memorial forms are available. Please contact our office.