



Hello!

I hope everyone is enjoying the summer while staying cool & hydrated in the heat. It has been a busy few months for SBANYS. On May 18th, SBANYS was introduced on the Assembly floor and October recognized as Spina Bifida Awareness Month. Thank you to all who represented SBANYS at the Assembly session.

Also in May we held our annual Walk-N-Roll and had our most successful event to date. This year's event was held on two different days and locations- one in Long Island, NY and the other in Schenectady, NY. SBANYS raised more than \$47,000 for our programs and services. Thank you to all of our sponsors, donors and volunteers. It is because of your support that the Walk-N-Roll was such a huge success.

On July 26th, SBANYS and the Spina Bifida Center of CNY honored the 33rd anniversary of the Americans with Disabilities Act (ADA) with the "Go the Mile for the ADA" challenge. A friends and family picnic was also hosted in Dewitt, NY. Stay posted for pictures from the event!

SBANYS is happy to have two new interns to support our individuals. Welcome to Kathleen Watt from the SUNY Albany School of Social Welfare and Angela Marra joining our Employment Training Program. McKayla Dias has left the internship program and we thank her for her service and support.

Our virtual programs are still open and available to all who would like to join including our book club, support groups and advocacy training. For a list of all our programs and when they are scheduled, go to <https://mailchi.mp/sbaneny/sbanys-programs>.

I hope you continue to enjoy the summer and join us for our upcoming events!

Shelley Miller  
Board Chair

## ISSUE #94, JULY 2023

### WALK-N-ROLL

### SBANYS PROGRAMS & NEWS

### NEWS TO USE

### DARE TO DREAM

### BYRAM HEALTHCARE

### GET INVOLVED

## SBANYS BOARD

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# WALK-N-ROLL FOR SPINA BIFIDA

## 2023 Walk-N-Roll

We accomplished some amazing milestones during this year's Walk-N-Roll, making it one of our most successful seasons! Thank you to all of those that have made that success possible, including participants, volunteers, donors, the planning committee, Board of Directors, and our sponsors!

Check out our recap video provided by Byram Healthcare: <https://youtu.be/L04aUnVdnlk>

## Thank you to our 2023 planning committee!

Co-Chairs Heather Horwedel and Michelle Miller, Jessica Ryder, Joe Slaninka, Dan Bussani, Mary Langelier, Megan Connors, Meghan Smith, Paul Lukasiewicz III, and Peggy Smith.



## Thank you to our Bronze sponsors!







# 2023 WALK-N-ROLL FOR SPINA BIFIDA





# SBANYS Programs & News

## Adult Group

SBANYS adult group brings people from across the country to meet virtually in a safe space for all of us to discuss the daily obstacles and successes people with Spina Bifida experience. Adult group consists of focused discussions, open chat, and game nights! Adult Group takes place on the 4th Tuesday of every month. **Next group is Tuesday, August 22nd via Zoom at 5:30pm.** If you have not already registered to join, do so here:

<https://us02web.zoom.us/meeting/register/tZErdOurqz8oGNRQrAhgW1rgMxYBLHm-XqYQ>

## Equipment Exchange

Contact [admin@sbanys.org](mailto:admin@sbanys.org) if interested!



A local organization is looking to donate a used power chair. The chair has tilt and recline functions that allows for personal care. It is joy stick control with a zero turning radius. It has been in use for about 7 years. The chair has one mechanical defect. It does not go into neutral so it will only move using the controller. This defect prohibits the ability to roll or move the chair without power. This defect would only be an issue of it was used outside of a residence and it ran out of power because the wheelchair is very heavy!

## Assembly Introduction

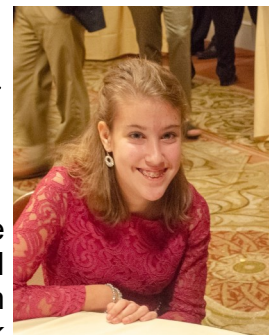
This past Spring, the Spina Bifida Association of New York State visited the Assembly Floor where October was officially recognized as Spina Bifida Awareness Month. Watch the full introduction here:

<https://www.youtube.com/watch?v=2uBtfzW-Nr8>



## Welcome SBANYS two new interns!

Welcome Angela Marra! Angela is joining us as the 5th intern in SBANYS Employment Training Program, providing paid administrative experience for teens and adults in the Spina Bifida community!



Welcome Kathleen Watt, our newest Master in Social Welfare Intern from SUNY Albany! Kathleen will be interning here until May 2024 as part of her program. She graduated from Plattsburgh State University with a dual degree in Social Work and Human Development Family Relations. She has interned at Clinton County District Attorneys Child Advocacy Center (CAC) as well as Court Appointed Special Advocates (CASA) for the children of DC. She currently works at Northern Rivers, immersing herself in the field as much as possible. Feel free to contact her at 518-399-9151 or [socialworkintern@sbanys.org](mailto:socialworkintern@sbanys.org).

# New to Use

## RESEARCH

### All of Us Research Program

Historically the disability community has been excluded from research. All of Us is working to improve health care through research, building a diverse database that can inform thousands of studies in variety of health conditions. Members of the Spina Bifida community are invited to join what will be one of the most diverse health databases in history. Learn how you can get involved here: <https://allofus.nih.gov>

### Reproductive Health in Women with Spina Bifida: a Mass General Hospital Genetics Counseling Capstone

Participate in research by M.S. candidate in Genetic Counseling Allison Wong. This work will assess how supported participants felt after genetic counseling, its perceived utility to the SB community, and ways to improve the genetic counseling practice for the SB community via a short survey and 60 min interview. For more information, contact: [awong@mghihp.edu](mailto:awong@mghihp.edu)

### Parent to Parent NYS survey on BIPOC (Black, Indigenous, and People of Color) families of children and adults with physical or developmental disabilities.

Parent to Parent hopes to shed light on the unique perspectives and concerns of BIPOC families within the special needs community. This survey aims to provide needed information on how Parent to Parent NYS can better serve BIPOC families. All information will be kept confidential, for Parent to Parent NYS' use only. Should you have any questions, please contact [mbaker@parenttoparentnys.org](mailto:mbaker@parenttoparentnys.org)

<https://www.surveymonkey.com/r/BIPOCFAM>

## UPCOMING EVENTS

### Albany Nature Bus, August 26th

Mohawk Hudson Land Conservancy and CDTA are partnering once again to connect Albany City residents to nature. New this year is the Schenectady Nature Bus, one day per month in July and August. This free bus service brings you to popular outdoor locations where you can enjoy free programming on most weekends. Click the link to see the bus schedules: <https://www.cdfa.org/nature-bus>

### NYAIL Our Path Forward 2023 Statewide Conference, September 12-13th

Partake in an exciting lineup of workshops, keynote speakers and interactive sessions. Register to attend here: <https://ilny.us/attendee-registration>.

**Please Note:** SBANYS Frank Bucino Jr. Memorial Scholarship is available to assist with the cost of attending! <http://sbanys.org/chapter-programs/financial-scholarships/>

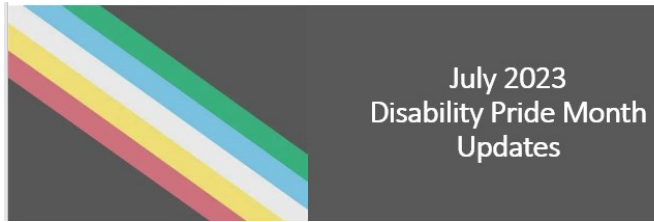
NYAIL is also seeking nominations for the **David Veatch Advocacy Achievement Award**, to be presented at the 2023 Conference. The David Veatch Advocacy Achievement Award is awarded during the NYAIL Statewide Conference, to an individual who has shown a passion for advocacy for individuals with all types of disabilities. Please send award nominations to [conference@ilny.org](mailto:conference@ilny.org) and let them know why the person you are nominating deserves to be recognized!

### Love From Liam CHOP Spina Bifida Clinic Family Fun Day, Saturday, October 7th

Enjoy a day of fun with games, basket raffles, food, and much more with your friends in the Spina Bifida community. Learn more and register here: <https://www.eventbrite.com/e/love-from-liam-chop-spina-bifida-clinic-family-fun-day-tickets-623251681557?aff=oddtcreator>

# News to Use

## DISABILITY PRIDE MONTH



In honor of the anniversary of the ADA, July is Disability Pride Month! This month serves to celebrate the history, struggles, achievements, and experiences, of the disability community.

### What Does the Disability Pride Flag Represent?

The parallel stripes stand for intracommunal solidarity. The colors on the flag symbolize various disability experiences. The black background mourns people with disabilities who have died due to negligence, suicide, rebellion, illness, and eugenics. Each of the stripes represent types of disabilities:

- Red: physical disabilities
- Gold: cognitive and intellectual disabilities
- White: nonvisible and undiagnosed disabilities
- Blue: psychiatric disabilities
- Green: sensory disabilities

**How can you participate?** We suggest learning about SBANYS' 2023 You Make a Difference Award recipient, Judy Heumann by reading her book: *Being Heumann* or watching Crip Camp on Netflix! <https://judithheumann.com/>

## COMMUNITY OPPORTUNITIES

### NYC Physicians & Medical Students Wanted

Stanford Medicine Alliance Disability Inclusion and Equity (SMADIE) is working on a project with UCSF and Positive Exposure.

Positive Exposure is embarking on a photographic and multimedia campaign promoting doctors with disabilities. We already had a photo shoot in the Bay Area. Now, Rick is looking to photograph and interview medical students and physicians with disabilities in New York City.

If you are a physician or know one who would be willing to be photographed and interviewed by Rick sometime in the next few months, email—[smac\\_national\\_announcements-bounces@lists.stanford.edu](mailto:smac_national_announcements-bounces@lists.stanford.edu))

## HEALTH

### Byram Urology Health Newsletter

Byram's Summer Newsletter includes various health resources and information on UTIs and catheterization. You can also check out how Byram has supported SBANYS by sponsoring this year's Walk-N-Roll events! Click here to read the newsletter:

<https://myemail.constantcontact.com/Urology-Health-Newsletter----Summer-2023.html?oid=1102312324043&aid=VVA7Yri5g>

### Spina Bifida Resource Network Newsletter

Find articles about aging and Spina Bifida as well as staying hydrated this summer here:

<https://api.neonemails.com/emails/content/iXj1yyzsHnWy0whQhdNSBcB-stACuc1EDPM1AXWWSNDY=>

### New Health Information Development Tool

A new CDC tool now helps you develop health information for adults with intellectual and developmental disabilities and extreme low literacy (IDD/ELL). Audience research shows that a few materials that often work well for adults with IDD/ELL include:

- social stories (short stories that tell the reader what to expect in a social situation)
- animated videos
- interactive products (e.g., products that ask the reader to answer questions or put a series of pictures in order)

Check out the tool here: <https://www.cdc.gov/ccindex/index.html>





SPINA BIFIDA ASSOCIATION  
OF NEW YORK STATE

# DARE TO DREAM GALA

Cheers to 30 Years!



Dinner, Auction, & Entertainment  
Saturday, November 18th, 2023 at 5:00pm  
Hilton Garden Inn  
235 Hoosick St, Troy, NY 12180



Honorary Chair: Stella Porter, WNYT  
You Make a Difference Award: In  
Memory of Judy Heumann



# DARE TO DREAM GALA

## *Celebrating 30 years of service*



### Individual & Corporate Sponsorship Levels

#### **\$5,000 Titanium Sponsor**

- Event announcements and opportunity to speak.
- Full-page color ad in the event program and SBANYS newsletter
- Logo listed on Dare to Dream website
- Company tagged in social media posts (10)
- Acknowledgment in event press releases
- Logo included in evening presentation (x10)
- Reserved table for eight (8) guests
- Company materials provided to participants of Spina Bifida Clinic(s) (monthly)

#### **\$2,500 Gold Sponsor**

- Event announcements
- 3/4 page color ad in the event program and SBANYS newsletter
- Logo listed on Dare to Dream website
- Company tagged in social media posts (6)
- Logo included in evening presentation (x6)
- Six (6) tickets to the event
- Company materials provided to participants of Spina Bifida Clinic(s) (quarterly)

#### **\$1,000 Silver Sponsor**

- Event announcements
- Half-page ad in event program and SBANYS newsletter
- Logo listed on Dare to Dream website
- Company tagged in social media posts (4)
- Logo included in evening presentation (x4)
- Four (4) tickets to the event
- Company materials provided to participants of Spina Bifida Clinic(s) (bi-annually)

#### **\$500 Bronze Sponsor**

- Event announcements
- Quarter-page ad in event program and SBANYS newsletter
- Logo listed on Dare to Dream website
- Company tagged in social media posts (2)
- Logo included in evening presentation (x2)
- Two (2) tickets to the event
- Company materials provided to participants of Spina Bifida Clinic(s) (1x)

#### **Honorary Committee**

##### **\$350 Two Star Honorary Committee**

Two complimentary event tickets  
Listing on website and event program

##### **\$200 Shining Star Honorary Committee**

One complimentary event ticket  
Listing on website and event program

Event Program Advertisements: \$400 Full page - \$250 Half page - \$100 Quarter page





# Thank you to our Presenting Sponsor!



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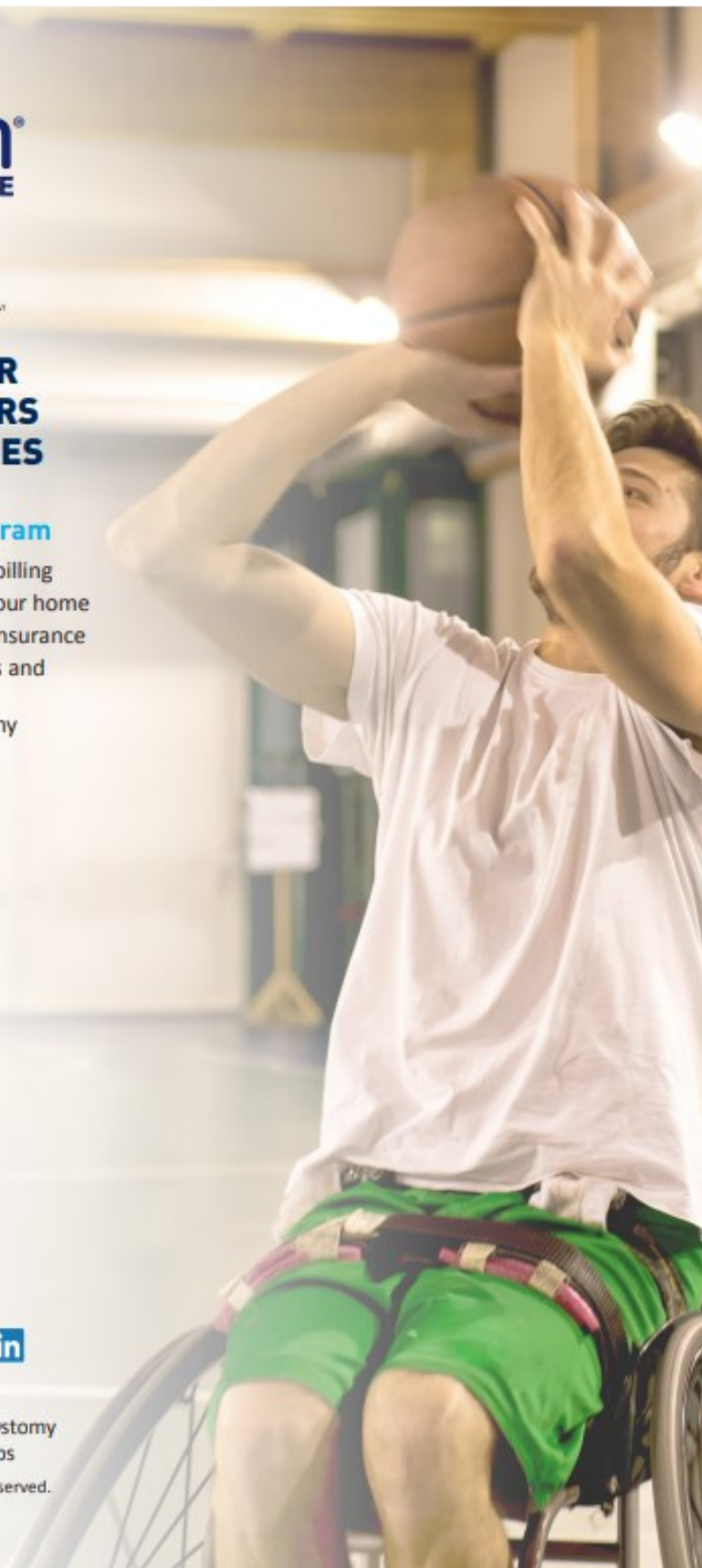
 SCAN ME

[byramhealthcare.com](https://byramhealthcare.com)   

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Diabetes | Enteral Nutrition | Breast Pumps

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SPINA BIFIDA ASSOCIATION  
OF NEW YORK STATE

## ABOUT SBANYS

**Contact:** [admin@sbanys.org](mailto:admin@sbanys.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**

**S**upport

**H**ealth & Wellness

**A**wareness

**R**espect & Dignity

**E**mpowerment

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## UPCOMING EVENTS!

*October, Spina Bifida Awareness Month*

*Strut & Stroll, Adaptive Fashion Show for All*  
October 25th, 2023

*Dare to Dream Gala*  
November 18th, 2023



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## 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!

## COMMITTEES TO JOIN

- 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.