

Calendar of Events

September 9	Kick Off Meeting / Board Elections <i>Museum of disAbility History, Amherst</i> 7PM
Sept 28	Step Up for Down Syndrome <i>Sahlen Field, 275 Washington St, Buffalo</i> 11AM
October 12	DSPG 40th Anniversary Celebration <i>Santoras Pizza Pub & Grill, Williamsville</i> 5PM
TBD	Halloween Party
Nov 2	Fall Dance <i>MaGruders, 4995 Broadway, Depew</i> 5:30PM
TBD	Holiday Party
September 20-22	7th Annual LuMind Family Weekend <i>Great Wolf Lodge, Niagara Falls, Ontario</i>



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In an effort to reduce our carbon footprint, we will only be mailing printed versions of this newsletter to anyone not currently on our email list. You can receive a printed copy by mail by sending a request to dspg@dspgwny.org.



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



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



August 2019

UPCOMING EVENTS

Kick Off Meeting / Board Elections

September 9

Our Annual Meeting and Board Elections will take place Wednesday, September 9 at 7pm at The Museum of Disability History. We will share our annual report, a treasurer's report, and hold elections for positions on our Board of Directors. We are also excited to provide information on the Able Act and Person Centered Services. To RSVP on line go to <https://form.jotform.com/dspgwny/Sept-2019>

Step Up for Down Syndrome Walk

September 28th



Advance registration for Step Up is open! Register before September 9th and receive a FREE t-shirt. Brochures will be mailed soon or register on line at <https://form.jotform.com/dspgwny/Step-Up-2019>. Walk-ins are welcome the day of the event for \$10.

The schedule of events has changed for 2019. Lunch will begin at 11:30am and the walk will take place at 1:00pm with ice cream to follow.

Registration is \$10 with a free t-shirt before September 9 and \$10 the day of the walk. Includes lunch and ice cream. Children under 2 are free.

For more info go to dspgwny.org, check our our Facebook page or contact Gretchen White at gretchen.w@dspgwny.org or 716-465-0128.

Down Syndrome Parents Group's 40th Anniversary Celebration

October 12th

Celebrate the 40th anniversary of the Down Syndrome Parents Group on Saturday, October 12 at Santora's Pizza Pub and Grill on Transit Road in Williamsville from 5:00-8:00. We'll have a short program beginning at 5:30 and dinner will be served from 6:00-7:00. Come enjoy dinner and activities with our DSPG family. Tickets are \$5 per person. Children under 2 are free. To register on line go to <https://form.jotform.com/dspgwny/DSPG-40th>

Halloween Party

TBA

Fall Dance

November 2nd

Join us November 2 from 5:30 to 9pm at Magruders, 4985 Broadway Depew, for our annual fall dance. Tickets are \$5. Register on line at <https://form.jotform.com/dspgwny/fall-dance-2019> by October 28. Email Janet Poreda at janpo788@aol.com with questions only.

Holiday Party

TBA

2019 7th Annual LuMind Family Weekend at Great Wolf Lodge

September 20th - 22nd

12th The LuMind IDSC Foundation Family Weekend provides families an opportunity to connect and meet other families with a loved one with Down syndrome while individuals with Down syndrome experience a fun-filled weekend amongst their friends. It includes the Niagara Falls, Ontario one!
<https://www.lumindidsc.org/2019familyweekend/>

Resource Corner

Adult Down Syndrome Center - Appetite Regulation

Leptin is a hormone that contributes to appetite regulation and satiety. There are some data that show that individuals with Down syndrome have increased leptin levels which correlates with higher rates of obesity. This is consistent with reports of some family members and caregivers who have shared that their loved ones with Down syndrome never seem to get full. For more information go to <https://www.facebook.com/adultdownsyndromecenter>

caregiver.com

Find Information on guardianships, conservatorships and powers of attorney. <https://caregiver.com/articles/special-needs-turning-18/>

Normal "Abnormal" Lab Values

https://www.advocatehealth.com/assets/documents/subsites/luth/downsyndrome/normal_abnormal_lab_values.pdf

Brain Train

Dr. Brian Skotko is offering a five-week summer challenge to improve brain health in a loved one with Down syndrome. It's called the Down Syndrome Brain Train. Sign-up below for the introduction. <https://www.downsyndromebraintrain.com/>

Adult Down Syndrome Center - Boundries

When does hugging become inappropriate? The article linked below includes a question from the mother of a 14-year-old son with Down syndrome about boundaries related to hugging and touch. The answer provides good suggestions for addressing the situation. <https://www.irishtimes.com/life-and-style/health-family/my-son-14-has-down-syndrome-and-is-hugging-people-inappropriately-1.3918554>

Down Syndrome Australia - Down Syndrome and Mental Health

Written for individuals with Down syndrome and their families, this 11-page summary provides information and tips for promoting and maintaining good mental health. Dr. Chicoine and Dr. McGuire's book Mental Wellness in Adults with Down Syndrome was used in the development of this resource. An article about the resource and the link to download it can be found here: https://www.downsyndrome.org.au/news/new_publication_mental_health.html

Skin, Hair, and Nail Concerns in People with Down Syndrome

A presentation given by Erin Dominiak, MD, a physician at the Adult Down Syndrome Center, and Cristina Cassata, a woman with Down syndrome at the center. The presentation slides can be viewed at the following link: https://gallery.mailchimp.com/.../890.../Skin_Hair_and_Nails.pdf

In 1979 the Down Syndrome Parents Group of Western New York (DSPGWNY) was established.

Since then, we have supported hundreds of families, as well as promoted awareness of Down syndrome and acceptance of individuals born with Down syndrome. PLEASE VISIT dspgwny.org TO LEARN MORE.

Support for New Parents • Social Groups • Informational Meetings and Resources • Hospital Visits
Volunteer Scholarships • 40 years of experience supporting individuals with Down syndrome right here in WNY!

Thank You To Our Donors

All donations through United Way

All donations through
Embrace the Difference

Michael Ciesiulka and all donations
through his Facebook fundraiser

Board News

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 with questions or to receive a copy of the qualifications for the 2019-2020 school year. Applications for the fall of 2020 are due on May 30, 2020.

Board Elections

At our Annual Meeting on September 9, we will elect four Board Members for a term of three years. If you are interested in running for a position, please e-mail dspgwny@gmail.com by September 1st. If you would like more information about being a Board Member, e-mail us or call any board member listed on page 3. *We would love to see some fresh faces getting more involved in our organization.* We will e-mail the slate of candidates and have them available in print at the annual meeting on September 9th where we will hold elections.

As always, if you have anything you'd like to share, contact any of the board members below or send an email to dspg@dspgwny.org.

National Down Syndrome Congress Convention Overview

The Hallgren family attended their first NDSC Convention in Pittsburgh with 8 other families from our WNY DSPG group, others from our area, and families from all over the country. The theme this year was "rivers of opportunity" and the convention certainly lived up to that claim. There was a dizzying array of activities and workshops. The convention itself was extremely well run with over 2000 participants and 900 volunteers. As first-timers, we attended an orientation our first night in, while others had signed up for special advocacy sessions and research round tables. There were also many vendors and exhibitors to explore.



While parents and care givers attended workshops, our young adults participated in their own sessions, gaining independence, making new friends and having fun in a safe and supportive environment. Nick and Amy also gave a blood donation for the "Crnic Institute Human Trisome Project", which is a research project aimed to improve the health of children and adults with DS, including those with autoimmune diseases, Alzheimer's, and cancer.

Overall, it was an incredible, almost overwhelming experience. But as we know, we just need to take one day at a time, learn as much as we can, and continue to listen and learn from each other. Thank you DSPG for the scholarship. ~ by Janell Hallgren



There were 15 workshop options for each session with options for families with infants and young children, school-aged, teens and young adults, and caregivers and siblings. Topics included: Life Planning and Circles of Support, Nutrition for DS, Self-Advocacy, Behavior topics, Sleep Apnea, ABLE Accounts and Financial Freedom, Alzheimer's and DS, and Can My Child Learn to Drive.

Mini Golf Outing

Our first ever event at the Broadway Driving Range in Depew was a great day of golf, hot dogs & ice cream!



DSPG BOARD MEMBERS

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