



dada2 FOUNDATION

SPECIAL
EDITION

The DADA2
Foundation
MOMENTUM REPORT

DRIVING TOWARD CONSENSUS

November 18, 2021

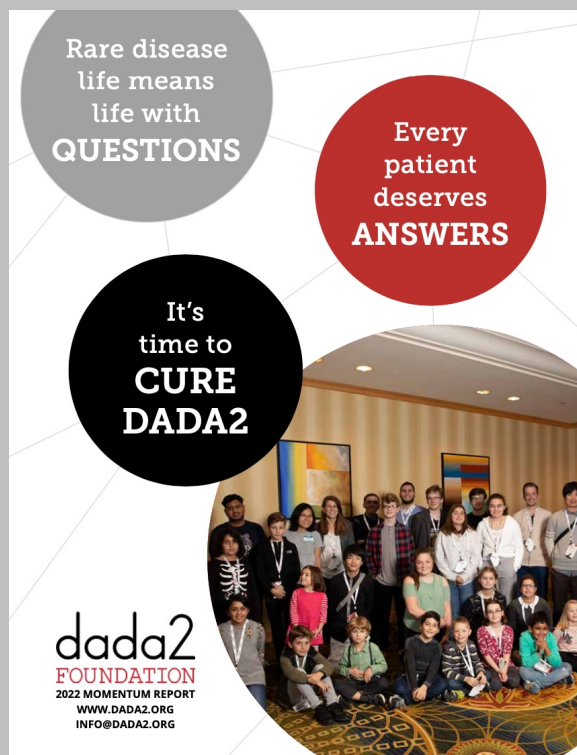
THE FIRST-EVER DADA2 FOUNDATION MOMENTUM REPORT

This is a special edition of the DADA2 Foundation Newsletter, *Driving Toward Consensus*. In this report, instead of looking at what has happened, we look ahead to all we have planned. That ability to look ahead with so much vigor is because of the work of this community. So, we thank you!

Highlights in the Report:

We are so thrilled to share with you the big questions we are answering in 2022:

- **Just how big is the DADA2 Community?** There are more DADA2 patients yet to be diagnosed than we may have ever thought possible. Through a prevalence study published this year, we learned that there may be as many as 35,000 worldwide! Today, we only know of +/- 600, so there is a long way to go.
- **What do we not yet know about ADA2?** We are expanding our scope from focusing on international conferences to adding to the scientific understanding of the disease. You will see those six initiatives highlighted in the center pages of this report.
- **What can we learn about DADA2?** Specifically, we are ready – and already deeply invested in - launching a Natural History Study and Patient Registry that will create a repository of information on patient data for researchers and clinicians to learn from. The next edition of our newsletter will focus on the Registry.



A NOTE FROM OUR FOUNDER

Chip Chambers, M.D.

It is with immense humility and gratefulness that I get to write this letter to you, and more importantly,

present to you the first Momentum Report for The DADA2 Foundation.

What is in these pages represents the collective work of 500+ scientists, doctors, hundreds of patients, and countless hours of work to take the next steps in understanding DADA2 - the Deficiency of Adenosine Deaminase 2. Even in the midst of a global pandemic, the commitment to finding a cure for this disease has not waned.

In fact, the desire to answer the biggest questions about DADA2 is growing.

I am encouraged every day by the energy shared among our research community, the curiosity of clinicians who seek the best way to care for patients, and the determination of patients and families to live their life to the fullest in the face of a rare diagnosis.

How will we get there? With your help, we will. And, the DADA2 Foundation itself is growing to support the work. We now have staff and contractors who are using their skills honed in other industries and areas of expertise to help make all of this happen.

As I reflected on the last several years, we simply thought it was time to update you with the content of what's in this book. If you would like a printed version, simply fill out this form and we will mail it to you. Then, share this book with your colleagues, family, and friends. Tell them your story of being involved with DADA2. Most importantly, share why you are eager to see all of these critical questions answered.

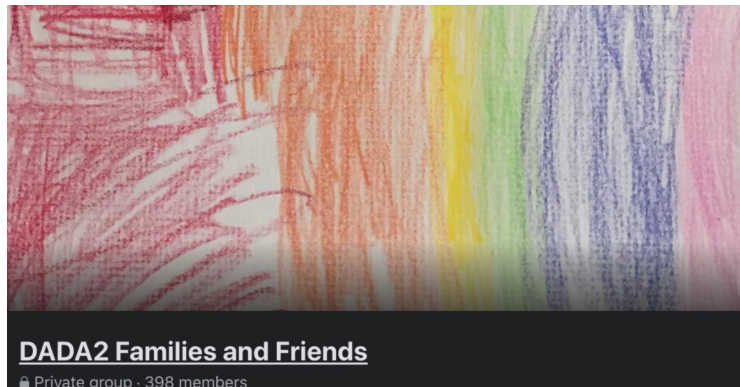
Finally, thank you for your interest and investment in DADA2. We could not be where we are today without you.

Sincerely,

SUPPORTING EACH OTHER: Private Facebook Families and Friends Page

For several years, our community of patients has banded together on a closed Facebook Group specifically designed to encourage and inform newly-diagnosed families as well as those who have been living with the disease for a long time. On that page, patients share tips and tricks of how to give medications, what next steps to take and how to get the next level of care. While none of this advice is intended to replace that of a medical doctor or care team - we

always encourage patients to seek next steps with their provider first - this group has proven to be a great resource. We share this resource to our community's clinicians to pass on to their patients. You can access the group [here](#). You can also follow our other social media properties on Twitter, LinkedIn or our Foundation's Public Facebook Page.



DONATE to The DADA2 Foundation

We would love to be a part of your year-end giving. Please consider a donation to the DADA2 Foundation if you are able. Otherwise, know that we are immensely grateful for your engagement!

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

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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

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