

MARK YOUR CALENDARS

Mar. 7 | Disability Awareness Day at State Capitol

9 am - 4 pm
State Capitol - Bismarck

Mar. 19 | DG Bowling Party

2:30 pm - 4:30 pm
Midway Lanes, Mandan

Mar. 21 | World Down Syndrome Day

Mar. 25 | OMPC Bikers 4 Bikers Fundraiser

12 pm - 3 pm - HIT
2640 Sunset Dr., Mandan

Mar. 25 | YESS Mocktail Party

6 pm - 8 pm
Hillside Community Center
1719 Boulevard Ave, Bismarck

Apr. 25 | DG Board Meeting

6 pm - Designer Genes Offices

Jul. 25 | DG Board Meeting

6 pm - Designer Genes Offices

Jul. 31 - Aug. 4 | iCan Bike Camp

Aug. 27 | DG Picnic

4 pm - 7 pm
Sertoma Park, Bismarck
See more dates on back page ...

DESIGNER GENES ADVOCATING AT THE NORTH DAKOTA LEGISLATURE

Thanks to everyone that has taken the time to write testimony, email a legislator, show up for a hearing, or share information on social media. Below are highlights on the bills that Designer Genes has been advocating for and monitoring.:

SB 2012 – Department of Health and Human Services Budget

Includes Developmental Disabilities and Early Intervention provider increases, funding for the Inclusion Program for Child Care, Family Support funding, Guardianship funding
Status: Passed Senate, Moves to House

SB 2276 – Paying Family Caregivers on Medicaid Waivers

Status: Passed Senate, Moves to House

SCR 4004 – Study on Accessible Transportation

Status: Passed Senate, Moves to House

SCR 4016 – Study on Accessible Housing

Status: Passed Senate, Moves to House

SB 2302 – Prohibiting Discrimination based on disability for receiving organ transplants

Status: Passed Senate, Moves to House

HB 1035 – Changes to DD Eligibility and creation of a Cross-Disability Waiver *Status: Failed in the House – Intent to include with SB 2012*

The ND Legislature's website – ndlegis.gov – is where you can find your district legislators, watch live and past video of hearings and floor sessions, upload testimony prior to a hearing, and track legislation. Opportunities to speak out on bills can appear and disappear quickly, so keep watching and speak out!



WORLD DOWN SYNDROME DAY 2023

World Down Syndrome Day is the time to tell others about the positive potential of individuals with Down syndrome. If anyone is considering a peer presentation at their school, church, or service group, please contact Designer Genes as a resource for information and more!

JOIN THE #LotsOfSocks CAMPAIGN

The #LotsOfSocks campaign exists to raise awareness about Down syndrome. #LotsOfSocks gets people talking on World Down Syndrome Day (WSDS), celebrated each year on March 21.



www.worlddownsyndromeday.org/lots-of-socks

BE A PART OF THE #LOTSOFSOCKS FUN!

1. Wear your own choice of socks that are going to get noticed - they might be mismatched socks or your wildest and most colorful socks, whatever takes your fancy! If someone asks you about your socks you can tell them, "I'm wearing them to raise awareness about Down syndrome."
2. Invite others to rock #lotsofsocks on Monday, March 21st! Remember to post lots of photos to your social media channels and don't forget to tag #DGND and #LotsofSocks.

MEET TIANA



Tiana Staudinger is joining Designer Genes part-time as a temporary program assistant. She also works as a direct service professional for HIT, Inc. and is awaiting word on her medical school application. She'll be assisting with the Youth Empowering Social Status events and set up Designer Genes' 2023 events. Welcome Tiana (pictured with Liz Romanick)!

OUR PLACE MOTORCYCLE CLUB
PRESENTS THE 7TH ANNUAL
BIKERS 4 BIKERS



Lunch • Games
Face Painting
Bake Sale •
Silent Auction

SATURDAY
MARCH 25, 2023
12 P.M. TO 3 P.M.

HIT INC.
2640 SUNSET DRIVE
MANDAN, ND



Join the fun and support helping bring iCan Bike Camp to Bismarck.



Designer Genes thanks Our Place Motorcycle Club for raising over \$25,600 to help individuals learn to ride a bike independently!



BIKERS FOR BIKERS IS BACK

JOIN OMPC - OUR BUDDIES IN LEATHER

Come support the iCan Bike Camp at the OMPC Bikers 4 Bikers event on Saturday, March 25. Drop in at any point from 12 – 3 pm at HIT, Inc. (2640 Sunset Dr., Mandan). Here's just a few of the things you won't want to miss:

- Not cook! We'll have lunch waiting.
- Buy a raffle ticket to win a ride during the opening loop at the 2023 Walk for Down Syndrome
- Get sweet! Buy something at the bake sale.
- Get tattooed! OK, maybe just get your face painted.
- Dance to the tunes from our friend and DJ, Steve LaFramboise.
- Bid on a silent auction item and play a little Bingo
- Make bikers and Designer Genes happy! All funds raised go to support the 2023 iCan Bike Camp.

OPMC has raised \$25,600 since the start. Please bring your family and friends and help us support our buddies as they support us!

ROCKIN' MOM'S RETREAT REPORT

BY RACHEL JORDAAN, MOM TO HENRY

In September 2022, I was able to attend the Down Syndrome Diagnosis Network (DSDN) Rockin' Mom's Retreat in Washington D.C. This was made possible by fundraising and a grant from the North Dakota State Council on Developmental Disabilities. If you haven't taken advantage of this grant to attend a conference or workshop, I highly recommend it.

The theme of the Rockin' Mom's Retreat was taking care of yourself. We as mom's aren't able to care for our children if we haven't taken care of ourselves. Most of the speakers focused on this topic and how important it is to have your tribe to help you care for your family. We aren't made to do this alone and we need to be aware that our tribe may not just be immediate family or friends. Be willing to look further.

We also had a chance to attend the GLOBAL round table which had multiple staff members from the GLOBAL Down Syndrome Foundation. The first speaker was Dr. Lina Patel, author of *Potty Time for Kids with Down Syndrome: Lose the Diapers, Not your Patience* and she discussed information from her book. Next was Dr. Joaquin Espinosa who spoke on his work with research discoveries to elongate lifespan and improve health outcomes in individuals with Down syndrome. Then Dr. Melissa Parisi spoke on National institute of Health funding for Down syndrome research and research opportunities for those with Down syndrome. Finally, Dr. Nicole Baumer addressed us about the new updates to the 2022 AAP Health Guidelines for Children with Down syndrome. All of this was incredibly exciting to hear about from the professionals working in those areas. There are some great things coming down the pipeline regarding research for Down syndrome.

Overall, this was such a great opportunity to attend, and I went home feeling refreshed and better able to care for those I love and having even more people, other Rockin' moms, in my circle that I can connect with about what my family is going through. It's important to remember that we are not alone in this journey and to ask for and accept help if you need it.

PREPARING FOR 2023 MEDICAID RENEWALS

As a result of the COVID-19 public health emergency ending, states will soon be restarting Medicaid eligibility reviews. For the many with disabilities and who are dependent on Medicaid for their services, a mistake in eligibility and the possibility of losing coverage is something to be avoided. Fortunately, there are steps you can take to be ready.

1. Make sure North Dakota's Medicaid agency has your current mailing address, phone number, email, or other contact information so they can easily contact you about your Medicaid coverage. You can do this by calling 1-866-614-6004 or emailing applyforhelp@nd.gov. You can also stop in at your closest Human Service Zone office – find yours at www.hhd.gov/human-service-zones.
2. Check your mail regularly. The state Medicaid agency will mail you a letter about the status of your Medicaid coverage. This letter will also let you know if you need to complete a renewal form to see if you still qualify for Medicaid.
3. Complete and send in your renewal form (if you get one). Fill out the form and return it to your Medicaid agency to help avoid a gap in your Medicaid.
4. Don't hesitate to ask for help if you are confused and/or in disagreement. Reach out to Designer Genes at 701-391-7421 or Family Voices of North Dakota (children and youth) at 1-888-522-9654.

RESOURCES MENTIONED ABOVE:

North Dakota State Council on Developmental Disabilities Consumer Leadership Grants | www.nd.gov/scdd/grants
Down Syndrome Diagnosis Network - Down Syndrome Support | www.dsdiagnosisnetwork.org
Global Down Syndrome Foundation | www.globaldownsyndrome.org
American Academy of Pediatrics Pediatric Health Guidelines - Health Supervision for Children and Adolescents With Down Syndrome | bit.ly/3IXtr2q - (aap.org)

MARK YOUR CALENDARS

Continued from front page ...

Sept. 23| DG 20th Annual Walk for Down Syndrome

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

October 2023

Down Syndrome Awareness Month

Oct. 24 | DG Board Meeting

6 pm - Designer Genes Offices

Dec. 2 | Supper with Santa/ Annual Meeting



A · DOWN · SYNDROME · SUPPORT · NETWORK

DESIGNERGENESND.COM

PO BOX 515

BISMARCK ND 58502-0515

info@DesignerGenesND.com



walk for down syndrome



DESIGNER GENES SAYS LET'S CELEBRATE HERE'S A FEW ITEMS BLESSING OUR ORGANIZATION

THANK YOU TO OUR GIVING HEARTS

Being part of 2023 Giving Hearts Day raised just shy of \$10,000 for Designer Genes. Thanks to everyone that said #helpsomeone and contributed.



GRATEFUL FOR MEMORIAL GIFTS

Over the past year, we've had the honor of receiving memorial donations from families that have named Designer Genes as a memorial recipient when a loved one passes away. Our thanks and warm thoughts to the Connor, McMerty, Schorsch, and Keegan families, amongst others.

CELEBRATING OUR MEMBERS

Designer Genes' Birthday Card Project Committee has been sending out birthday cards to our members with Down syndrome over the past year.

Big thanks to Vanessa Erickson, Jen Klein-Schafer, Melissa Plesuk, and Deb Yeager for this work and effort. If your loved one did not receive a card, please send Roxane an email at roxane@designergenesnd.com and we'll get you on the list!

EVERY CHILD IS GIFTED. THEY JUST UNWRAP THEIR PACKAGES AT DIFFERENT TIMES.