

BUILDING AWARENESS & BRIGHT FUTURES FOR INDIVIDUALS WITH DOWN SYNDROME & THEIR FAMILIES

DESIGNER GENES NEWSLETTER

FALL 2019

MARK YOUR CALENDARS

Nov. 18 | Family Meet-Up -Chat About Medicaid

6 p.m. - 8 p.m. - Juniper Workantile

Dec. 14 | Supper with Santa - Annual Meeting

6 p.m. Social, 6:30 p.m. Supper Harvest Catering & Event Center

Jan. 21 | DG Board Meeting

6 p.m. - 8 p.m. - Juniper Workantile

Feb. 9 | Designer Genes Bowling Party

4 p.m. - 7 p.m. - Midway Lanes

WORLD DOWN SYNDROME DAY CELEBRATION WEEKEND

Mar. 20 - Celebrate Siblings Event for Families

with Brian Donovan, creator of Kelly's Hollywood

Mar. 21 - World Down Syndrome Day

Morning - Sibling Celebration

Afternoon - Family Activity & Our Place

Motorcycle Club Fundraiser

Sept. 26 | Annual Walk for Down Syndrome

10 a.m. Registration - 11 a.m. Walk Bismarck State Capitol Grounds

Supper with Santa Designer Genes Annual Meeting

Saturday, December 14th – 6 p.m. Social – 6:30 p.m. Dinner New Location: Harvest, 308 West Main St., Mandan, ND

It's time to pull out those dancing shoes and your holiday best! The Designer Genes Supper with Santa and Annual Meeting is set for Saturday, December 14! We're moving to a new location - Harvest Catering & Event Center in Mandan. Santa's been told to direct his sleigh to Mandan, so he'll be



there with bells on. Dress code is everything from sparkly and fancy to cowboy boots.

This serves as your formal notification of Designer Genes' Annual Meeting. Individuals with and without Down syndrome are invited to take part in the meeting. Stories and activities will be available to keep our under 18 year olds occupied while the meeting is taking place. And, when business is done it's time to DANCE!

Remember we are at a new location – Harvest Catering and Event Center on Main Street in Mandan. There is parking in the lot to the south of Harvest Catering and street parking available.

RSVP is required to Roxane by December 6th at 5 p.m. to

http://bit.ly/SupperWithSanta. Please know that if you RSVP, we will purchase a meal for you and your guests, and we'll be excited to see you!



FAMILY MEETING - SUPPER AND A CHAT ABOUT MEDICAID

Monday, Nov. 18th, 6 – 8 p.m. Juniper Workantile, 122 N. 4th St., Bismarck

Door between Sweet Treats and Toasted Frog. Parking can be difficult, but parking is available for free in the 3rd St. and Main St. Parking Ramp. Child Care and supper will be offered, so please RSVP to http://bit.ly/MedicaidMeet.



This conversation about Medicaid will be applicable across the lifespan of our loved ones' with Down syndrome. Medicaid is public health insurance that supports individuals with Down syndrome of all ages. Individuals can be eligible many different ways, and maintenance of eligibility can look different because of that. Right now, Medicaid is funded by (roughly) 50% North Dakota State General Funds and 50% federal dollars. Knowing who is in charge of the funding helps advocates know where to watch for changes. While Medicaid is often seen as a safety net for individuals, Medicaid for our loved ones with Down syndrome can mean their ticket to earn, learn and belong.

COMMUNITY RESOURCES YOU SHOULD KNOW

ROUGHRIDER AMBUCS

RoughRider AMBUCS is a nonprofit charitable organization whose mission is to inspire people to conquer challenges related to mobility and independence. They fulfill this mission by providing scholarships to therapy students, providing Amtryke therapeutic tricycles, and completing other acts of community service to benefit people with disabilities in the Bismarck/Mandan area.

An Amtryke can be adapted many different ways, for riders of all sizes, to accommodate a variety of rider needs and disabilities. Being able to ride a bike is a milestone that many take for granted. RoughRider AMBUCS hopes to help more individuals in our community achieve this dream, as well as to be able to increase their own wellness by being able to join their family on a bike ride. For more information, please contact Kristina Bouley at 701-391-1267 or email roughriderambucs@gmail.com.

Tracy's Sanctuary house

TRACY'S SANCTUARY HOUSE

Tracy's Sanctuary House in Bismarck provides temporary sanctuary for out-of-town families during a time when their loved one is in a life-threatening crisis. They offer a "home away from home" as a place of privacy, comfort and compassion to these individuals. Tracy's received a grant from the North Dakota State Council on Developmental Disabilities to reach out to families who have individuals with developmental disabilities who may come to Bismarck for medical care. They currently are able to help up to 22 families. The individual does not need to be inpatient to stay there. For more information contact Tracy's Sanctuary House at 701-258-5889.

LOOKING TO THE FUTURE

In 2020, Designer Genes will be offering the opportunity to look into the crystal ball and create future plans for the organization. The membership will be asked to consider the question "What seems impossible, but if we could we would ...?"

Go to http://bit.ly/FeedbackDG if you have thoughts to share. And remember, we are about supporting members across the lifespan and that won't change.

MEMORIAL TRIBUTES

"A life that touches others goes on forever. Always on my mind and forever in my heart."

In past year, the below individuals who lived with
Down syndrome have been remembered by memorial
donations to Designer Genes. We honor their memory.
Edward Dzura – Brother to Michelle Hougen
Clive Kuppler – Child to Hollie and Lewis Kuppler
Debbie Stiles – Sister to Betta Archambault

LET'S CELEBRATE OUR FAMILIES & FRIENDS

- Optimist Club of Bismarck held their annual bowling tournament and chose Designer Genes as their local charity. They presented a check for \$1,175 to the Designer Genes Board of Directors and we celebrate our awesome team Luke Weinberg, Caleb Clarys, Shawna Unruh, and Ryan Suchy.
- 25 two-wheel bike riders joined us for the 2019 iCan Bike Camp. Big shout-out to iCan Shine and their field staff, Heather Lundeen (Camp Director), Bismarck Parks & Recreation, Our Place Motorcycle Club, Sanford Foundation (Great American Bike Race Funds), and our many sponsors.
- Roxane Romanick was awarded the Division of Early Childhood (a division of the Council For Exceptional Children) Parent/Family Award for her years of work in the early childhood field, parent support, and family leadership. She received the award at the International DEC conference in Dallas.

The Designer
Genes team
rocked the
bowling alley
with their
competitiveness!
Great job Luke,
Caleb, Shawna
and Ryan!





Cristian McMerty was selected as the 2019 Century High School Homecoming King, alongside Queen Lauren Ware. Congratulations Cristian!

Time for Giving Heart's Day – February 13th

This is the third year you'll find Designer Genes lined up with other great non-profits for Giving Heart's Day. We continue to say "Yes #COUNTME!". The donations made during last year's Giving Heart's Day provided about \$9,000 to assist with Designer Genes programming and family support. Thank you to all those who gave from the heart.

Thank you once again to the Schmid Family for donating the annual membership fee for Designer Genes to participate. This membership in the Impact Institute, the Giving Heart's Day creators, continues to provide Designer Genes with learning opportunities, the ability to network with other Giving Heart's organizations, and participation in the Giving Heart's Day event. We also rely on our members and supporters to meet a \$4,000 Giving Heart's Day match annually.

How can you help in promoting Giving Heart's Day and supporting the mission of Designer Genes?

Here's a few ways you can help:

- Share Giving Heart's info with your circle of friends and encourage them to consider a donation
- Share a match source with Roxane or one of the Designer Genes Board members
- Make a personal pledge to Designer Genes to help us meet our \$4,000 Giving Heart's Day match
- Donate: ☐ \$100 ☐ \$50 ☐ Other \$___
- Help make Thank You Calls on Feb. 13th

Let us know by emailing info@designergenesnd.com, if you'd like more information or want to help on Feb. 13th.



WORLD DOWN SYNDROME DAY COME JOIN THE CELEBRATION - MARCH 20 & 21

Mark your calendars for a one-of-a-kind World Down Syndrome Day celebration! We'll be celebrating both March 20th & 21st with events in Bismarck. Make plans to join us and watch for more information in the near future. Here's a few things to look forward to!

Friday, March 20

Come help us Celebrate Siblings at an Evening with Brian Donovan. Brian is the director of the award winning documentary, Kelly's Hollywood (Amazon Prime Video), about the intimate relationship he had with his spectacular sister who was born with Down syndrome (www.kellyshollywood.com). Brian has toured internationally speaking about inclusion, equality and how imperative it is for everyone to be given the chance to pursue their dreams. For anime fans, Brian is also well know for his role as the voice of Rock Lee from the critically acclaimed Naruto series.

Saturday, March 21

The Sibling Celebration will continue Saturday morning with a workshop specifically for our best support partners – teen brothers and sisters who support individuals with Down Syndrome! The afternoon and evening will feature Family Fun and the Our Place Motorcycle Club Fundraiser - Bikers for Bikers! Get ready for fun!

Way to Walk for Down Syndrome

Thank you all for a great 2019 Walk for Down Syndrome.

Here's some to celebrate!

- 85 Teams Registered
- Over \$70,000 Raised
- Motorcycles, Dinosaurs and Cheerleaders
- Exceeded 2018 totals for Day-Of, Total Raised by Teams, and Online Totals

Huge Thanks to our Ambassadors/Hosts:

- Learning: Dr. Jason Hornbacher, Superintendent
 Bismarck Public Schools; Tate Johnson, sophomore
 Legacy High School; Kylie Doppler, Tate's 2018 Choir Teacher
- **Earning**: Wayde Sick State Director Career and Technical Education; Jimmy Young Bird, ranch hand Healing Horse Ranch; Jim Baker, Jimmy's boss at Healing Horse Ranch
- Belonging: Caprice Knapp, State Director, Medical Services Department of Human Services; Ryan Suchy and family



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