



PO Box 321
Grand Haven, MI 49417
imdsa.org

Dear friend of the International Mosaic Down Syndrome Association,

IMDSA is now 23 years old and has almost 1,200 members worldwide. Only 2 to 4% of the total Down syndrome population falls into this category, or 1/27,000 live births. It is an invisible disability because most people with mDs don't have all the physical characteristics of a person with Ds. It is a spectrum disorder wherein some folks are as involved as a person with Ds and some aren't diagnosed until they are adults. IMDSA is a virtual organization made up of an executive director and a small group of volunteers, including parents, self-advocates, researchers and core allies. The organization has made significant strides in the last 23 years to increase the scope of support in communities worldwide for these families. They do this by:

- Hosting Research and Retreat conferences each year where families, researchers and self-advocates come together to connect and participate in research. The 2021 Research and Retreat weekend was held at Jellystone Park in Quarryville, PA.
- Hosting their first Virtual Meetup.
- Mailing Parent Swag Bags to new parents. One of our Self-advocates heads up this project.
- Starting private birth clubs within Facebook for families to connect with other families that have kids close in age.
- Establishing a Dads Facebook Group for dads of children with mosaic Down syndrome to provide another venue for support to our community.
- Continuing to partner with researchers from Virginia Commonwealth University, The University of Wisconsin-Madison, Colorado State University, MIT, Emory University, LuMind IDSC Foundation, and the Linda Crnic Institute for Down Syndrome. These researchers have been successful in getting a separate seat on the NIH Board for mosaic Down syndrome. They have also helped a few families that have a child that has been diagnosed with Down syndrome get data to prove that their child has mosaic Down syndrome. Their research will benefit the full spectrum of the Down syndrome community. The researchers around the world are interested in working with our children and adults because they have cells that are identical in every way except that some have an extra 21st chromosome and some don't. Since the Alzheimer's gene is also on the 21st chromosome, this has implications for the population at large.

For the past several years, we've had fundraisers in honor of World Down Syndrome Awareness Day (March 21) to raise funds for imdsa. We are thrilled to announce that we will have a bowl-a-thon and silent auction at Chipper's Lanes on Horsetooth on March 6, 2022, from 5 to 7 p.m. Our event last year was a success even with COVID-19 issues. Chipper's has assured us that they will be able to follow all the requirements to keep everyone safe during the event. We want to bring awareness and acceptance of people with all types of Down syndrome. We will have 32 lanes with teams of six to fill Chipper's Lanes. We will also have a silent auction during the bowl-a-thon. There are four levels of sponsorship:

- \$500 level -- The name of the organization or individual and logo will be on the official banners, and the expense of one team of 6 people to bowl will be covered.
- \$300 -- The name of the individual or organization and their logo will be on the official banners, and the \$20 per person cost will go down to \$15 each for two hours of bowling, a ball, shoes and admission to the silent auction if you decide to have a bowling team.
- \$200 to \$250 -- The name of the individual or organization and their logo will be on the official banners.

In previous years, we have had more than 200 folks, ages 2 to 74 at all different ability levels, having a fun evening bowling and connecting with each other. We are asking you to consider joining us in this project. Please contact Roxanne Batezel by text or phone at 970-980-7486 or at sensaonline2@yahoo.com with any questions. I am enclosing a donation form as well.

Thanks so much for your consideration of this request.

A handwritten signature in blue ink that reads "Roxanne K. Batezel".

ROXANNE K. BATEZEL
Mother of adult with mDs
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970-980-7486

"Uniting Unique People in a Unique World"