



SBANENY News to Use

WELCOME LETTER

I hope that our newsletter finds everyone staying safe and healthy! The recent months have been a bit of a learning curve for most of us; learning to work from home, teaching from home, taking classes from home. As a society we are generally not adapted to being home. I hope that you have taken some time to reflect upon your life and make adjustments where necessary. I also hope that you have spent your time doing some fun activities with your family!

SBANENY is still moving forward and we too had to make a few adjustments. Just so you know we have transitioned our support services to virtual. So if you need us, please do not hesitate to reach out via email, phone for Facebook. We will certainly get right back to you.

SBANENY has made adjustments to our spring calendar but one event we were able to host for the first time was a young family pool party on March 8th. Thank you to Goldfish Swim in Colonie for sponsoring the event. Check out pictures from the fun day inside!

We also had to make a few changes to our Walk-N-Roll & 5K that was scheduled for May 16, 2020. We will be having a Virtual Walk-N-Roll & 5K on May 16th, so please make sure you register for this event. You can go to www.sbaneny.org to register yourself or your team. There is no cost for this event. Make sure your phone is charged so you can share some great photos as you are out walking, rolling and running. Also...you will not want to miss out on the great prizes we have in store for you.

We will be having our Walk-N-Roll & 5K at Central Park in Schenectady on September 5, 2020. You can register for that event as well; the individual Walk-N-Roll registration fee is \$5 and 5K registration fee is \$20. Walk-N-Roll T-Shirts will be available for those who raise \$100 or more. We will be enjoying another great day together with breakfast, Zumba, walking, rolling, racing, lunch and an ice cream social. I look forward to seeing everyone in person on September 5, 2020!

Lastly, the new event we added to our calendar last year was the Car Show at Morris Ford in Burnt Hills, NY. We are going to be having this event once again this year, but we are moving the date from June to July. It was decided that it would be best to go one more month out, giving extra time to make sure the environment is ready for a gathering of friends and their cool cars.

I hope everyone is staying safe and healthy. 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.

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APRIL 2020

SBANENY UPDATE

VIRTUAL WALK-N-ROLL & 5K

COVID-19
RESOURCES

NEWS TO USE

EVENTS CALENDAR

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
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Jessica Ryder
Joe Slaninka

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Julia Duff

SBANENY UPDATES

SBANENY VIRTUAL SERVICES

SBANENY is closely monitoring Coronavirus (COVID-19) developments and modifying our services to comply with state directives and support individuals and families at home. See below for service updates to support people living with Spina Bifida, their families and service providers.

Telephone Support

We know this is confusing, challenging and isolating. Call SBANENY at 518-399-9151 if you need someone to talk to.

Social Media

SBANENY will continue to share informational updates on Facebook and Instagram. New on Facebook:

- * Weekly themes:
Monday—Community Conversations
Wednesday—at home wellness opportunities
- * New private individual and family Facebook group:
www.facebook.com/groups/682622139220749/



Virtual Programs

Through Zoom, SBANENY is facilitating educational webinars, information sessions and casual hangouts. **Upcoming:** Two educational webinars; one for parents of school age children and one for teens and young adults, both facilitated by Julie Yindra and sponsored by SBANENY.

* **Wednesday, 4/22/2020 at 6:00PM: How can I help my child with Spina Bifida learn at home?** This is for parents of school-age children to better understand the typical learning profile and challenges for children with Spina Bifida and the ways in which online learning may be particularly difficult for these students.

* **Wednesday, 4/29/2020 at 6:00PM: Taking Charge of my Learning in a Virtual Platform:** This is for high school and college level students with Spina Bifida to learn to cope effectively with the new challenges of online learning. Understanding executive function challenges and how online learning can often compound these challenges will be emphasized.

* **Register by contacting SBANENY!**

* SBANENY is hosting our first virtual session for **the adult Spina Bifida community on Thursday, 4/23 at 6:00 PM.**

E-News: SBANENY is keeping the community updated on the changing status of NYS and Federal programs, benefits and services through regular email news.

SBANENY will continue to keep you informed to the best of our ability regarding the impact of COVID-19 on the Spina Bifida community.

Please refer to the CDC and NYSDOH websites for the most recent updates and information on prevention, protections and managing stress and anxiety.

<https://www.cdc.gov/coronavirus/2019-ncov/>

<https://coronavirus.health.ny.gov/home>



SBANENY Conference— POSTPONED

The SBANENY Conference scheduled for Saturday May 30th-31st at the SUNY School of Public Health is postponed due to social distancing and updates with the venue. The conference committee is working on finalizing event details and plan for the Conference will take place in the spring of 2021. *Sorry for any inconvenience this may have caused, and I appreciate your flexibility and understanding during this time.*

ADVOCACY REPORT

For three weeks, SBANENY staff, interns and consumer advocates met with 17 Assembly members and 11 Senators to discuss what Spina Bifida is, the experiences of individuals living with Spina Bifida and parents of individuals with Spina Bifida, the way SBANENY supports and serves the Spina Bifida community and steps New York State can take to enhance the lives of people impacted by Spina Bifida.

KEY POINTS IN MEETINGS

- The impact of Spina Bifida depends on the type, location on the spine, size of the opening and in-utero experience. Generally, Spina Bifida impacts a person's ability to get around, socialize, learn and live independently.
- People with Spina Bifida have unique experiences and SBANENY houses the expertise to respond to a broad range of requests for services, provide systems navigation, advocate and offer programs.
- SBANENY is the only affiliate chapter of the Spina Bifida Association in New York State. As a result, we respond to requests for services and invite consumers to participate in programming statewide.

SBANENY has annually requested funding from New York State to improve our ability to provide support services and respond to a statewide need. **Because of all of the individuals who were dedicated to the SBANENY mission: the representatives who championed our cause, consumers and friends of the community who wrote letters and made phone calls, and advocates who joined our meetings throughout the years, SBANENY has been included in the budget for the first time!**

Thank you to everyone who participated in our advocacy efforts. Thank you to the representatives who took the time to learn about Spina Bifida, SBANENY, and demonstrated your support for our request!

POOL PARTY!

Thank you Golf Fish Swim for hosting our young family pool party on March 8th!



SBANENY Walk-N-Roll & 5K UPDATE

VIRTUAL Walk-N-Roll & 5K Saturday May 16th 2020

SBANENY has postponed our annual Walk-N-Roll for Spina Bifida® & 5K that was scheduled to take place in Central Park, Schenectady on May 16, 2020 to September 5, 2020. However, we know the Walk-N-Roll is an important celebration of the Spina Bifida community. The Walk-N-Roll & 5K does raise critical funds for SBANENY but it is the networking, support, awareness and connections that make this event so important.

Therefore, on May 16th SBANENY will be hosting a Virtual Walk-N-Roll & 5K so that during a time of social distancing, the Spina Bifida community can still come together.



• CONTESTS AND PRIZES

- **TEAM WHO RAISES THE MOST MONEY: SBANENY BASKET**
- **INDIVIDUAL WHO RAISES THE MOST MONEY: \$25 GIFT CARD**
- **SPIRIT: INDIVIDUAL OR TEAM (SOCIAL MEDIA CONTEST POSTED IN THE FACEBOOK EVENT): 2 FREE ENTRIES TO THE 2021 EVENT**
- Individuals who raise \$100 will receive a Walk-N-Roll T-Shirt (2019 shirts available to be shipped immediately, 2020 shirts available to be shipped in the summer).

Anyone can participate in the Virtual Walk-N-Roll & 5K! Have relatives or friends who have not been able to join you in the past? This is the event for them! Registration is **FREE**. Team captains can still create and register teams but, we are asking you do not participate as a team and follow social distancing protocols. For registration instructions and sponsor opportunities visit www.sbaneny.org.

- 5K participants competing are required to provide a GPS screenshot of their course to the google form. 5K participants must complete their run/roll between 5/15/2020-5/17/2020 and must submit their times by Tuesday May 19th to be considered for top time contests.
- 5K Prep: Visit www.facebook.com/SBANENY for the 6 week training program.
- STRAVA: Join SBANENY's new prep group through Strava, a social media and tracking app for active individuals! <https://www.strava.com/clubs/sbaneny-5k-prep-club-584763>

Sign up today! <https://runsignup.com/Race/NY/Schenectady/VIRTUALWALKNROLL5K>

Share it on social media: <https://www.facebook.com/events/212055086793712/>

We hope to see you in person on September 5th!



CORONAVIRUS (COVID-19) RESOURCES

General – Comprehensive Resources Covering Multiple Areas of Concern/Interest

SPINA BIFIDA ASSOCIATION (SBA): COVID-19 Guidance for People Living with Spina Bifida: Resources Specifically for the Spina Bifida Community. Topics include: Spina Bifida & COVID-19, Mental Health, Health and Hygiene, Helping Children Understand COVID-19 and School Closings, and Managing Emotions: <https://www.spinabifidaassociation.org/covid19/>

ADMINISTRATION FOR COMMUNITY LIVING (ACL): Caregivers, Education Guidance, Insurance and Waivers, Telehealth, DSP's, Long-Term Care, Isolation and Caregiver Resources: <https://acl.gov/COVID-19>

ROSE F. KENNEDY CHILDREN'S EVALUATION AND REHABILITATION CENTER: Food, Education, Youth, Health and Hygiene, Housing, Employment, Mental Health and Multilingual Resources: https://mcusercontent.com/b5ba8e60a1cc093a382200353/files/a9bcf499-f0e7-4f73-a755-01cb8974160e/RFK_CERC_COVID_19_Resource_Guide_04_10_20_1_.pdf

LIVE ON NY: Nutrition, Insurance, Mental Health, General Resources: <https://www.liveon-ny.org/covid-19>

Health

NYS DEPARTMENT OF HEALTH

UPDATES FOR NYS PERTAINING TO COVID-19: What You Need to Know, Symptoms and Prevention, Knowing Your Rights (Paid Sick Leave, Unemployment, Insurance): <https://coronavirus.health.ny.gov/home>

COVID-19 GUIDANCE FOR HOSPITAL OPERATORS REGARDING VISITATION: https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf

GUIDANCE FOR RESIDENT AND FAMILY COMMUNICATION IN ADULT CARE FACILITIES (ACFs) AND NURSING HOMES (NHs): https://opwdd.ny.gov/system/files/documents/2020/04/4.10.2020-doh_covid19_acf-nh_residentfamilycommunication.pdf

CENTERS FOR DISEASE CONTROL AND PREVENTION: How to Protect Yourself, What to do if you are sick, Tips for Coping and Stress: <https://www.cdc.gov/coronavirus/2019-nCoV/>

HYDROCEPHALUS ASSOCIATION: Hydrocephalus Association's Medical Advisory Board provided recommendations regarding COVID-19 for patients with Hydrocephalus: <https://www.hydroassoc.org/covid-19/>

NATIONAL HEALTH COUNCIL: Avoiding Discrimination While Treating COVID-19: <https://nationalhealthcouncil.org/avoiding-discrimination-while-treating-covid-19/>

SEE ALSO: General Resources

Office for People with Developmental Disabilities

COVID-19 IN PLAIN LANGUAGE: opwdd.ny.gov/system/files/documents/2020/04/covid-19-flyer.pdf

OPWDD GUIDANCE FOR PROVIDERS AND FAMILIES: Hospital Visitation, Residential Services, Day Services: <https://opwdd.ny.gov/coronavirus-guidance>

TELEHEALTH: <https://opwdd.ny.gov/system/files/documents/2020/04/4.14.2020-updated-opwdd-telehealth-guidance-from-4.9-with-revisions-shown.pdf>

Education

NEW YORK STATE EDUCATION DEPARTMENT: Education Guidance & Learning Resources for P-12 schools, colleges and universities, licensed professionals, adult education programs, and NYSED employees: <http://www.nysed.gov/coronavirus>

SEE ALSO: General Resources

CORONAVIRUS (COVID-19)

RESOURCES CONTINUED

Financial Support

NATIONAL DISABILITY INSTITUTE: Promoting Financial Health and Resiliency for People with Disabilities and Their Families During the COVID-19 Pandemic: <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/03/financial-resiliency-tips.pdf>

NY ALLIANCE: https://nyalliance.org/Financial_Resources

ECONOMIC IMPACT PAYMENTS: <https://www.irs.gov/newsroom/supplemental-security-income-recipients-will-receive-automatic-economic-impact-payments-step-follows-work-between-treasury-irs-social-security-administration>

Employment

U.S. DEPARTMENT OF LABOR: Workplace Safety, Wages, Hours and Leave, Unemployment Insurance Flexibilities, Support for Dislocated Workers and States: <https://www.dol.gov/coronavirus>

DISABILITY WORKFORCE GPS: Coronavirus (COVID-19) and Other Disability Focused Federal Resources: <https://disability.workforcegps.org/resources/2020/03/18/19/05/Coronavirus-and-Other-Disability-Focus-Federal-Resources>

Benefits and Insurance Programs

COVID-19 AND SOCIAL INSURANCE AND BENEFITS PROGRAMS: SSI, SSDI, SNAP, HUD, Medicaid, Medicare, TANF, Unemployment Insurance: <https://www.nyaprs.org/e-news-bulletins/2020/4/6/cornell-on-covid-19-and-social-insurance-and-benefit-programs>

SEE ALSO: General Resources, Employment

Mental Health

NEW YORK STATE OFFICE OF MENTAL HEALTH: Public Resources for Managing Anxiety: <https://omh.ny.gov/omhweb/covid-19-resources.html>

HEADSPACE: Headspace is science-backed meditation and mindfulness. Headspace is providing a special New York collection of meditation, sleep, and movement exercises to support you through stressful and challenging times: <https://www.headspace.com/ny>

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION: Tips for Social Distancing, Quarantine, and Isolation During an Infectious Outbreak: <https://www.samhsa.gov/sites/default/files/tips-social-distancing-quarantine-isolation-031620.pdf>

SEE ALSO: General Resources

At-Home Activities

NYS KIDS ROOM: https://www.dos.ny.gov/kids_room/508/fun2.html

CALIFORNIA STATE COUNCIL ON DEVELOPMENTAL DISABILITIES: Ideas for Activities While Sheltering in Place: <https://scdd.ca.gov/wp-content/uploads/sites/33/2020/03/ENG-FINAL-Activities-While-Sheltering-In-Place-3-18-2020-rev-2..pdf>

KIDS OUT AND ABOUT: <https://rochester.kidsoutandabout.com/content/250-creative-ways-keep-your-family-sane-during-covid-19-crisis>

101 MOBILITY: 101 offers instructional videos for individuals using a wheelchair. Yoga can help promote mental clarity and focus, as well as reduce stress, tension and anxiety: <https://101mobility.com/blog/wheelchairyoga/>

NEWS TO USE

STUDY: Gynecological and Reproductive Health for Women with Physical Disabilities.

From Natalie Jenkins: Research Coordinator from NYU Langone Health – Rusk Rehabilitation.

This study is seeking women with physical disabilities to take part in online surveys about their personal experiences with periods, pelvic exams, pregnancy, and communication with health care providers.

- There are five separate surveys; the time needed to participate will depend on the number of topics each woman is eligible for.
- Each survey will take approximately 10-15 minutes.
- \$10 will be given for each survey completed.



Women's Health and Disability Study

RUSK RESEARCH

Participants Needed

You may be eligible to participate if you are:

- ✓ Between 18-50 years old
- ✓ Have a physical disability

Not sure if you qualify for this project?

- Contact our team and we will be happy to discuss any questions or concerns.
- Our team can screen you in person or over the phone.

Study participation consists of:

- An initial screening phone call that takes about 5-10 minutes
- Surveys via email about experiences related to gynecological and reproductive health issues

For more information, please contact our study coordinator, Natalie Jenkins, at:

☎ 646-501-7759 or 347-638-3644
@Natalie.Jenkins@nyulangone.org

All information collected will remain confidential
Compensation available



Text4Caregivers
by Parent to Parent.

Caring for a special needs child can feel overwhelming at times, leaving little or no time for the caregiver. Parent to Parent of NYS, with funding from the Developmental Disabilities Planning Council, has created a free support service that will distribute timely and relevant self-care and stress-management support through text messaging. As a caregiver, you take care of others; this service exists to remind you to take care of you. Available in English and Spanish, the goal of Text4caregivers is to offer special need caregivers easy access to a wide variety of information and resources. Sign up today:

<https://platform.trumpia.com/onlineSignup/ddpctext/text4caregivers> (ENG)
<https://platform.trumpia.com/onlineSignup/ddpctext/spanish> (ESP).



JUDITH HEUMANN

American Disability Rights Activist, One of TIME's 100 Women of the Year list of the most influential women of the past century, Author of memoir Being Heumann, and featured in "Crip Camp."

Check her out on The Daily Show with Trevor Noah: Defying Obstacles in "Being Heumann" and "Crip Camp"- The Daily Show : <https://www.youtube.com/watch?v=ybcQbpSVo3c>

Be sure to check out Crip Camp: A Disability Revolution now streaming on Netflix. A groundbreaking summer camp galvanizes a group of teens with disabilities to help build a movement, forging a new path toward greater equality.

Due to COVID-19, Double H Ranch made the difficult decision to suspend the traditional Summer Residential Camp for 2020.

They will be hosting summer camp ONLINE.

More information will follow. We are sorry to all the campers who cannot attend this year. We hope we will be able to return for our Fall Family weekend!





**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

123 Saratoga Road
Scotia, NY 12302

RETURN SERVICE REQUESTED

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***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.



**Become a sponsor, plan to attend,
or donate at sbaneny.org.**

ABOUT SBANENY

Our purpose is

Support

Health & Wellness

Awareness

Respect & Dignity

Empowerment

UPCOMING EVENTS

VIRTUAL WALK-N-ROLL & 5K

May 16th, 2020

SBANENY Car Show

July, 2020

WALK-N-ROLL & 5K

September 5th, 2020

Central Park, Schenectady, NY

Eric Crow Memorial Golf Tournament

October 3, 2020

Eagle Crest Golf Club, Clifton Park,
NY

COMMITTEE MEETINGS

Dare to Dream— May 13, 2020

Walk-N-Roll— May 18, 2020

Board of Directors— 5/19/2020

COMMITTEES TO JOIN

Board Development

Business and Finance

Conference

Dare to Dream

Walk-N-Roll & 5K

Direct Mail Campaign

FOR MORE INFO:

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Call us toll free: 855-722-6369

VISIT OUR WEBSITE —

FIND US ON SOCIAL MEDIA!

Website: sbaneny.org

Facebook: [/SBANENY](https://www.facebook.com/SBANENY)

Instagram: [/spinabifidaassoc_neny](https://www.instagram.com/spinabifidaassoc_neny)