

May 2019 Newsletter

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Spotlight On



The impact a person can have on an entire community can be stunning, even if that person is with us far too briefly. **Eli Reischl** enriched those around him during his life of just under 4 years, and

although illness took him from us in 2017,

Spring Fling Talent Show and Annual Meeting

Our annual Spring Fling celebrates Down syndrome with a talent show and our annual meeting. As always, if there's time left after the show, we'll do some dancing, too!

When: Saturday, June 1, 5:30 - 8:00 PM Where: Highland Community Center, 14224 Bel-Red Rd, Bellevue, WA 98007



Click <u>HERE</u> to RSVP.

Come enjoy dinner, desserts, and refreshments! Free fun for all family and friends!

Interested in volunteering? We could always use your help. Click <u>HERE</u> to sign up.

Want to Perform in the Talent Show?

Share your talent on stage at our Big Time Talent Show during the Spring Fling! Whether you want to be part of a group or on your own, join us for a fun, supportive evening guaranteed to empower. Show us what you've got!

Email <u>maura@downsyndromecommunity.org</u> to register for the talent show.

Registration deadline: Friday, May 24

2019 Puget Sound Buddy Walk - Exciting News!

The Down Syndrome Community of Puget Sound is thrilled to share that the 2019 Puget Sound Buddy Walk will be hosted by the **Woodland Park Zoo**! We are so grateful for their partnership and their dedication to inclusion. Mark your calendars for Sunday, **October 6th** and watch our monthly newsletters and Facebook for more information. Registration will open in July.



PTANCE VINCLUSION VRE

Ready, Set, Kindergarten

Another successful year of classes of Ready Set Kindergarten just wrapped up. This program is designed for parents whose kids are entering kindergarten the following fall.

ne continues to stimulate conversations and action to make his community more inclusive today through the **Eli's Park Project**. His mom Paige, dad Bryan, and older brothers Jaxon and Wesley share with us the beautiful ideals he inspired.

Will you share your family's story and how Eli impacted your lives?

"When we found out Eli, our third boy, had Down syndrome we were shocked and, I'm embarrassed to admit. heartbroken. The next 19 weeks of pregnancy we researched and read, prepared and worried and met Dr. Partridge who tried to warn us that babies who happen to have Down syndrome are more beautiful and amazing than we could imagine. She was so right. Our sweet boy brought our family, and everyone he met, unsurpassable amounts of love and joy. And he introduced us to a whole new world we never even knew we wanted and needed so much. Eli opened our minds and expanded our hearts forever. Our family calls Eli our wayfinder. He left us a legacy of love and a path to follow toward a more inclusive world. I know my life will never be as bright and beautiful as it was with Eli in it, and I hold firmly the

knowledge that it will be brighter and more beautiful for others because he was." included in the general education environment. At the following classes, guest teachers shared information for behavior, accommodations, and IEP goals. We finished the sessions with a parent panel that included parents of older kids. One of our parent participants says that because of the classes, "I feel empowered to be a more informed advocate for my child." Another parent says, "I definitely felt like I had a team of people cheering me on toward the goal of full time inclusion." We invite all parents of kids entering kindergarten Fall of 2020 to look out for registration for the next session of Ready Set Kindergarten later this summer.

Down Syndrome and Autoimmunity

Message from Dr. Partridge

Greetings. I'm writing to share that I had the pleasure of appearing on KING 5's New Day Northwest program this week along with Bernard Khor, a physician and researcher at Benaroya Research Institute at Virginia Mason. Together we talked with host Margaret Larson about how people with Down syndrome are at increased risk of developing autoimmune diseases, such as type 1 diabetes, hypothyroidism and celiac disease -



chronic disorders that can take a heavy toll and require lifelong management.

We went on the show because we want you to know we're leading the charge to take care of the current and future health needs of people with Down syndrome. Our partnership with BRI allows Bernard and other scientists to study donated blood samples and health information to learn more about why individuals with DS are more vulnerable to autoimmunity. Our goal is to identify better ways to treat, and ultimately prevent, autoimmune diseases in people with Down syndrome as well as the general population. This effort relies on the participation of people with DS and their family members.

To watch our interview on New Day Northwest, click HERE.

To learn more about our Down syndrome biorepository and how you can help, click <u>HERE</u>.

Or, email us at downsyndrome@benaroyaresearch.org.

We're always happy to tell you more about our work! We believe that through better understanding of autoimmune diseases in people with Down syndrome, we can improve treatments and quality of life for everyone.

Rebecca Partridge, MD Director, Virginia Mason Down Syndrome Program

Save-the-Date for Upcoming DSC Events

Mark your calendar for these upcoming events:

Summer Picnic

Enjoy a summer afternoon at the park with friends from our community! Town Square Park in Federal Way has a splash park, playground, zip line, basketball courts and more so there's something for everyone! **When**: Saturday, July 13, 11AM - 2PM



Where: Town Square Park, 31600 Pete von Reichbauer Way South, Federal Way, WA 98003

Megarama Day

Spend a day on picturesque Whidbey Island playing cowpoke with your family - horseback rides, havrides, and lunch-on the kid-friendly, expansive M-Bar-C Ranch.

To continue reading the Spotlight On article about **Eli's Park Project**, check out the entire <u>post</u> on the DSC website.

Stay Connected



Please check the DSC online <u>Events Calendar</u> regularly! When: Saturday, Aug. 10, 2019, 9:30 AM - 3:00 PM Where: M Bar C Ranch, 5264 Shore Meadow Road, Freeland, WA

DSC Friends Meet-Ups

DSC Friends Meet-Ups are hosted by the DSC at no cost to you! Please join us and have fun!

Babies/Toddlers (ages 0-3)

Contact: Caewyn Barnett at <u>caewync@gmail.com</u> and Angela Allen Martin at <u>angela@fpskirkland.com</u>

Мау

Get excited, we're going to the POINT DEFIANCE ZOO!! When: Saturday, May 18, 10:00 AM - noon. Please plan to arrive as close to 10:00 as possible for this event. Where: Point Defiance Zoo, 5400 N Pearl St, Tacoma, WA 98407 RSVP: Caewyn Barnett, or be looking for the event on our DSC Friends 0-3

Facebook page.

Kids (ages 4-7)

Contact: Courtney Criss at <u>courtney.spears@gmail.com</u> and Jessica Voetmann at <u>jessica.voetmann@gmail.com</u>

May

Join us for a private play time at We Rock the Spectrum in Federal Way. The gym has a trampoline, zip line, swings, indoor play structure, and arts and crafts area. Hope to see you there!

When: Saturday, May 25, 2019 at 1:00 - 3:00 PM

Where: We Rock the Spectrum - Federal Way, 34930 enchanted pkwy, Suite 180, Federal Way, Washington 98003

RSVP: Courtney Criss or on our Facebook Event.

Tweens (ages 8-12)

Contact: Jessica Evertt at jessicaevertt@hotmail.com

May

The Tween group is taking the month of May off but check out the fun June activity!

June

We will be meeting at Jamie Kivela's house in Redmond to decorate cookies and have some fun playing around the yard. When: Saturday, June 8, 2:00 - 4:00 PM Where: Jamie Kivela's house, Redmond RSVP: Jessica Evertt or on our Facebook Event for the Kivela's home address

Teens (ages 13-19)

Contact: Kate O'Leary at <u>kate.oleary@hotmail.com</u>, Julie Habegger at <u>jahabs@aol.com</u> and Betsy Kavanaugh at <u>elizakavi@gmail.com</u>

Be looking for information or an event on our DSC Friends Teen Facebook page.

Moms' Night Out

Contact: Maura Dunn at maura@downsyndromecommunity.org

Join us for an evening at one of our mom's house! We'll have some appetizers, drinks and dessert. When: Saturday, May 25, 7:30 PM Where: Jessica Voetmann's house, Edmonds RSVP: Jessica Voetmann or on our Facebook Event for her address

Challenge Air

Join Challenge Air on Saturday, August 24, 2019 from 9 AM -5 PM at the Historic Flight Foundation located at Paine Field in Mukilteo for their annual Fly Day for kids with special needs between the ages of 7-21 years. Pilots, agencies, volunteers and families of kids with special needs are invited to enjoy a fun day of flying. Registration required and each participant must have their own email.



Click <u>HERE</u> to register.

Outdoors for All and SDOT - Free Adaptive Bike Rentals

In collaboration with the Seattle Department of Transportation, Outdoors for All is now offering FREE daily adaptive bike rentals for children and adults with disabilities at the Adaptive Cycling Center in Magnuson Park, select Seward Park Bicycle Sundays, and White Center Bicycle Playground. With the largest adaptive bike fleet in the country, anyone can find a bike that works for them!

The park has miles of trails to enjoy and is just across the street from the Burke-Gilman Trail for those interested in a longer ride. All ages and abilities welcome.



Click <u>HERE</u> for more information about the rentals at Magnuson Park. Click <u>HERE</u> for more information about rentals at Seward Park Bicycle Sundays and White Center Bicycle Playground.

Washington State Fathers Network - Upcoming Events

Check out these fun upcoming events hosted by the Washington State Fathers Network:



Free Professional Photo Session and Photos for Dads and their Children When: Sunday, June 2, 9 AM - 1 PM Where: Woodinville Media Group, 19501 144th Ave. NE, Building C suite 600, Woodinville, WA 98072 Click <u>HERE</u> for details.

Washington State Fathers Network Mixer When: Sunday, June 9, 9:30 - 11 AM Where: Microsoft Store University Village, 2624 NE University Village St. Seattle Click HERE for details.

36th Annual Fathers Network Campout When: June 14th, 15th, and 16th 2019 **Where**: Washington Park, Anacortes, WA Click <u>HERE</u> for details.