



dada2

FOUNDATION



DRIVING TOWARD CONSENSUS

February 2023

Dear DADA2 Community:

Greetings from an early Spring in the Southeast US! It's February, which means we should still see a shot of winter, but instead we already have tree buds. I'll take it!

February also brings a recognition of something this community holds dear: **Rare Disease Day**. Around the globe, thousands are taking steps to cure many of the world's 7,000 diseases that affect tens of millions of people. DADA2 may only represent 600 of those people – that we know of – today. But we know there are more people out there.



Having a rare disease might feel like a lonely endeavor. I know it felt that way, and still does, for my family. That is why we are so committed to building a community around DADA2 through the Foundation. **Today, the DADA2 community includes the following people, all committed to solving this disease:**

- **Researchers** who spend countless hours in labs looking at genes and cells, determining what's off to begin with and what medications fix it.
- **Doctors** who ask questions and put puzzle pieces together to make a plan for your care.
- **Pharmaceutical companies** who we hope will analyze data that can lead to clinical trials in the future.
- **Counselors** who spend hours with patients and families to help ease the mental impact of feeling alone and sick.
- A growing **DADA2 Foundation staff** who works everyday to coordinate, build relationships, share information and move initiatives forward. Be sure to check out our Research Engagement Director, Julie Williams, as she discusses a feature of the Registry below.
- **Families and caregivers** who devote their lives to navigating this disease on behalf of their loved one, while also living life to the fullest!
- And, of course, **patients** who make their voice heard so friends and family know about their disease and provide support.

The community extends beyond us to other non-profits, advocates, legislators, and media who share about rare diseases in general. Community truly is so important, and we are eager to share more ways this year on how we are building the DADA2 community as a resource.

This month, join us to bring recognition to the work we're doing and is yet to be done to cure DADA2 and every other rare disease in the world.

Chip Chambers, M.D.
Founder and President, DADA2 Foundation

Rare Disease Day 2023

Rare Disease Day began in 2008 to coordinate all of the efforts already happening around the globe to bring awareness to rare diseases. Officially, they are working on equity in social opportunity, healthcare and access to diagnosis and therapies for people living with a rare disease. The day is observed on the 28th of February – also considered the rarest day of the year. EURODIS along with 65+ organizations partner to support efforts surrounding the day.

What can you do to celebrate Rare Disease Day? If you are comfortable, share about your experience with others. You can do that one-on-one or in a group or on social media. Every new person who hears about rare diseases, including DADA2, can become more compassionate and more eager to join in the fight.

We put a few resources on our homepage to help you share!

My dada2 Story

TO HONOR 2023



RARE DISEASE DAY®

www.dada2.org

Ideas to Celebrate Rare Disease Day

Patient Registry Sneak Peek: Body Scan Survey



We are thrilled to give an update on the DADA2 Patient Registry! Watch this very short video from Certified Genetic Counselor and DADA2 Foundation Research Engagement Director, Julie Williams. In this clip, she explains the details of our body survey and how it will help the Registry capture that patient-reported data that is often the missing puzzle piece to reaching the quality of life we want for every patient. There is nothing for you to do today! This survey will launch when we launch the Registry this year. But, we hope it gets your brains going as you think about how YOU can contribute your story if you are a patient or family member, or what you will watch for in the data that comes out of this Registry.

CELEBRATING OUR COMMUNITY IN ACTION

JOURNAL



New Century Ag Agronomist Andy Grundstad, who works at the Ambrose elevator, will be featured by the DADA2 Foundation on World Rare Disease Day, Feb. 28.

Rare medical condition doesn't hamper goals

Speaking with an air of positivity, Andy Grundstad said he's managed to reach a number of milestones he set for himself. "I went to NDSU, that was one of my main goals. I became an agronomist, that was my second. I live at the family farm, that was the third. And I married a great woman," he said, his wife, Kirstie.

All that, despite a laundry list of physical ailments plaguing Grundstad, 34, for "about 30 years."

Those ailments, including systematic inflammation known as vasculitis, double vision, numbness, vertigo and even strokes are all directly attributable to a gene mutation disorder called DADA2.

It's extremely rare. Since being uncovered by researchers in 2014, roughly 500 cases have been disclosed worldwide.

"Who would think that a small-town U.S. kid, Class B school, would have something that is so rare?" Grundstad asked.

That rarity is also one reason Grundstad is being featured by the DADA2 Foundation as the organization's "poster boy" during World Rare Disease Day on Feb. 28.

Dr. Chip Chambers, founder and president of the DADA2 Foundation said the day is a global initiative to bring awareness to the more than 7,000 rare diseases currently known.

Chambers called DADA2 a "disease of mimicry."

"Because there can be so many different symptoms," said Chambers.

Those myriad symptoms can make definitive diagnosis hard for physicians unfamiliar with the disease, Chambers said.

Some patients present with symptoms like Grundstad -- inflammation, stiffness and strokes. Others present with compromised immune systems, up to and including failure of the bone marrow to manufacture red and white blood cells. Still others, Chambers said, can experience no symptoms.

In layman's terms, DADA 2 is an enzyme deficiency caused by a genetic mutation.

More specifically, according to literature published by the National Institutes of Health, DADA2 is caused by genetic mutations in the ADA2 gene that encodes the adenosine deaminase 2 (ADA2) protein.

According to the DADA2 Foundation, patients like Grundstad have virtually no ADA2 in their systems. That lack seems to play a role in destabilizing the lining of blood vessels, leading to a condition known as vasculitis.

Grundstad was formally diagnosed with vasculitis at the age of eight in 1997.

For **Andrew Grundstad**, a DADA2 patient in North Dakota, US, community is the small town where he has grown up and where he now works as an adult. For 30 years, Andrew's neighbors and friends supported his family when he had no answer for his symptoms. He now is diagnosed and still enjoys the same love and support from the same community, only today as a married man with a dream job he worked hard to achieve. [Read the full article](#) published this week by his local paper, [The Journal](#) in Divide County, and watch for more of his story in some special edition DADA2 newsletters next week.

The DADA2 Facebook Families and Friends page is a great place to find community, and to share stories and ideas among one another! Make sure you follow if you are a patient or caregiver (of course, a doctor should advise all your care). You can also find us on our other online communities below:



Who's Engaged in DADA2?



At our last conference in 2020, we welcomed researchers, clinicians, and other interested individuals from:

39 Countries
129 Cities
173 Institutions

IMPORTANT UPDATE:

The 4th International Conference on DADA2 is delayed to October 2023

Yes, we would like to see everyone sooner; however, we have been made aware of events around the world that are of interest to many in this community and would make travel difficult. We also anticipate much greater progress on our Website and Patient Registry by the Fall, which will make our time together more productive. Thank you for your understanding.

Mark Your Calendars: October 5 & 6 2023, in Bethesda, Maryland, U.S.A.

DONATE to The DADA2 Foundation

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