



dada2

FOUNDATION



DRIVING TOWARD CONSENSUS

January 2023

Dear DADA2 Community:

Welcome to a new year of discoveries, collaboration, and encouragement with the DADA2 Foundation and every one of us who is working to treat and cure this disease!

I just have to start with this: at the end of 2022, we did it. We met AND exceeded our fundraising goal. Altogether, **this community raised more than \$105,000 in November and December!** This is most we have ever raised at a year end, and also includes more individual donors than we have ever had before.



I have one word: grateful. I am grateful for the funds, yes, because we can invest in the mission of the Foundation to foster collaboration that will find a cure. But I am more grateful for what those funds mean. It means that the work that this network is doing – in the labs, the clinic rooms, the late nights asking questions and learning, and the conversations around conference room and dinner tables – is all leading somewhere. It means more and more people are taking notice of this disease that affects people today but is affecting so many more people who don't yet know it.

These funds will help us have possibly the most momentous year we've had since our founding. We will launch the Patient Registry in the near future and we will host a conference (see updated dates below), which means we will get to see each other again in person! We are so grateful for that.

I know a lot of behind the scenes work is happening throughout this network. In today's edition, take a look at an interview with Dr. Kelly Brown and Sarah Bowers, Ph.D. candidate, in Vancouver, which highlights their work on mutations in the ADA2 gene. Then, we invite your feedback for our new website, which we will launch this year with so many more resources than we currently have.

We hope your New Year is off to a happy and healthy start. If you need anything from us, please don't hesitate to reach out!

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

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.

Mutations & What Do They Mean



Mutations are one of the most complex aspects of any genetic disease. Dr. Kelly Brown and Sarah Bowers, a Ph.D. candidate, at University of British Columbia in Vancouver, British Columbia, Canada, are dedicating time and attention to learning more about the various impacts of mutations on the ADA2 gene. Their research produced some anticipated outcomes, and some new ones. [Watch their video](#) and [read the full study here](#).

Help Us with the *new* DADA2.org

We are completely revamping the DADA2 website in 2023. We have some great ideas that we've dreamed up and that other rare disease organizations use, but we want to hear more ideas from you!

Send us an email by January 25 so that we can evaluate ideas and potentially add them to the site. We want this to be as useful to newly and formerly diagnosed patients, to researchers, and to clinicians.

Thank you for taking the time!

And while you're thinking about the website, please be sure to follow each of our social media properties wherever you like to get updates!



Tell Us Your Thoughts!

It's a blank canvas and we need your ideas!



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Publications of Note this Month

Patient Update: Adela Wee

"I believe that my experience can help other patients, and my enthusiasm about my rare condition generally helps to get other medical professionals excited as well."

Adela is a robotics engineer. She's used to asking questions and living in the middle of curiosity and discovery. It's exhilarating and fulfilling in her career; and as a DADA2 patient, Adela takes that same approach to learning about her disease and lending an infectious energy to those around her. She's learned about the Patient Registry and knows it can lead to more answers, more drug therapies, and a cure one day. And, as a speaker at our conferences, she's experienced the impact that gathering can have for patients to get to know one another and share experiences. Read below for more of her story and what she's excited about for DADA2 discovery in 2023!

Tell us briefly about your DADA2 journey?

Like many others, I had symptoms of low grade fever and joint pains, and as I grew older the joint pains and skin rashes would come and go, with few answers. In my late teens and into my 20s, I had a diagnosis of vasculitis, but was being treated with immunosuppressants that were targeting my symptoms, rather than the actual cause. It was frustrating to be put on "better" treatments that didn't resolve many of my existing issues. So after consulting some genetics experts, I found that I had the mutation described in literature about DADA2, and soon after I was admitted into the study at the NIH. Since that point I have been relatively normal, but I am dependent on a drug technology that may not work forever and still leaves me immunocompromised. With improvements in protein and gene therapy, I am eager to see what cures might be possible for this rare disease!

What does your day-to-day look like and how does DADA2 impact it?

I've been fortunate to be well enough to pursue my career in robotics engineering, so much so that in the past year I co-founded an engineering firm focused on sensor development and automated onshore manufacturing. I'm constantly learning new things and thinking of ways to challenge the status quo and push in new directions. It's been a great personal opportunity. Sometimes managing the stress is challenging because I know that my mutation is always there, and I don't want to make any excuses based on my pre-existing condition. Additionally, the medication coverage can vary from year to year depending on the insurance plan. But overall, the current anti-TNF therapy has really helped to make sure that I can pursue a challenging, fulfilling career in groundbreaking technology.

When you heard about the Patient Registry, what did you think?

From previous discussions with other professionals in the pharmaceuticals field, it was very obvious that a Patient Registry would help to build up the evidence needed to convince any companies to invest in finding a better long-term solution. So I am excited for the opportunity this registry will bring.

How do you think your experience as a patient can contribute to the research of DADA2?

I consider myself one of the lucky ones that have made it to being able to pursue a career. I very much enjoy digging into the science behind my condition. Of course I believe that my experience can help other patients, and my enthusiasm about my rare condition generally helps to get other medical professionals excited as well.

Switching gears, tell us about your experience at the DADA2 Conferences in the past. What benefit do you as a patient see from the conference?

The conference is a great way for the patients from around the world to meet each other, and share experiences and information. I think it's also a great time for us to all learn about the science and the research that is happening in the field as well.

What do you hope for DADA2 research and discovery in 2023, knowing we will have more data and more collaboration this coming year?

I am hopeful to hear in more detail about the research, specifically if there are improvements to the treatments, models, or understanding of the mechanisms behind the disease.

Your generosity in 2022 blew us
away!

Thank you for giving so
significantly.

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Amazon has announced that AmazonSmile will
wind down by the end of February, so make it
count this month with us!

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