



## SBANENY News to Use

### WELCOME LETTER

Happy Summer!

I hope that our newsletter finds you safe, healthy, and staying cool. It is that time of year when SBANENY would typically be gearing up for a day of sailing or night at a baseball game. We wish we could be attending these programs together and are looking forward to the day when we can all safely gather again!

Even though we cannot meet in-person, SBANENY continues to host programs virtually. Virtual hangouts for teens, parents and adults have been taking place via Zoom. SBANENY is also hosting our first virtual trivia for adults on Tuesday, July 28th. Be sure to join in on one of our upcoming virtual meetings to connect with new and old friends. Also - keep an eye out for our new virtual programs coming soon.

This month, SBANENY published our 2019 Annual Report. In 2019, SBANENY expanded our consumer reach, provided new programming, and raised Spina Bifida awareness, all supporting our mission: to build a better and brighter future for all those impacted by Spina Bifida. Keep reading for the full report!

Save the date! SBANENY has transitioned our fundraising calendar to virtual this year. The 10th Annual Walk-N-Roll & 5K is taking place Saturday, September 5th. Contests, prizes, and t-shirts are all mirroring our typical in person event. And check us out on Facebook where we are sharing weekly memories with pictures from each event since 2011. Register to participate—you will not want to miss out on the fun!

As summer rapidly comes to an end, we are working hard to finalize our fall and winter calendar. Coming up this fall we have the Eric Crow Memorial Golf Tournament taking place Saturday, October 3rd. SBANENY is also hosting our 8th annual Dare to Dream gala virtually this year. We look forward to sharing our auction items with you online.

Remember, you can always reach out to SBANENY at [admin@sbaneny.org](mailto:admin@sbaneny.org) or 518-399-9151 for information, support, or with virtual program ideas!

I look forward to seeing everyone soon.

Tracy Paige  
Board Chair

***Disclaimer:** Spina Bifida Association of Northeastern New York 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 #82  
JULY 2020

SBANENY UPDATES

ADA ANNIVERSARY

VOTING

SPONSOR  
OPPORTUNITIES

NEWS TO USE

COVID-19 RESOURCES

SBA UPDATES

EVENT DATES AND  
COMMITTEES TO JOIN

SBANENY BOARD

*Chair:* Tracy Paige

*Vice Chair:* Jim Dunham

*Immediate Past Chair:*

Margaret Smith

*Treasurer:* Dave Wentworth

*Secretary:* Jessica Ryder

*Directors:*

Chris Darby-King

Robert Derrick

Helen Eggenberger

Peggy Felt

Paul Lukasiewicz

Jessica Ryder

Joe Slaninka

Executive Director

Julia Duff

# SBANENY UPDATES

**Equipment Exchange:** Stander available.

The stander is good for a person up to 160 lbs. and can help with strengthening leg and postural muscles. Email the office for more information: [admin@sbaneny.org](mailto:admin@sbaneny.org).



**SBANENY Facebook group:** Join our new private [Facebook group](#) for individuals and families with Spina Bifida.

**Virtual Programs**—Adult Trivia coming up Tuesday July 28th @ 5:30PM. Register [HERE!](#)

## SAVE THE DATE

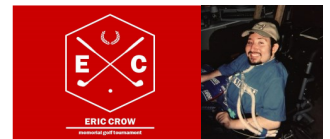
\* **Virtual Walk-N-Roll & 5K for Spina Bifida Presented by the Daily Gazette**

- \* Saturday, September 5th 2020.
- \* Registration is free, contests and prizes, 2020 t-shirts and more.
- \* SBANENY celebrates our 10th anniversary of the Walk-N-Roll in 2020. Check out our Walk-N-Roll memories on [Facebook](#) and [Instagram!](#)
- \* [Sign up today!](#)



\* **Eric Crow Memorial Golf Tournament:** Saturday, October 3rd, 2020.

- \* Sponsor opportunities available. Stay tuned for additional details!



\* **Virtual gala—Dare to Dream with SBANENY:** Saturday, November 21, 2020.

- \* Online silent auction, live auction, and entertainment.
- \* Tickets: \$10.00 tax deductible donation.



\* **SBANENY Education Day:** April, 2021.

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## SBANENY's 2019 Annual Report is now available!



SBANENY's Annual Report features a story from Mary, an adult with Spina Bifida in a doctor's appointment being asked, "When did you get Spina Bifida?" To read the full story and how SBANENY makes a difference through advocacy and education, visit the [SBANENY website](#).

- \* *Our summer appeal aims to raise \$5,000 to support SBANENY's advocacy and education programs. [Give today!](#)*

Click the image to read SBANENY highlights in 2019 including ways to get involved, increased education, expanded advocacy and awareness, and program development!

# 30th Anniversary of the Americans with Disabilities Act, July 26, 2020



Americans with Disabilities Act

## 30 Mile Challenge

SBANENY Board member Joe Slaninka celebrated the 30th anniversary of the ADA by riding his hand-cycle 30 miles on Sunday, July 26th. Joe recruited individuals with Spina Bifida and other friends of the community to participate. Check out SBANENY's Facebook for pictures from the challenge!



## Celebrating the 30th anniversary of the ADA!

**Disability Matters Podcast:** Joyce Bender welcomes Maria Town, President and CEO of the American Association of People with Disabilities (AAPD) and Kelly Buckland, Executive Director of the National Council on Independent Living (NCIL) to reflect on the ADA and the impact of this legislation. Available on demand on [Spotify](#), [Apple](#), and [Voice America](#).

**July 28th: New York Association on Independent Living (NYAIL):** NYAIL is celebrating the ADA by facilitating a panel, [The ADA: Then and Now](#) from 10:00AM-12:00PM. Moderated by Denise Figueroa, a distinguished advocate with over 40 years in the disability rights movement and Executive Director of the ILCHV. Panelists are:

- Judy Heumann, International Disability Rights Consultant
- Jim Weisman, President and CEO of United Spinal Association
- Cliff Perez, Vice President of NCIL and Systems Advocate at ILCHV.

**July 30th: Please join the NYS Division of Human Rights (DHR)** on Thursday from 10:30AM-12:00PM for "Commemorating 30 Years Since the Americans with Disabilities Act (ADA) in New York State." This virtual event will celebrate the passing of the ADA, landmark legislation that has impacted the lives of millions of Americans by increasing access and opportunities for people with disabilities in our workplaces and communities. [RSVP today!](#)

For more information, resources, clips and events, visit <https://www.adaanniversary.org/>.

## ARE YOU REGISTERED TO VOTE?

Two weeks ago, we celebrated National Disability Voter Registration Week from July 13, 2020-July 17, 2020. In 2020, over 35 million people with disabilities will be eligible to vote. See below for everything you need to know to vote:

- [Check your registration](#)
- [Register to vote](#)
- [Vote by mail](#)
- [Get election reminders](#)
- [Pledge to register—17 years old and under](#)
- [Polling place locator](#)
- [Complete the 2020 Census!](#)
- [Voting in NYS for people with developmental disabilities](#)

# SBANENY's 10th Annual Walk-N-Roll for Spina Bifida

## SPONSOR BENEFITS



|  | <b>PRESENTING</b><br><b>\$5,000</b> | <b>PLATINUM</b><br><b>\$2,500</b>   | <b>GOLD</b><br><b>\$1,500</b>       | <b>SILVER</b><br><b>\$700</b>       | <b>BRONZE</b><br><b>\$300</b> |
|--|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------|
| <b>Pre- Event Benefits</b>             |                                     |                                     |                                     |                                     |                               |
| <b>Event Naming Rights</b>             | "Presented By"                      |                                     |                                     |                                     |                               |
| <b>Registration Page</b>               | Option to share contact information | Option to share contact information | Option to share contact information | Option to share contact information |                               |
| <b>Pre-Event Emails</b>                | "Presented By" & Logo               | Logo/Link                           | Logo                                | Logo                                | Logo                          |
| <b>Media Announcements</b>             | "Presented By"                      | Name                                | Name                                |                                     |                               |
| <b>Press Release/ Calendar Listing</b> | ✓                                   | ✓                                   | ✓                                   | ✓                                   | ✓                             |
| <b>SBANENY Website</b>                 | Logo 100%                           | Logo 80%                            | Logo 60%                            | Logo 40%                            | Logo 20%                      |
| <b>Event Website</b>                   | Logo 100%                           | Logo 80%                            | Logo 60%                            | Logo 40%                            | Logo 20%                      |
| <b>Community Posters</b>               | "Presented by" & Logo               | Logo                                | Logo                                | Logo                                | Name                          |
| <b>Social Media Event Page</b>         | "Presented by"                      | Name & Link                         | Name & Link                         | Name                                | Name                          |
| <b>Event Benefits</b>                  |                                     |                                     |                                     |                                     |                               |
| <b>Social Media</b>                    | Day of speaking opportunity         | Day of speaking opportunity         | Day of speaking opportunity         | Day of speaking opportunity         |                               |
| <b>Event Announcements</b>             | "Presented by"                      | Name & Link                         | Name & Link                         | Name & Link                         | Name                          |
| <b>T-Shirt</b>                         | "Presented By" & Logo               | Logo 60%                            | Logo 40%                            | Logo 20%                            | Name                          |
| <b>Post-Event Benefits</b>             |                                     |                                     |                                     |                                     |                               |
| <b>Newsletter Ad</b>                   | 1 full page ad 1 edition            | 1/2 page ad 1 edition               | 1/4 page ad 1 edition               | Logo                                | Name                          |
| <b>Social Media</b>                    | "Presented By"                      | Name & Logo x3                      | Name & Logo x2                      | Name & Logo                         | Name                          |
| <b>Thank you letters</b>               | "Presented By"                      | Logo                                | Logo                                | Logo                                | Name                          |



# Dare to Dream with SBANENY

## Virtual Gala

Online Silent Auction, Live Auction & Entertainment

November 21, 2020

6:00 PM



### Individual & Corporate Sponsorship Levels

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

- Acknowledgement the night of the event with the opportunity to speak
- Full-page color ad, on inside or back cover of event program and in one SBANENY newsletter
- Logo and listing, with a link to your website, on SBANENY website & 4 Facebook posts
- Logo placed on 10 slides during the event presentation
- Inclusion in media announcements
- Acknowledgement in event press releases
- Inclusion in all donor thank you letters
- Ten complimentary tickets

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

- Acknowledgement the night of the event with an opportunity to speak
- Full-page ad in event program and in one SBANENY newsletter
- Logo and listing, with a link to your website, on SBANENY website & 2 Facebook posts
- Logo placed on 5 slides during the event presentation
- Inclusion in media announcements
- Acknowledgement in event press releases
- Inclusion in all donor thank you letters
- Ten complimentary tickets

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

- Acknowledgement the night of the event
- Half-page ad in event program & in one SBANENY newsletter
- Logo listed on SBANENY website & 1 Facebook post
- Logo placed on 2 slides during the event presentation
- Inclusion in all donor thank you letters
- Four complimentary tickets.

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

- Acknowledgement the night of the event
- Quarter-page ad in event program and name listed in one SBANENY newsletter
- Name listed on SBANENY website & 1 Facebook post
- 2 complimentary tickets.

#### **Honorary Committee**

##### **\$275 Two Star Honorary Committee**

- Two complimentary event tickets
- Listing on website and event materials

##### **\$150 Shining Star Honorary Committee**

- One complimentary event ticket
- Listing on website and event materials

#### **Event Program Advertisements**

- \$400** Full page ad
- \$250** Half page ad
- \$125** Quarter page ad
- \$ 50** Eighth page ad

For additional information contact:  
Julia Duff 518-399-9151 or [admin@sbaneny.org](mailto:admin@sbaneny.org)

# NEWS TO USE

## National Disability Institute (NDI)

- In response to COVID-19, NDI created the [Financial Resilience Center](#) (FRC). The FRC answers frequently asked questions about COVID-19 Economic Impact Payments; Employment and Unemployment; Public Benefits; Housing, Food, and Healthcare; Money Management; Scams; and more.
- [#ResilientPwD](#) is a text messaging campaign to deliver information, tips and interventions to people with disabilities and chronic health conditions. Texts are sent two times per week for six months and are intended to help combat stress and feelings of isolation, build positive thinking and establish new behavior patterns that promote emotional well-being and financial resilience.

## Independent Living Center of the Hudson Valley (ILCHV)

- **Virtual Pilates**— Join the ILCHV for a 6-week seated Pilates based movement class starting August 19th at 5:00pm. Each class is 45 minutes and will be hosted by Liz Ann Kudrna, a certified Pilates instructor who uses a wheelchair. Liz is committed to giving individuals a workout tailored to their own fitness level and goals. The classes are free. You must have the capacity to connect via zoom to participate. *To register, call Barbara Devore at 518-274-0701 or email her at: [bdevore@ilchv.org](mailto:bdevore@ilchv.org).*

## ProActive Caring

- Teaching Mindfulness to Support Family Members of Persons with Disabilities. Access the free e-manual for stress reduction [here](#).

## Your Dream Your Team

- A [new website](#) supporting job seekers with disabilities has been launched. The website is designed for multiple audiences, including youth with disabilities pursuing employment, as well as the people and organizations who support them.

## SNAP COVID-19 Information

Parents of a child receiving Medicaid (including waivers) are eligible for the P-EBT food benefits, even if they did not previously receive food stamps. To access your P-EBT food benefits you will need to select a PIN number over the phone by calling the following toll-free number:

1-888-328-6399. For more information visit the [website](#).

## Office for People with Developmental Disabilities (OPWDD)

- COVID-19 Guidance:
  - [Day Services](#)
  - [Home Visits](#)
  - [Return to Residence Following an Extended Stay](#)
  - [Community Outings](#)

## Families Together/Youth Power!

- [Virtual Youth Leadership Forum](#), August 12-14 & 17-19, 2020 via Zoom. This FREE 6-day event (2.5 hours a day) is for young people ages 14-24 to speak up, build leadership and self-advocacy skills, and prepare to take on leadership roles. Learn about:
  - Leadership & Communication Skills; Systems and Grassroots Advocacy; Strategic Sharing/Disability Disclosure; Disability History, Rights and Pride; Resources to Reach YOUR Goals; Financial Literacy and Living on my own/ILCs

## Dance for All Bodies

- Dance for All Bodies offers adaptive dance classes. Due to COVID-19, they are now providing virtual dance classes on Zoom. A schedule of classes can be found by visiting their [website](#).

## Angel City Virtual Games

- The 2020 [Angel City Virtual Games](#) mirrors all components the physical Games would have showcased: sport clinics & competitive opportunities, special events and community building. The Virtual Games will last 4 weeks as opposed to 4 days and there is still time to register for the second and third weeks starting 8/3/2020 and 8/24/2020.

## Lead Center Quarterly Newsletter

- Read the full newsletter [here](#) to learn about the 30th anniversary of the Americans with Disabilities Act (ADA), Medicaid Buy-In, financial empowerment and resiliency webinars, addressing barriers to employment and more.

# RESOURCES

## COVID-19 Related Resources

- ⇒ [Spina Bifida Resource Network: COVID-19 Resources: Some Financial Tips](#)
  - ⇒ Credit Card Debt
  - ⇒ If you receive your Stimulus Payment as a prepaid debit card
  - ⇒ ABLE Accounts and Stimulus Payments
- ⇒ [Assessing Racial and Ethnic Disparities Using a COVID-19 Outcomes Continuum for New York State](#)
- ⇒ [American Association on Health and Disability \(AAHD\) Resources for people with Disabilities](#)
- ⇒ [Talking to Teens about COVID-19](#)
- ⇒ [Five Things About Staying Mentally Healthy During the COVID-19 Outbreak.](#)
- ⇒ [Employees: How to Cope with Job Stress and Build Resilience During the COVID-19 Pandemic](#)

## Spina Bifida Association

[Spina Bifida Association Update on COVID-19 – July 2020](#)

[Spina Bifida Association Education Days](#)

- CHARLESTON, SC – 8/8/2020
- SEATTLE, WA – 10/3/2020
- LANSING, MI – 10/17/2020
- KANSAS CITY, MO – 10/24/2020

[SB-You Webinars](#)

- [Do you need a special needs trust?](#)

VOLUNTEER OF THE YEAR AWARD  
Congratulations Lyndsi!

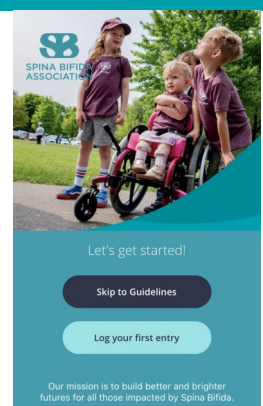


## The Spina Bifida Association Mobile App is now available!

Now you can have the Guidelines for the Care of People with Spina Bifida and Symptom Tracker in the palm of your hands!

This App is free and features an interactive way to view all 24 Guidelines and a symptom tracker for you to track your health to share with your physicians at an upcoming appointment.

- Click [HERE](#) to download on an Apple device.
- Click [HERE](#) to download on an Android device.





# SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK

## ABOUT SBANENY

*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!

*Virtual Walk-N-Roll & 5K*  
September 5th, 2020

*Eric Crow Memorial Golf Tournament*  
October 3, 2020

*Dare to Dream with SBANENY, Virtual Gala*  
November 21, 2020



**Become a sponsor, donate or register to  
attend today at [sbaneny.org](http://sbaneny.org)!**

## JOIN THE TEAM!

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

### COMMITTEE MEETINGS

- Dare to Dream**— July 27, 2020
- Walk-N-Roll**— July 27, 2020
- Fundraising and Marketing**—August 3, 2020
- Governance** - August 10, 2020
- Board of Directors**— September 12, 2020

### COMMITTEES TO JOIN

- Conference
- Dare to Dream
- Walk-N-Roll & 5K
- Direct Mail Campaign
- Advocacy

## ESTATE PLANNING MEMORIALS & HONORARIUMS

*Have you considered including SBANENY in your estate plans?*

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