



# dada2

## FOUNDATION

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DRIVING TOWARD CONSENSUS

April 7, 2021

We are planning a patient & family gathering! We invite every DADA2 patient and family member to mark their calendars for **Friday, May 14th from 11:00 a.m. Eastern to 1:00 p.m. Eastern** and **Saturday, May 15th from 8:00 a.m. Eastern to 10:30 a.m. Eastern**. There is no perfectly convenient time given all of the timezones we are in, but we hope that this keeps the gathering in daytime hours for most and can flexibly work around work, school and sports/activities. Here's a quick sample of topics we'll cover:

- Updates on the science and clinical care for DADA2
- Conversations among patients and families on day-to-day life
- Status of the research on consensus and treatments in the future
- Post-conference connections and activities that can keep us all connected

*We intend this conference to be primarily for patients & families. If you are a researcher/clinician, please visit our [YouTube page](#) to view all sessions from our November 2020 scientific conference. If you have further questions, please feel free to contact us at [info@dada2.org](mailto:info@dada2.org).*

REGISTER TODAY

### Clinician Spotlight: Dr. Ombrello

Dr. Amanda Ombrello is the clinician at the National Institutes of Health in Washington, D.C., who is treating a global patient cohort. She's been working with DADA2 patients since before it was identified, and has stayed with the work for more than a decade. So what is she looking forward to? What's on the horizon for day-to-day care? [Take a few minutes to catch up with Dr. Ombrello.](#)



### Family Spotlight: The Puzio Family

Aisha's three girls were diagnosed with DADA2 in 2020 - in the middle of a pandemic. Can you imagine experiencing recurring fevers in April of 2020 with all the heightened awareness of fevers? It's possible you can! The Puzios wasted no time in finding the right care for their girls, and shared their story on social media in December. The result? Community, comfort, and even some investment from family

and friends to find a cure! [Check out their story.](#)



## Grants and Partnerships: What's On the Horizon?

We want to hear from you: *what grants could the DADA2 Foundation be of help in securing?* We know that research is underway across the globe, and while we are not a granting organization, we can work alongside in making connections, assisting in writing, or being a partnering non-profit organization as is required for some grants. Email us at [info@dada2.org](mailto:info@dada2.org) and let us know. In the meantime, [here's one grant](#) we are curious about to bring to the attention of this group. Let us know if we can be of help!

## OF NOTE

- As part of Rare Disease Day, Dr. Chip Chambers published an article in a major Tennessee newspaper about the lessons that today's COVID world is using from the rare disease community in finding treatments and cures, and an end to this pandemic. [Take a read.](#)
- Nashville, Tennessee, joined dozens of other locations around the United States to light up city monuments for Rare Disease Day. Below are just a few of the locations in the U.S. that lit up, but check out [this international list on Twitter!](#)



Delaware River Joint Toll Bridge in Pennsylvania



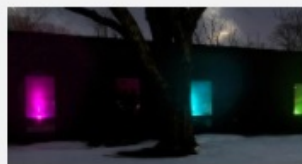
National Institutes of Health in Washington, DC



Zakim Bridge in Massachusetts



Governor Mario M. Cuomo Bridge in New York



NORD's Danbury Office in Connecticut



Korean Veterans Memorial Bridge in Tennessee

## GET INVOLVED

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**The DADA2 Foundation**  
Pursuing a cure for DADA2, together.  
Non-profit Organization Management · N

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meta [How it Works](#) [Discover Feeds](#)

#### Deficiency of Adenosine Deaminase 2 (DADA2)

First reported in 2014, deficiency of adenosine deaminase 2 (DADA2) is a genetic disease affecting the blood vessels and the immune system. This disease results in a range of symptoms that may include recurrent strokes, severe systemic inflammation, immune deficiency, and damage to many of the body's tissues and organs. As an extremely rare condition, there is still much to learn. Find the latest research on DADA2 in this feed.

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February 23, 2021

**Clinical Features and Outcomes of Childhood Polyarteritis Nodosa: A Single Referral Center Experience.**

Modern Rheumatology  
Nilsde Tekatze MD, Borna Acar

**LATEST DADA2 PAPERS**  
We're partnering with Meta to [bring the latest papers.](#)