

families * self-advocates * friends

dsapgwny NEWS

August 2025

UPCOMING EVENTS

August 17 - Family Picnic



We will be hosting our family picnic on Sunday, August 17, 2025 from 11am-2pm! Meet us at the George F. Lamm Post 622, 962 Wehrle Drive, Williamsville, NY 14221. We will have face painting, games, music and, balloon creations.

The DSPG will provide bottled water, pop, chips and hot dogs. Please feel free to bring a treat or side dish to share.

Please RSVP by Wednesday, August 13. Register online at <https://form.jotform.com/dspgwny/picnic25>

October 4 - Step Up for DS Walk



We are excited to celebrate our another year at Canalside with food trucks, games, a warm up with Fitness Ability and music by Strictly Hip. Registration is \$15 and includes a free event t-shirt if submitted before September 7. After that date a limited number of shirts will be available for purchase at the walk. A \$5 food truck voucher to be used on the day of the event will be provided to everyone at registration. This is a rain or shine event.

Registration is now OPEN. To join us go to
<https://dspgwny.org/step-up-registration/>

October 11 - Walk to End Alzheimer's

With the connection of aging with Down Syndrome and IDD and Alzheimer's disease, we are joining the fight by participating in the Walk to End Alzheimer's. You can help by donating or joining the DSPG Team on October 11! To register as part of Down Syndrome Parents Group, visit our page, https://act.alz.org/site/TR?team_id=954813&pg=team&fr_id=18797 then click "Join My Team." For more info contact team captain Janet Poreda at japo788@aol.com. We would be grateful to have your support! **Together, we can end Alzheimer's and all other dementia.**

Oct 25 - Halloween Trick or Treat

The DSPG of WNY is hosting its 11th annual Halloween Event at Bornhava on Saturday October 25 from 10AM-12PM. Wear your costumes and bring your treat bags as kids will trick or treat around the back path. This free event is for DSPG family members and families of children who attend Bornhava. Siblings are always welcome at all our events. **RSVP by October 22 or contact Amy at amy.m@dspgwny.org with questions.**

<https://form.jotform.com/dspgwny/TrickorTreat25>



Nov 8 - Fall Dance

Come dance with us on Saturday, November 8, 2025 from 6PM to 9PM, at Magruders, 4995 Broadway in Depew. There will be a charge of \$5 per person, to cover the food provided by the DSPG. **Please register by November 4 at the link below.**

Food will include: pizza, salad, snacks, and drinks. If you would like to bring a dish to pass, please do so. Dances have been so well attended that we are requiring a RSVP. Please do not bring additional guests. Parents and guardians are expected to stay for the duration of the event. Thank you for your understanding! <https://form.jotform.com/dspgwny/falldance25>

If you would like to sign up with cash or check or have any questions please contact Wendy at weedyslisz@yahoo.com.



Resource Corner

Medical Academy of Pediatrics and Special Needs

Fall 2025 Functional & Translational Medicine Conference

Beyond Chromosome 21: Translating Genetic Insight into Whole-Child Care for Down Syndrome
<https://www.medmaps.org/events/fall2025>

The Health benefits of Music for people with Down syndrome

<https://adscresources.advocatehealth.com/resources/health-benefits-of-music-for-adults-with-down-syndrome/>

Routines involving Writing and Copying

<https://adscresources.advocatehealth.com/routines-involving-writing-or-copying/>

Grief and Loss and Podcast Episodes

<https://adscresources.advocatehealth.com/resources/grief-podcast-episodes/>

NYS Access Pass for Parks, Recreation and Historic Facilities

New York State Parks offers an Access Pass that provides people with disabilities and their companions complimentary admission to all state parks!
<https://parks.ny.gov/admission/access-pass/>

5 Spiritual Comforts for parents of kids with disabilities - Free E-book

<https://view.flodesk.com/pages/5df181b3154bd20026a1aeaa>

Misunderstandings Caused by Different Perceptions

Some people with Down syndrome perceive time differently which can lead to confusion.
<https://adscresources.advocatehealth.com/resources/misunderstandings-caused-by-different-perceptions/>

Free Digital Skills Training for people with disabilities

<https://thearc.org/our-initiatives/digital-literacy/>

Down Syndrome Center Podcasts

These podcasts are hosted by Kishore Vellody, MD, medical director of the Children's Down Syndrome Center in Pittsburgh. Medical issues of children, teens, and adults with Down syndrome are discussed. Topics include COVID-19, Alzheimer's disease, regression, behavior, atlantoaxial instability, grief, and more.
<https://adscresources.advocatehealth.com/down-syndrome-podcast-series-for-parents-educators-and-medical-professionals/>

New resource on diagnostic overshadowing

Doctors or health professionals sometimes assume that a symptom or health issue is part of having Down syndrome, rather than investigating the cause and potential treatment further. <https://downsyndromeuk.co.uk/>

Positive About Down Syndrome

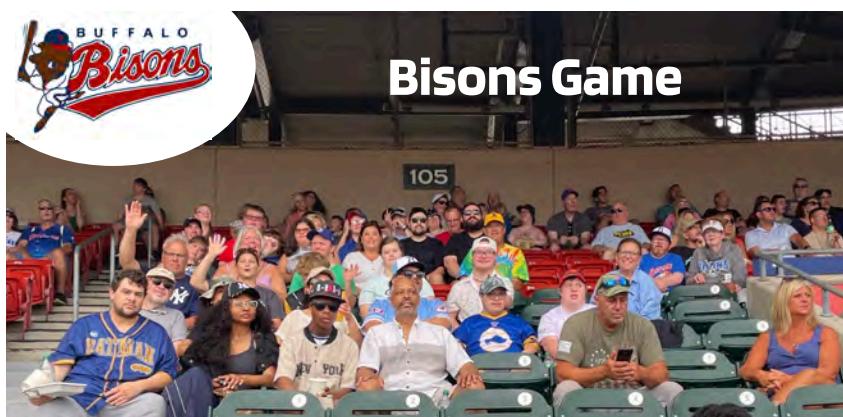
A website by parents for parents and parents-to-be. positiveaboutdownsyndrome.co.uk/

Down Syndrome Regression Disorder Symposium 2025

<https://secure1.chla.org/site/TR;jsessionid=00000000.app20121a>

Study on New Treatment of Severe Obstructive Sleep Apnea

Does your loved one with Down syndrome have trouble wearing a CPAP mask for the treatment of severe obstructive sleep apnea? (OSA) We are doing a research study to see if placing a surgically implanted nerve stimulator to treat OSA significantly improves the neurocognition and expressive language skills in people with Down syndrome, ages 10-21. This device has already been tested and FDA-approved for use in adults with moderate to severe OSA who are unable to use CPAP. If you are interested in learning more about this research study, please contact the research team by calling Dr. Hartnick at (617) 573-4206 or by e-mail at Christopher_Hartnick@meei.harvard.edu.



Board News

We 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.

College Scholarship Winner

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 with questions or for a copy of the qualifications for the 2025-2026 school year. **This year's winner for the 2025-26 school year is Nicolas Slisz!** Nick has volunteered with us for many years to support his sister Carly.

Applications for the fall of 2026 are due May 30, 2026. We welcome our loved ones with Down syndrome to volunteer at our events.



Barbara Wakefield 1959-2025



On July 29th we lost a long time, avid board member, tremendous advocate and beautiful soul, Barb Wakefield to ALS. Barb and her family have been members of the DSPG since Alison, her youngest daughter, was born with Down syndrome 22 years ago. Most recently she held the position of co-President as well as chairing and tirelessly volunteering at numerous events. She was always willing to take on any task to help our group move forward in advocating for our loved ones with Down syndrome. Barb will be sorely missed by all those whose lives she touched.

DSPG BOARD MEMBERS

President:

Amy Monson - 716-997-2843

Vice President:

Gretchen White - 716-465-0128

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

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

President Posthumous Emeritus:

Barbara Wakefield

**Thank You
TO OUR DONORS!**

Donations from Give716

In Memory of Barbara Wakefield

Michael Ciesiulka Facebook fundraiser

National Fuel Gas Company

Pay Pal Giving Fund

The Ranjan family

Donna Zaperal

Calendar of Events

August 17 **DSPG Family Picnic**
*George F. Lamm Post 622
962 Wehrle Drive, Williamsville 14221
11AM - 2PM*

Oct 4 **Step Up for Down Syndrome Walk**
*Canalside, 44 Prime Street, Buffalo 14202
11AM-2PM*

Oct 11 **Walk to End Alzheimer's**
*Buffalo Outer Harbor: TERMINAL B
825 Fuhrmann Blvd Buffalo, NY 14203
9:30AM registration / 11AM walk*

Oct 25 **Halloween Trick or Treat**
*Bornhava, 25 Chateau Terrace, Amherst
10AM - 12PM*

Nov 8 **Fall Dance**
*Magruders, 4995 Broadway, Depew
6PM - 9PM*



The DSPG News is published quarterly in February, May, August, and November



<https://www.facebook.com/DSPGWNY>



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