



## SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK



### SBANENY Newsletter

#### WELCOME LETTER

Happy fall and Spina Bifida Awareness Month!

I hope you are easing into the cooler weather, returning to school, and enjoying fall activities! While our programs and events have taken a different form, I hope you were able to attend one of our virtual programs this summer or join us at one of our future programs this fall and winter.

October is Spina Bifida Awareness Month and SBANENY is hosting a variety of free wellness webinars on topics including urology, self-care, and adaptive fitness. Register to attend or access the recordings inside this newsletter. You will also find our healthy reminder checklists developed in collaboration with the National SBA to help support positive physical, mental, and social health for the Spina Bifida community. Find more information on our upcoming programs and awareness month initiatives inside!

SBANENY celebrated our 10<sup>th</sup> Annual Walk-N-Roll virtually on Saturday September 5<sup>th</sup> with online trivia, raffles, and contests. While we wish we could have celebrated in person, it was great to welcome teams and members of the community from across New York State who were newly able to participate this year.

The 3<sup>rd</sup> Annual Eric Crow Memorial Golf Tournament benefitting SBANENY took place October 3<sup>rd</sup> at Eagle Crest. SBANENY would like to share a huge thank you to Helen Eggenberger and family for planning and hosting this event and helping us pursue our mission to build a better and brighter future for all those impacted by Spina Bifida!

Save the date! SBANENY's annual Dare to Dream Gala is taking place virtually on Saturday November 21, at 6:00pm. The event includes an online auction kicking off November 1<sup>st</sup> through November 22<sup>nd</sup>. Saturday evening enjoy musical performances by Madison VanDenburg from American Idol, our You Make a Difference Award ceremony honoring Kim Hill, the Executive Director of the NYS Assembly Task Force for People with Disabilities, our featured auction items, and SBANENY updates.

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!

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 #83 OCTOBER 2020

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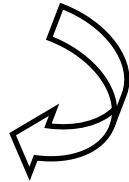
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# AWARENESS MONTH HIGHLIGHTS

## Urological Updates Webinar, 10/8/2020

Dr. Alex Rehfuß presented on urology protocol, continence practices, renal function, and the Spina Bifida clinic at Albany Medical Center. If you were unable to attend the webinar and would like to view the presentation you can access it [HERE](#).

## Self-Care Workshop, 10/13/2020

Time to relax, reset and recharge with our Self-Care Workshop presented by Shameka Andrews. Shameka presented on what is self-care and facilitated a conversation with our guests about what that means to you. Email [admin@sbaneny.org](mailto:admin@sbaneny.org) to access the slides.

## Office for People with Developmental Disabilities Webinar (OPWDD), 10/15/2020

Katie Tittlemore from OPWDD presents on available services, eligibility and answers questions from the community. You can access the recording [HERE](#).

## Americans with Disabilities Act (ADA) 30th Anniversary Panel, 10/19/2020

SBANENY and speakers Cliff Perez, Shameka Andrews, and Jim McDonald celebrated the 30th anniversary of the passing of the ADA by presenting to the SUNY Albany Learning from Alumni cohort discussing the history, passage, and legacy of the ADA. To watch the recording, visit this [LINK](#).

## Adaptive Fitness Presentation and Zumba Demo, 10/29/2020

Join Joe Slaninka and Lisa Dennis as they discuss adaptive fitness, athletics, and host a 15 minute Zumba session! Joe is an adult with Spina Bifida who is a wheelchair athlete and basketball coach. Lisa is an adult with Spina Bifida and a certified Zumba instructor since 1987. Register to attend at 5:00pm [HERE](#).

## Express Feedback for Good™

### A way to give without spending this Spina Bifida Awareness Month!

From now until October 28th you can give to SBANENY without spending simply by sharing your feedback on popular brands and companies!

### How does it work?



Text “SpinaBifida” or visit this [LINK](#) to sign up for FREE. Upon signup, select SBANENY and start giving feedback! Feedback isn’t a survey. It’s a quick hitting emoji-based review that only takes 60 seconds.

### How does SBANENY benefit?



For every eligible piece of feedback, \$2.00 is donated to SBANENY. Each person can provide feedback on up to 75 different brands and companies raising \$150.00. Collectively, we aim to raise \$5,000!

### How will funds raised be used?



This campaign is supporting virtual programs for people living with Spina Bifida and their families. SBANENY's programs connect individuals living with Spina Bifida to vital information, resources, and each other. You can help support these programs!



# ADULTS WITH SPINA BIFIDA

## HEALTH & WELLBEING CHECKLIST

### ARE YOU...

- ☐ Completing daily skin checks? Healthy skin = healthy you.
- ☐ Maintaining your continence routine?
- ☐ Tracking pain/concerning symptoms in the SBA Guidelines app?
- ☐ Moving for at least 30 minutes a day?
- ☐ Finding time for self-care?  
Meditate, journal, contact a mental health professional, call a friend, spend time outside
- ☐ Seeking resources and support?

### HAVE YOU...

- ☐ Rescheduled any cancelled non-emergency medical appointments?  
Annual testing considerations such as ultrasounds or other evaluations.
- ☐ Scheduled your in-person annual appointment with your urologist, neurosurgeon, physical therapist, etc?
- ☐ Requested individual or group support from the National SBA or your local SBA chapter?

### WHY IS THIS IMPORTANT?

- ☐ Recognizing how the pandemic could be affecting you could help you.
- ☐ Physical and mental health are intertwined - both need taking care of.
- ☐ So you can feel and be your best.

# PARENTS OF CHILDREN WITH SPINA BIFIDA

## HEALTH & WELLBEING CHECKLIST

### ARE YOU...

- ☐ Completing daily skin checks on your child?
- ☐ Maintaining your child's continence routine?
- ☐ Tracking pain/concerning symptoms in the SBA Guidelines app?
- ☐ And your child being active for at least 30 minutes a day?
- ☐ Finding time to take care of yourself?  
Meditate, journal, contact a mental health professional, call a friend, spend time outside
- ☐ Seeking needed resources and support?

### HAVE YOU...

- ☐ Rescheduled any cancelled non-emergency medical appointments?  
Annual testing considerations such as ultrasounds or other evaluations.
- ☐ Scheduled any in-person annual appointments with your child's urologist, neurosurgeon, physical therapist, etc.
- ☐ Requested individual or group support from the National SBA or your local SBA chapter?

### WHY IS THIS IMPORTANT?

- ☐ Recognizing how the pandemic could be affecting you and your child could help both of you.
- ☐ Physical and mental health are intertwined - both need taking care of.
- ☐ So you and your child can feel happy and healthy.

# Dare to Dream

with SBANENY

**SATURDAY**  
**NOVEMBER 21, 2020**  
**6:00PM**

Due to public health concerns, we are moving our Dare to Dream gala to a device near you! Join the Spina Bifida Association of Northeastern New York for our 8th Annual Dare to Dream Virtual Gala.

- \* **TICKETS:** \$10.00 per person. Registration is required to bid on our online auction and attend the evening gala.
- \* **AUCTION:** SBANENY is hosting an online auction from November 1, 2020 - November 22, 2020. A special category of our featured items will be available November 19, 2020 - November 22, 2020!
- \* **EVENING GALA:** Join SBANENY on the evening of November 21st for our gala including musical performances, recognition ceremonies and SBANENY and auction updates.

**Gala welcome and performance by American Idol top 3 finalist: Madison VanDenburg!**



Madison VanDenburg is an 18-year-old pop singer/ songwriter from upstate NY. Since her appearance on American Idol she has been featured on TV and performed in front of live audiences coast to coast, from the San Francisco 49ers' Levi's Stadium in Santa Clara to the Times Union Center in Albany, and in countless live stream sessions.

**SBANENY You Make a Difference Award  
Honoree: Kimberly Hill**



Kimberly Hill is a disability advocate and the Executive Director of the NYS Assembly Task Force on People with Disabilities. Kim has played a critical role in raising awareness for people living with disabilities in the NYS legislature and facilitates an annual Legislative Disabilities Awareness Day at the Legislative Office Building in Albany.

## Virtual Auction Details!

- \* Please do not register using the "Register" link on the BiddingOwl page. Visit this [LINK](#) to register!
- \* With Dare to Dream transitioning to virtual, please read the [event page](#) and [frequently asked questions](#).
- \* All bidding opens at 7:00pm (11/1 & 11/19) and closes on November 22, at 12:00pm.

**Thank you to the 2020 Dare to Dream Sponsors!**

Socha Management, The Daily Gazette, Mobility Works, PhRma, CBRE, 1st National Bank of Scotia, First NY FCU, Media Well Done and 180 Medical.

*Thank you to The Daily Gazette for your support of our annual events!*

# THE DAILY GAZETTE

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to SBANENY as you  
Dare to Dream  
for the consumers  
that you serve!”*



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# SBANENY Updates

**Virtual Programs**—Adult Group Tuesday October 27th at 5:30pm! Register [HERE](#)

**Social Welfare Intern**—This September SBANENY welcomed our new Social Welfare Intern, Conlee Deleonardis! Conlee is with us through May, 2020 and is helping support our individual and family services. For support, information and resources, referrals, programming or systems navigation, contact Conlee at [casemanager@sbaneny.org](mailto:casemanager@sbaneny.org) or by calling the SBANENY office!

**Legislative Resolution**—The New York State Senate and Assembly passed a resolution proclaiming October as Spina Bifida Awareness Month. Visit [HERE](#) to read the resolution. Limited copies available in the SBANENY office. Request yours by emailing [admin@sbaneny.org](mailto:admin@sbaneny.org)!

**CLYNK recognizes October as Spina Bifida Awareness Month!** Check out Sandi, Alyson and Zoe discussing how they use CLYNK to support SBANENY [HERE](#).

**Fall Family Weekend at the Double H Ranch**— Individuals living with Spina Bifida ages 5-21 years old are invited to attend the Spina Bifida Fall Family Weekend at Double H Ranch VIRTUALLY from 10/23-10/25. There is still time to sign up and attend. For more information visit this [LINK](#).



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# NEWS TO USE

## National Disability Institute (NDI)

- October is National Disability Employment Awareness Month and NDI has compiled a list of resources to use during the COVID-19 pandemic. The Career One Stop portal provides information on finding a new job, resume building, and unemployment assistance. Access the portal [HERE](#)
- If you are receiving benefits you may have questions about taxes. To learn more about how unemployment assistance affects your taxes click [HERE](#)

## Resources for Integrated Care

- Resources for Integrated Care will be offering a webinar that discusses non-opioid pain management, including effective, person-centered pain management options, challenges health plans and physicians face in providing chronic pain management and strategies for addressing pain management needs during the COVID pandemic.
- The webinar will be on November 10th from 2:30-3:30pm. You can register [HERE](#)

## UGG Universal Adaptive Footwear Line

- Popular shoe brand UGG has released it's first line of adaptive footwear, designed for individuals with disabilities. The new collection contains the same iconic UGG styles with double zippers, rear pull tabs, and toggle-adjusted shoe laces. Perfect for the winter weather that is approaching!
- Shop the warm and cozy collection [HERE](#)

## The Partnership on Employment & Accessible Technology (PEAT)

- PEAT posted a new episode of its Future of Work podcast series on "Accessibility Solutions for Employees." In this episode, Mike Hess, founder and executive director of the Blind Institute of Technology, discusses the positive impact of accessibility solutions on employers and employees.
- Listen to the podcast [HERE](#)

## Halloween Fun For Everyone with New York Life

- Halloween may look a little different this year, but there are plenty of safe and fun virtual options for you and

your family! New York Life will be hosting a virtual event with Story Pirates on 10/31! The Story Pirates is a nationally renowned group of top comedians, musicians, best-selling authors and incredible teachers with fifteen years of experience creating content that celebrates the imaginations of kids.

- New York Life will be offering showings 10/31 at the following times:
  - 10 am EST
  - 1 pm EST
  - 5 pm EST
  - 7 pm EST
- Click [HERE](#) to register and select a time slot

## Mental Health Association in New York State

- MHANYS will be hosting a webinar aiming to reduce stigmatizing attitudes and beliefs by promoting a comprehensive understanding of mental health, the importance of self care, treatment seeking behaviors, and hope for recovery. The webinar is taking place October 22nd from 12:00-1:00pm. Register [HERE](#).
- MHANYS will hold a webinar focusing on Mental Health in the workplace on November 17th from 10-11am. This webinar will reframe the conversation about mental health and talk about risk factors, interventions and resources. Click [HERE](#) to register.
- MHANYS School Mental Health Resource and Training Center, in consultation with State and National Experts, has put together a [series of resources around bullying prevention](#) in recognition of October as Bullying Prevention Month. Among the highlights including an [e-book](#) and an array of other resources.

## Books 4 the Disabled: Just Ask!

- Books 4 The Disabled did a reading of Supreme Court Justice Sonya Sotomayor's new children's book "Just Ask!" a story that teaches kids that it's okay to be different and when they come across kids who have differences they do not understand, all they have to do is ask!
- Listen to the reading [HERE](#)

# VOTER REGISTRATION INFORMATION

Election day is November 3rd! It's time to vote and make your voices heard. Keeping track of dates and deadlines can be confusing. Below is some useful information to help you this election year.

## Important Dates and Deadlines

- October 27th: Last day to apply online, by email, fax or to postmark an application or letter of application by mail for an absentee ballot
- November 2nd: Last day to apply IN-PERSON for absentee ballot.
- November 3rd: Last day to postmark ballot and deliver an in-person ballot. Must be received by the local board of elections no later than Nov. 10th. Military Voter Ballots must be received no later than Nov. 16th.

## Voter Registration Status

- Not sure if you are registered to vote? Use the registration tool from Vote.org to check! Simply input some information and it will tell you if you are registered to vote! Click [HERE](#) to access the site.

## Register to Vote

- The deadline to register and vote in this upcoming election was October 9th. However, if you would still like to register you can do it online by following the link [HERE](#). Registration is important and takes only a few minutes!
- Too young to register? You have to be 18 to register to vote, however you can take the pledge to register! Sign up [HERE](#) to receive voter registration info, reminders, and updates. You will also be reminded to register on your 18th birthday!

## Absentee Ballots

- To request an absentee ballot, click [here](#). The following deadlines apply to absentee ballots:
  - **In Person:** Received 1 day before Election Day.
  - **By Mail:** Postmarked 7 days before Election Day.
  - **Online:** Received 7 days before Election Day.

## Absentee Ballots cont.

- **Voted ballots are due:** Postmarked on Election Day and received 7 days after Election Day. Voted ballots can also be turned in by hand on election day.

## Election Day Reminders

- Keep track of all the important election season deadlines by registering for reminders [HERE](#)

## Polling Station Locators

- If you are planning on voting in person this year, click the link [HERE](#) to find the polling station closest to you! All polling stations will be adhering to COVID-19 and social distancing procedures, making it safe to vote.

## Information for People with Disabilities

- Every American has the right to vote. There are federal and state laws to protect your right to vote! The Office for People With Developmental Disabilities (OPWDD) is committed to ensuring that voter rights are upheld for everyone. OPWDD offers assistance with voter registration. If you or someone you know could benefit from voter registration assistance, contact the OPWDD National Voter Registration Act State Coordinator Mike Orzel at: 518-474-2757 or [mike.orzel@opwdd.ny.gov](mailto:mike.orzel@opwdd.ny.gov).
- For more information on OPWDD's assistance with the voter registration process click [HERE](#).





**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***

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## UPCOMING EVENTS!

*Virtual ADA 30th Anniversary Panel*

October 19, 2020

*Virtual Adaptive Fitness Workshop*

October 29, 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)!**

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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 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**— October 28, 2020

**Walk-N-Roll**— TBD

**Fundraising and Marketing**—November 9, 2020

**Governance** - November 5, 2020

**Board of Directors**— November 14, 2020

### ***COMMITTEES TO JOIN***

Conference

Dare to Dream

Walk-N-Roll

Direct Mail Campaign

Advocacy

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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.*