



Hello,

I hope your summer is off to a great start!

Happy Independence Day, America! You're beautiful!

SBANYS enjoyed a productive spring with two Walk-N-Roll events in Schenectady and Long Island. We were able to raise critical funds that will indeed be put to good use in assisting those affected by Spina Bifida in New York State.

As the summer rolls on, we celebrate Disability Pride in July! We commemorate the signing of the Americans with Disabilities Act of 1990, prohibiting discrimination against people with disabilities in employment, transportation, education, public accommodations and access to government programs and services. On July 26th, we invite you to join our celebration by attending TRAIID on the Trails in Syracuse. The event features food and music whilst you learn about community resources geared towards healthy living and inclusive recreation. The celebration continues with the SBANYS Education Day on Saturday and Sunday. This is an opportunity to receive education updates in healthcare, advocacy, housing, recreation, and mental health.

We have other exciting programs coming up including our first time participating in the Disability Pride Parade. SBANYS will be tabling and marching at the Resource Center for Accessible Living's 2nd Annual Disability Awareness Parade on July 20th in Kingston. We continue to offer our virtual adult group on the 4th Tuesday of the month via Zoom at 6:00pm. This August, we have two events including a night at the ballpark on Thursday, August 1st where attendees can cheer on the Tri-City Valley Cats. We also are going sailing with Y-Knot Adaptive Sailing at Camp Chingachgook on August 11th!

Please go to our newly formatted website at www.sbanys.org to learn more about these programs, other exciting things that SBANYS is doing, and how you can get involved to help those that are impacted by Spina Bifida in New York State.

Thank you for your continued support! Enjoy your summer!

Sincerely,

Joe Slaninka
SBANYS Board Chair

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 #98
JULY 2024

TRAIID ON THE TRAILS

EDUCATION DAY

DISABILITY PRIDE

SBANYS UPDATES

NEWS TO USE

WALK-N-ROLL RECAP

GET INVOLVED

SBANYS BOARD

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AMERICANS WITH DISABILITIES ACT ANNIVERSARY CELEBRATION

**TRAIID on the Trails meets Walk-N-Roll for Spina Bifida
A First Mile Challenge along the Erie Canalway**

What to Expect:

Enjoy local music and learn about community resources focused on healthy living and inclusive recreation. Join kids and families impacted by Spina Bifida and other disabilities from Central New York for a fun afternoon of inclusive outdoor recreation. Participants can test out various recreation opportunities, complete a 1-mile walk and roll, a family-style picnic, 50/50, and visiting with local vendors and service organizations.



Register Now!



**Friday, July, 26th, 2024
3:00–7:00pm**



Inner Harbor, Syracuse, NY



**REGISTER
HERE**



SPINA BIFIDA ASSOCIATION
OF NEW YORK STATE



Participation is free! Registration is required!

Spina Bifida Education Day

EMPOWERING MINDS & ENRICHING FUTURES



Collegian Hotel

1060 E Genessee St, Syracuse, NY, 13210

SCHEDULE:

SATURDAY, 7/27, 9:00AM-4:45PM

8:30AM: Registration

9:00AM: Welcome from SBANYS

9:15 AM: Neurosurgical Updates

10:15AM: Navigating Bladder Health with Spina Bifida

11:15AM: Mobility & Positioning

12:00PM: Bowel Management for Spina Bifida Patients

1:15-2:00PM: LUNCH AND VENDOR VISITS

2:00PM: Disability Rights Movement

3:00PM: Housing Rights and Resources

4:00PM: Adaptive Sports: Grassroots to the Peaks of Competition

SUNDAY, 7/28, 9:00AM-1:00PM

9:30AM - Spina Bifida Global Learning Collaborative

10:00AM - Safe Space CNY: The Canary and the Coalmine

11:15AM - Mental Health & Wellbeing Panel

\$20

REGISTRATION FEE

*Registration Deadline: 7/23/24

*Kids 12 and under attend free

*Childcare provided

**FOR INFORMATION ON REGISTERING, TRAVEL,
LODGE, AND FINANCIAL ASSISTANCE, VISIT:**

https://sbanys.org/gva_event/education-day/

JULY IS DISABILITY PRIDE MONTH!



Join one of the many celebrations taking place across New York State to commemorate the passing of the Americans with Disabilities Act in 1990. See below for a calendar of events and visit this Google Doc to sign up: https://docs.google.com/document/d/1e31dBMVwvFipyF3MXLjt21ztt_dhgg3/edit?usp=sharing&oid=109971787561304766459&rtpof=true&sd=true.

July 16th: Webinar: Great Lakes ADA Center: ADA 34th Anniversary Update! Time: 2:00pm.



July 17th: Webinar: Mid-Atlantic ADA Center: A Park for Everyone: Adaptive Initiatives at Patapsco Valley State Park. Time: 2:00pm.



July 20th: RCAL: 2nd Annual Disabilities Awareness Parade. Time: 11:00am. Location: 14 Thomas Street. Kingston, NY 12401. **SBANYS will be in attendance!**



July 22nd: ARISE: Proclamation at Oswego City Hall. Time: 7:00pm. Location: 13 West Oneida Street Oswego, NY 13126.



July 23rd: RCIL: Art and Music celebration for ADA. Time: 12:00-3:00pm. Location: 1607 Genesee St., Utica, NY



July 24th: Webinar: Demystifying Disability Inclusion: Celebrating the 34th Anniversary of the ADA. Time: 12:00pm-1:30pm EST.



July 25th: ARISE: ADA Celebration at Oswego Farmers Market. Time: 5:00-6:00pm. Location: West First St., Oswego, NY 13126.



July 25th: Webinar: Great Lakes ADA Center: ADA 34 Live! Participants will have the opportunity to answer questions on general ADA knowledge, the history of the ADA and noteworthy disability rights figures. Time: 2:00 pm.



July 26th: Disability Pride. Time: 2:00 - 6:00 PM EST. Location: 44 Prime St, Buffalo, NY.



July 26th: Access to Independence: ADA Celebration Event. Time: 1:00-4:00pm EST. Location: Suggett Park - 124 Access To Independence Groton Ave, Cortland, NY 13045



July 26th: Southern Adirondack Independent Living: Time: 11:30am - 1:30pm. Location: Aviation Mall - 578 Aviation Rd Ste 47, Queensbury, NY 12804.



July 26th: Self-Initiated Living Options (SILO): ADA Celebration. Time: 11:00 a.m.-2:30 p.m. Location: SILO office - 3253 Route 112 Ste 10, Medford, NY 11763



July 26th: ARISE: Celebrate the 34th anniversary of the ADA. Time: 11:00. Location: Syracuse City Hall – 233 E. Washington St.



July 26th: Western NY Independent Living Disability Pride Festival. Time: 2:00-6:00 p.m. Location: Canalside - 44 Prime St, Buffalo, NY 14202



July 26th: Center for Independence of the Disabled, NY: 34th ADA Anniversary discussion on disability inclusion and accessibility at the city and state level. Time: 1:00-3:00 pm. Location: Manhattan office (70w 38th Street, 3rd Fl) and via Zoom.



July 26th: ADA Anniversary Celebration. Time: 11:00am-2:30pm @ Morningside Park. W 122nd Street, BBQ Area 6, New York, NY 10025.



July 27th: Independent Living, Inc.: 34th Anniversary of the ADA. Walkway Over the Hudson. Time: 12—4:00 pm EST. Location: Hudson, Newburgh. 87 Haviland Road in Highland and 61 Parker Avenue in Poughkeepsie.



SBANYS Programs & News

UPCOMING SBANYS PROGRAMS

RCAL's 2nd Annual Disability Awareness Parade:

July 20th @ 10:00 am: SBANYS is marching in the Disability Awareness Parade to show our pride and raise awareness about Spina Bifida! If you want to join us, make sure to sign up soon and wear all your teal! We prioritize individuals living with Spina Bifida and their caregivers/family to walk/roll in the parade, but all are welcome to attend the parade. This is a free community event and is followed by a resource fair! https://sbanys.org/gva_event/rcals-2nd-annual-disability-awareness-parade/

Adult Group:

July 23th @ 6:00 pm: Adults living with Spina Bifida are invited to a monthly group held on Zoom to connect about their challenges, triumphs, and tribulations. From supporting each other's sorrows to celebrating each other's successes, this is the place to be! Join SBANYS on the fourth Tuesday of each month unless otherwise notified. https://sbanys.org/gva_event/adult-group/

Take Me Out to the Valley Cats Game:

August 1st @ 6:30 pm: All are welcome to join SBANYS at the Valley Cats Game for a night of baseball and fireworks! Purchase tickets at our group link while using the password: 30sbanys as some of the proceeds will come back to SBANYS. Tickets are \$14 a person and you will be sat right behind the Valley Cats dugout. https://sbanys.org/gva_event/take-me-out-to-the-valley-cats-game/

SBANYS Y-Knot Sailing Day:

August 11th @ 11:00 am: There is still time to register as a SAILOR for FREE adaptive sailing with Y-Knot Sailing at Camp Chingachgook! Join others in our community for a great day of sailing! Lunch is included by Y-Knot. Registration is first come first serve. https://sbanys.org/gva_event/adaptive-group-sailing/

SPINA BIFIDA ASSOCIATION
OF NEW YORK STATE

SAVE THE DATE

DARE TO DREAM GALA

Join us for an evening
featuring an auction,
dinner, and entertainment

Honorary Chair:
Stella Porter, WNYT

Hilton Garden Inn
235 Hoosick St, Troy, NY 12180

NOVEMBER 16TH, 2024

News to Use

ADVOCACY

Act Now to Protect Homecare Choices in New York: New York is planning to implement a single statewide fiscal intermediary by 10/1/24, which could place homecare in the hands of large businesses, limiting personal choice and potentially forcing people into nursing homes. Take action to prevent this from happening here: <https://www.protecthomecare.org/>.

Improving Access to Catheters: The Centers for Medicare and Medicaid Services (CMS) decided to increase insurance reimbursement codes for catheters from 3 to 6, enhancing the likelihood that insurance will cover the specific catheters prescribed by doctors. This decision follows advocacy by SBA and Independence Through Enhancement of Medicare and Medicaid (ITEM) Coalition. While SBA and ITEM Coalition had recommended increasing to 19 codes, this marks a significant step forward in improving access to medical supplies. Email Kathleen.watt@sbanys.org to receive a copy of the letter.

The Olmstead at 25: Protecting and Strengthening its Future: On June 22, 1999, the U.S. Supreme Court ruled in *Olmstead vs. L.C.* that people with disabilities must be able to live in the most integrated setting with community supports. The case was brought forth by Lois Curtis and Elaine Wilson, who were repeatedly institutionalized because they did not have adequate services to remain in the community in Georgia. A recording on this legislation can be viewed here: <https://www.youtube.com/watch?v=BCw5oC7OSTw>

BENEFITS

July 2024 Social Security Star: This edition emphasizes the importance of financial independence, with tools like the Social Security Statement and benefits estimator to aid in retirement planning; the top 5 ways to protect against identity theft; resources for individuals with limited English proficiency, including free interpreter services; defending against scams; introducing the Social Security Video Connect for conducting business; and reporting fraud, waste, or abuse against Social Security. Visit www.ssa.gov for more information and resources.

FINANCIAL RESOURCES

“Healthcare Workers for Our Future” Scholarship: This scholarship offers a two-year, full-ride scholarship to approximately 500 selected recipients, covering tuition, room, board, and related expenses at approved NYS public or private colleges or universities. Eligible fields of study include Registered Nurse, Respiratory Therapist, Clinical Laboratory Technologist, Radiologic Technology, and Surgical Technology. Funds are available for up to four semesters for full-time students and are adjusted for part-time students. Learn more here: <https://www.governor.ny.gov/programs/healthcare-workers-our-future-scholarship>.

HEALTH

Essential Summer Skin Care Tips for Individuals with Spina Bifida: This summer, it's crucial to take care of your skin to avoid breakdowns. Check for any redness that doesn't fade, black leathery areas, or generally unhealthy-looking skin. Prevention is key: avoid excessive pressure on your skin, maintain a balanced diet and hydration, control moisture, and act quickly if redness appears. For more tips on skin health and prevention, visit the Did You Look? Skin Integrity Bundle: <https://www.spinabifidaassociation.org/did-you-look/>.

Report on Improving the Diagnosis Experience: The National Council on Disability released a report highlighting challenges faced by people with disabilities in receiving unbiased and accurate information at diagnosis, with contributions from SBA President & CEO Sara Struwe. Key findings include the prevalence of bias among medical professionals during prenatal conversations and the lack of accurate information at diagnosis, often causing lasting trauma. Full report here: <https://www.ncd.gov/report/from-fetal-surgery-to-gene-editing-the-current-and-potential-impact-of-prenatal-interventions-on-people-with-disabilities/>.

INSURANCE

Free Assistance from Healthy Capital District: The Healthy Capital District offers free assistance to help individuals apply for free or low-cost health insurance, Medicaid programs, and connect to essential resources like food and transportation. This initiative aims to support community members in accessing the health

News to Use

and social services they need. For more information, visit: <https://www.healthycapitaldistrict.org/>

Medicaid Matters NY Tea Time Chat (2nd Tuesday of every month at 7:00 pm): Join the Tea Time Chat to share your experiences and connect with peers enrolled in Medicaid. A one-time Zoom registration will automatically add these monthly meetings to your calendar. <https://us02web.zoom.us/meeting/register/tZAldemsrTquG9XYIjYVXvrZMZU4niepNNbm#/registration>

SPINA BIFIDA ASSOCIATION

June What Is Happening: Find program recordings on Wheelchairs and Mobility, Men's Health Roundtable, Los planes IEP y la ley 504 para los estudiantes con espina bifida, options for advocacy and research! <https://mailchi.mp/sbaa/whatshappeningjune24>

July What Is Happening: Inside find upcoming programs and recordings with information on grief and coping, Urinary Incontinence and Adults with Spina Bifida, Medical Trauma, advocacy and research. <https://mailchi.mp/sbaa/whatshappeningjuly24-2142698>

RESEARCH

NYS Department of Health Releases New Report on Disability: This new report reveals that approximately 4.0 million adults (28.3%) in New York State live with a disability, with higher rates among females, those 65 and older and individuals with lower incomes, and highlights significant disparities among Hispanic and Black, non-Hispanic adults. Find more information here: https://www.health.ny.gov/statistics/brfss/reports/docs/2024-17_brfss_disability_status.pdf

Participate in MedStar's Probiotic Bladder Wash Study: MedStar National Rehabilitation Hospital in Washington, DC, is seeking participants for a research study to determine the optimal dosage of probiotic bladder wash to reduce urinary symptoms. For more information, email Christopher.R.Riegner@Medstar.net or call (202) 877-1560.

Participate in Penn State College of Medicine's Spina Bifida Clinic Research: Are you a healthcare professional with a Spina Bifida clinic? The Neurosurgery Department at Penn State College of Medicine is conducting research to understand how clinics handle the intake process for patients who do not speak or read English. Take a 5-minute survey to share the communication needs of the families and patients at your clinic. <https://redcap.ctsi.psu.edu/surveys/?s=33XYH94LERPMDNRE>

Participate in the Spina Bifida Sequencing Consortium: The Gleeson Lab at UC San Diego has expanded eligibility for their study to discover the developmental causes of Spina Bifida and explore new therapies. Individuals diagnosed with Spina Bifida (excluding Spina Bifida Occulta) or their parents are invited to participate by providing saliva samples, with participation from both biological parents preferred but not required. To enroll, fill out the form: <https://docs.google.com/forms/d/e/1FAIpQLSe13stoVNotxk0QquWRqLSDaolcJQkksOAmPPqSFykt9aNL6Q/viewform>

SAFETY



Summer Safety Tips
to Keep You & Your Family Safe

- LIFE JACKETS**
Wear a U.S. Coast Guard-approved life jacket when boating or during other recreational activities in or around water.
- LAKE SWIMMING**
Teach children that swimming in open water is different from a pool. Potential hazards can make open water more challenging.
- SUNSCREEN & LIP BALM**
Apply SPF 30 or higher for maximum protection.
- UV INDEX**
A high index number means greater risk of exposure to UV rays, which are strongest in spring and summer, 10am-4pm, and at higher elevations.
- BRIGHT SWIMSUITS**
Choose a color for your child's swimsuit that can easily be seen in water. Neon colors like neon orange or pink are easy to see.
- HYDRATION**
Hot summer temperatures can increase the risk of dehydration. Water is the best source!

ST PETERS HEALTH PARTNERS
A Member of Trinity Health

WALK-N-ROLL RECAP

Take a look back at our most successful Walk-N-Roll yet!



Participation: We had an incredible turnout with over 500 participants, including staff, families and community members, all coming together for a great cause.

Fundraising: Thanks to everyone's hard work and generosity, we raised a record-breaking \$61,000, which will go directly to supporting our community programs.

Activities: The event featured a lively mix of activities, from the walk itself to arts and crafts, a friends and family picnic, face painting, live music and a DJ that kept everyone energized! Thank you to our musical entertainers, The Chapters Rap with Steve Vaccaro in Long Island and DJ Brother Lou Roberts in Schenectady, and our picnic sponsors: Williston Park Rotary, Jersey Mikes, Subway, Felicos, Kevin Ryan & Gourmet Hot Dogs, Scotia Rotary, and Stewarts Ice Cream. Our face painters, Kirstin Knoblauch and Wayne Wizzo, also deserve a big thank you.

Community Impact: Beyond the funds raised, the event strengthened our community bonds and increased awareness of our initiatives.

SHOUT OUT TO THE TEAM WHO MADE THIS WEEKEND POSSIBLE!

Staff: Julia Duff, Kathleen Watt, Grace White, and Zach Garafalo

Interns: David Oliver, Angela Marra, and Francis Lee-Ciano

Board of Directors: Joe Slaninka, Shelley Miller, Jim Dunham, Jessica Murcin, Diane Skibinski, Andy White, Chris Darby-King, Dave Wentworth, Paul Lukasiewicz III, Abby Mundell, and Kevin Chamberlain

Committee Members: Crystal Hoey, Eddie Fletcher, Heather Horwedel, Jess Ryder, Joe Slaninka, Karen Navarro, Kerry Wallace, Lisa Dennis, Maleni Alvarez, Megan Nieckarz, Meghan Smith, Michelle Miller, David Oliver, Paul Lukasiewicz III, and Peggy Smith

Vendors Make a Difference: Thank you to our not-for-profit vendors: Center for Disability Services, Consumer Directed Choices, St. Catherine's Children Center, Living Resources, NYS Justice Center, Life Plan COO, Therapy Dogs International, Fidelis Care, and Double H Ranch.

We Have 2 More Walk-N-Rolls Coming Your Way! Register at www.sbanys.org!

- 7/26/2024: TRAIID on the Trails & Walk-N-Roll, Syracuse, NY
- 10/5/2024: Walk-N-Roll for Spina Bifida, Cluett Schantz Memorial Park, Milton, NY

Thank You for Walking and Rolling for Spina Bifida! We Hope to See You Later This Year or Again Next Year!



Thank you to our Titanium Walk-N-Roll Sponsors!

nationalgrid

THE DAILY
GAZETTE



SPINA BIFIDA ASSOCIATION
OF NEW YORK STATE

ABOUT SBANYS

Contact: info@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!

Disability Pride Parade

7/20/2024

Adult Group

7/23/2024

ADA Anniversary Events

7/26/2024-7/28/2024



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

Advocacy—8/14/2024

Walk-N-Roll— 7/15/2024

Dare to Dream — 7/22/2024

Governance— 7/16//2024

Board of Directors— 8/10/2024

COMMITTEES TO JOIN

Advisory Councils: Caregiver, Adult, Regional
Fundraising & Marketing

Dare to Dream

Walk-N-Roll

Advocacy

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.