



dada2

FOUNDATION

In this issue:

Letter from Chip

DADA2 Twin Study

#RAREis Video

Upcoming Programs

Research Roundup

DRIVING TOWARD CONSENSUS

Nov. 16, 2022

The year is coming to a close...*but not just yet!* There is still so much more to do in 2022.

As you'll see from this month's newsletter, sometimes you can learn even more from something that has been there since the beginning! Our feature story tells just that – about researchers and a set of now-adult twins who both are DADA2 patients. While they have been in the care of Drs. Barzaghi and Mortellaro for five years, they are just now publishing the impact of DADA2 on the sisters' genetically identical makeup, but different expression of the disease.



From their study, they can conclude this: there are more questions to answer! The key is this - STAY CURIOUS.

As we close 2022 and look toward a great, new year for the Foundation, we are continuing to ask the questions that will lead to a cure one day. In 2023, we will embark on two important initiatives. First, we will launch our DADA2 Patient Registry. Second, we are planning to hold an international conference for researchers, clinicians and patients – *in person* in the US. Answering each of these questions through research and conversation will one day end the diagnostic odyssey for so many DADA2 patients who don't yet know the cause of their symptoms. Join us, won't you? Ask the questions with us.

Sincerely,

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

Global updates

Anna Maria Beretta and Veronica Beretta are identical twins. They both have DADA2. They grew up in the same home living very similar lives to one another. Yet their experiences of living with DADA2 are different. Both experienced strokes as children, but years apart. Anna Maria required a bone marrow transplant for neutropenia in her twenties while Veronica relies on anti-TNF treatments. They each experience aspects of the different expressions of DADA2. How is that possible?

The twins' team of doctors and researchers have been studying their case since their diagnosis, and with our two clinical leaders in today's video - Drs. Mortellaro and Barzaghi - for the last five years. We are thrilled to highlight the milestone in their work: the publishing of a longitudinal study of DADA2 in

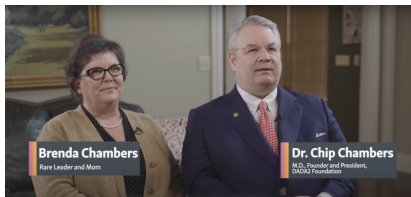
genetically identical twins. What's just as exciting about what they DID discover is what questions they can now tackle in the FUTURE because of what they learned. Watch this video to hear about the study, which you can read here. [Watch our video with closed captions here:](#)



Set Your Reminders for 2023

This coming year will be a landmark one for the DADA2 Foundation and for the DADA2 community around the world. Keep your eyes and ears open for announcements soon on these upcoming efforts and how you can be involved, because none of them will happen without the engagement of everyone on this list.

1. First, we will **launch the first-ever DADA2 Patient Registry**, which will essentially shine a spotlight on DADA2 by creating a secure database of as much DADA2 information as we can find. It will house clinical data, but will also include patient-reported data about what it's like to live with DADA2. Then, it can all be mined by researchers and clinicians who are moving closer to a cure. We look forward to inviting you to participate soon!
2. Second, we are **planning to host the 4th International Conference on DADA2 in Washington, D.C., U.S.A.** Dates will likely be in late Spring, so watch for those in the coming weeks. We will do all we can to ensure that as many people who want to be here can be here – from patients to clinicians to researchers. If you or your company are interested in being a corporate sponsor, please let us know. We have a team dedicated to creating a partnership to underwrite the conference so that we can create an incredible experience for all.
3. Third, we will **launch a new website** that will showcase more information on DADA2. We know that our Foundation is the first place many doctors refer their patients to after a diagnosis, so we want to make it easier to take that first step confidently as a DADA2 patient.



What Will You Do with your DADA2 Story?

How did the DADA2 Foundation start? Well, much like many patients' journeys – with mysterious symptoms in one family. Each of us reacts differently to a diagnosis of a rare disease, and for Chip and Brenda Chambers, their next step after identifying the cause of their children's illness was to form a Foundation. [Watch the video here.](#) We are grateful to Horizon

Therapeutics and the RARE IS group for helping to tell our story. **We hope it inspires you to answer: *what will I do with my DADA2 story?***

Other publications of note

Check out these recently published papers on DADA2, all completed by researchers around the world.

- [Pathogenic variant found](#)

- [Immunoglobulin response & DADA2](#)
- [DADA2 as consideration for cPAN](#)

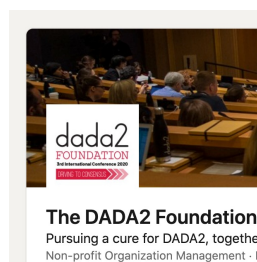
Keep us in Mind for Year End Giving

In just a few weeks, we will announce our **2022 End of Year Giving Campaign**. Last year, you helped us raise \$20,000 in just a matter of a few weeks. This year, we have an even greater goal because we have so much to do! As you think about giving this year, we ask that you will consider a donation to the DADA2 Foundation and watch for emails regarding what your contribution can do in the coming year. In the meantime, be sure to set your Amazon Smile account to DADA2 so that all of your holiday purchases can benefit the Foundation!

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DADA2 Foundation | 7051 Hwy 70 South #353, Nashville, TN 37221-2207

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