

families \* self-advocates \* friends

# dspgwny NEWS

May 2024

## UPCOMING EVENTS

### May 15 - Vicki Rubin Presentation



**BORNHAVA**  
Caregiver Workshop and Discussion Group Meeting  
In collaboration with the **dspgwny**

**Rescheduled and Now Location!**

**"Skills for Effective Advocacy"**  
Presented by Vicki Rubin, M.S. Ed.  
**AND a Light Dinner!**

Vicki Rubin, a local author and former BornHava Board Member, will present "Skills for Effective Advocacy". Vicki is a parent of an adult with special needs and author of *Being Jess: A Story of Hope*, "the powerful story of one family's survival when faced with adversity. Written with compassion, honesty, and humor, it tells of a family changed forever by the birth of a child with special needs, and their courageous decision to choose hope."

Vicki was the Manager of the Early Childhood Direction Center for Kinetics Health and Project Director of the Western New York State Education Department ECDC Program for 18 years before retiring.

If you would like to read her book, it is available on Amazon... and, BornHava has a few copies to lend!! If you would like to borrow a copy, please send Ann an email at [ann@bornhava.com](mailto:ann@bornhava.com) or, if in a BornHava program, a private Facebook message to Ann.

**Seating is limited to 35!**

**Wednesday, May 15, 2024**  
**6:00 p.m. to 8:00 p.m.**

**NEW LOCATION: Harlem Road Community Center, Classroom 1**  
**4255 Harlem Rd, Amherst, NY 14226**

The BornHava Caregiver Workshop and Discussion group is facilitated by Ann Lindrum-Capka, LGSW, the BornHava Licensed Clinical Social Worker. Attendance at every meeting is NOT mandatory. If you have any questions about this meeting, please contact Ann at BornHava (716-839-1805) or 303. REGISTRATION IS REQUIRED. This meeting is being held in collaboration with the DSPGWNy. If attending, please respect confidentiality and privacy of discussions that occur at these meetings. This meeting is open to all caregivers who care for a child with a disability.

Registration is required. SEATING IS LIMITED TO 35 adults. Registration will be taken in the order received. BornHava Caregiver Workshop and Discussion Group: Wednesday, May 15, 2024

**Please RSVP before May 10 at**

<https://form.jotform.com/dspgwny/bornhavamay24>

**Unfortunately, no childcare will be provided at this adult-only meeting.**

### July 28 - Day at the Bison's Game



Join us for a family outing to the Buffalo Bison's game on Sunday, July 28 at 1:05 pm when the Bisons take on the The Syracuse Mets. Tickets are free to immediate family members of the DSPG, but they are limited, so please only order tickets if you know you will use them.

**RSVP by July 20, to ensure time for mail delivery.**

Contact Janet at [janpo788@aol.com](mailto:janpo788@aol.com) or register online at <https://form.jotform.com/dspgwny/bisons24>

### August 18 - Family Picnic



Join us for a day of family fun on Sunday, August 18, 2024 from 11:00-2:00! We will meet at the George F. Lamm Post 622 located at 962 Wehrle Drive, Williamsville, NY 14221. There will be food, music, games, and lots of fun.

**Please RSVP by Wednesday, August 14.** Register online at <https://form.jotform.com/dspgwny/picnic24> or contact us with questions at [dspg@dspgwny.org](mailto:dspg@dspgwny.org).

### May 21 - Developmental Disability Day

The 36th Annual Developmental Disability Awareness Day will be held on Tuesday, May 21, 2024 at the Niagara Falls Convention Center. For more info go to [ddd.org/](http://ddd.org/)

### May/June - Calendar Photo Shoots

We are excited to bring back a our calendar for 2025! Join us at one of two photo shoots on June 1st or 2nd to have your loved one's picture included. Amherst State Park 6/1 (9:30-11am) and Knox Farm 6/2 (2-3:30pm). *Thanks to our generous photographer, you will also be able to download the photo for free!* The calendars will be ready for our walk in October.

**Please sign up through the links below by May 25.**

**AMHERST STATE PARK- 6/1:** 390 Mill Street, Williamsville 14221  
[signupgenius.com/go/5080F4AA9AC2CA6FF2-49335547-norhtowns#/](https://signupgenius.com/go/5080F4AA9AC2CA6FF2-49335547-norhtowns#/)

**KNOX FARM- 6/2:** 437 Buffalo Rd, East Aurora, 14052

[signupgenius.com/go/5080F4AA9AC2CA6FF2-49335788-southtowns#/](https://signupgenius.com/go/5080F4AA9AC2CA6FF2-49335788-southtowns#/)

### October 5 - Step Up for DS Walk



We are excited for our 17th year and the planning has begun! We will be back at Canalside with more food trucks, games, fun, a warm up with Fitness Ability and music by Strictly Hip!

Sponsor letters will be going out soon. If you think your employer or any one you know may be interested please let us know and we can get a request letter to them. Contact Gretchen at [gretchen.w@dspgwny.org](mailto:gretchen.w@dspgwny.org).

## Resource Corner

### Regression in Persons with Down Syndrome

<https://adsresources.advocatehealth.com/resources>

### Fantastic Friends Summer Camp

<https://www.signupgenius.com/go/4090D45AAA62EA6F49-48950534-summer>

### Arts Services, Inc. Arts Access Pass

ASI has been connecting Western New Yorkers to a wide array of arts and cultural programs and events through the Arts Access program. <https://www.arts-access.org/>

### Tips for Living with Housemates

<https://adsresources.advocatehealth.com/resources/tips-for-living-with-housemates/>

### When Things Change in My Life Story

<https://adsresources.advocatehealth.com/resources/when-things-in-my-life-change-story/>

### When Staff Members Leave Story

<https://adsresources.advocatehealth.com/resources/when-staff-members-leave-story/>

### Brittany's Baskets of Hope

<https://www.brittanysbasketsofhope.org/>

### Anesthesia

<https://adsresources.advocatehealth.com/resources/anesthesia/>

### Disaster Preparedness Guide for Caregivers

[https://www.ready.gov/sites/default/files/2024-02/ready-gov\\_caregivers-preparedness-guide.pdf](https://www.ready.gov/sites/default/files/2024-02/ready-gov_caregivers-preparedness-guide.pdf)

### Respond with care decal program in Niagara County

<https://www.wgrz.com/article/news/local/crime-niagara-county-sheriff-decale-program-respond/71-30c31131-09ac-4487-a3c1-429a649c8946>

### Pneumonia in People with Down Syndrome

<https://adsresources.advocatehealth.com/resources/pneumonia-in-people-with-ds/>

### Temperture Regulation in People with Down Syndrome

<https://adsresources.advocatehealth.com/temperature-regulation-in-people-with-down-syndrome/>

## iCan Bike Camp JULY 15th-19th, 2024 at The R.O.C.K.

425 Meyer Rd. West Seneca, NY

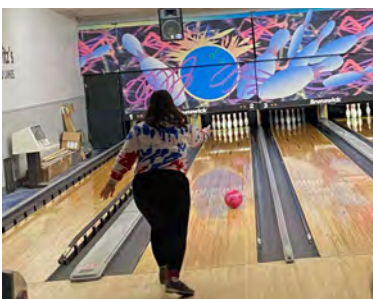
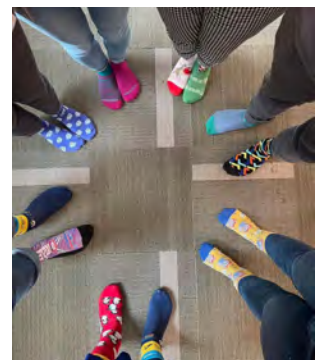


iCan Bike Camp uses adapted bicycles, a specialized instructional program, and trained staff to enable individuals with disabilities to learn to ride a two-wheeled bicycle.

Riders attend one 75 minute session each day for five consecutive days where they learn to ride while accompanied and encouraged by volunteer. Over the course of the week, we continually adjust the bikes in an effort to challenge riders appropriately as they gradually discover the skill and joy of riding.

Each athlete will select a session time and attend camp during the same session each day, Monday through Friday. Some Sessions are already full. They will be removed off the registration for when they reach capacity. To register, go to:

[thechampionprojectwny.com/icanbike](http://thechampionprojectwny.com/icanbike)



World  
Down  
Syndrome  
Day 2024!





## Board News

IWe would love more fresh faces to help plan and run our many events. Any assistance would be appreciated to keep our group going. If you can help out, please contact Amy at [amy.m@dspgwny.org](mailto:amy.m@dspgwny.org).

## College Scholarships

The DSPG is providing college scholarships to deserving high schoolers who have volunteered with us for at least 4 years. Please email [dspg@dspgwny.org](mailto:dspg@dspgwny.org) with questions or for a copy of the qualifications for the 2024-2025 school year.

**Applications for the fall of 2024 are due on May 30, 2024.**

We welcome our loved ones with Down syndrome to volunteer at our events.

## Thank you to our donors!

Donation from World Down Syndrome Day

PJ Cools Ice Cream Shoppe

YOLO Restaurant and Lounge

The Schaus Family

Adella Kirchmeyer

National Fuel Charitable Giving Employee Contribution

Cook Family Foundation  
at the Community Foundation for Greater Buffalo

## DSPG BOARD MEMBERS

### Presidents:

Amy Monson - 716-997-2843

Barbara Wakefield - 716-983-2140

### Vice Presidents:

Gretchen White - 716-834-0853

Maureen Hunley-Barnes - 716-472-1637

### Treasurer:

Janet Poreda - 716-695-1299

### Communications Coordinator:

Melissa Garrity - 716-534-6121

### Secretary:

Bonnie Zon - 716-632-0137

### Members at Large:

Darryl Barnes - 716-867-0072

Jason Brydges - 716-830-8636

Craig Donatelli

Lori Eckhardt - 716-906-7156

Maria Klee - 716-440-3862

Kyle Lappin

Emma Monson - 716-861-7807

Dana Oliver

David Rosenhoch

Gina Schueler

Wendy Slisz - 716-465-7574

### President Emeritus:

Carol Hetzelt - 716-832-4972

## We had a great turn out and lots of fun at the Valentine's Day Dance!



## Calendar of Events



- May 15 **Skills for Effective Advocacy Workshop**  
Presented by Vickie Rubin, M.S. Ed.  
Harlem Road Community Center, Classroom 1  
4255 Harlem Road, Amherst 14226  
6pm
- May 21 **Developmental Disabilities Awareness Day**  
Niagara Falls Convention Center
- June 1 & 2 **Calendar Photo Shoots**  
Amherst State Park - 9:30am (June 1)  
Knox Farm - 2:00pm (June 2)
- July 28 **Day at the Bisons Game**  
Sahlen Field, 1 James D Griffin Plaza, Buffalo  
1:05pm
- August 18 **Summer Picnic**  
George F. Lamm Post 622  
962 Wehrle Drive, Williamsville  
11am
- October 5 **Step Up for Down Syndrome**  
Canalside, 44 Prime St, Buffalo  
11am

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