

PURSUING WHAT'S POSSIBLE

IMPACT & VISION

dada2
FOUNDATION
WWW.DADA2.ORG

A DECADE OF MILESTONES
A FUTURE OF POSSIBILITY

The DADA2 Foundation began with the passion of a patient family and an unbridled spirit to connect global researchers around the goal of curing DADA2.

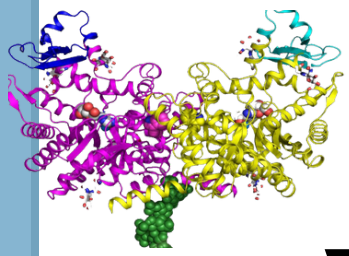
Following more than ten years of searching for answers for his daughter's symptoms, Dr. Chip Chambers ended their diagnostic odyssey at the National Institutes of Health in the United States where a new disease - deficiency of adenosine deaminase 2 (DADA2) - had been discovered alongside researchers in Israel. There, Dr. Chambers not only found treatment for his two diagnosed children, but also a global network of clinicians and researchers intent on finding answers with them.

That same spirit drives us today, where **a next wave of partnership and investment is the only thing that stands in the way of faster diagnosis, targeted treatment, and a cure for DADA2.** With the dedication of our network of researchers, clinicians, and patients, we are ready for what's next. We invite you to **join us in Pursuing What's Possible.**

DADA2 DISCOVERED

2014

The first papers identifying DADA2 published in the New England Journal of Medicine (NEJM) by teams at the National Institutes of Health in the U.S. and in Jerusalem, Israel.



DADA2 FOUNDATION FOUNDED

2016

Following the diagnosis of both of his children, Dr. Chip Chambers established the DADA2 Foundation to unite patients, physicians, and researchers around a shared mission: curing DADA2.

dada2 FOUNDATION

FIRST GLOBAL SCIENTIFIC CONFERENCE

2016

The Foundation convened the world's first conference on DADA2 with 136 scientists and clinicians from 16 countries, in addition to 69 patients & family members from six countries. During this gathering, the bone marrow phenotype was discovered.



ICD-10 CODE

2018

Just four years after the disease was discovered and named, the Foundation worked to establish an ICD-10 code - D81.32 - leading to faster and more certain diagnosis and treatment opportunities.



RARE AS ONE COHORT

2020

The Chan Zuckerberg Initiative - founded by Mark Zuckerberg and Dr. Priscilla Chan - awards the Rare As One Cohort grant totaling $450,000, to support capacity-building. The Foundation hires staff, launches an interactive website, and begins relationship with global organizations.

RARE AS ONE PROJECT

CONFERENCES CONVENE



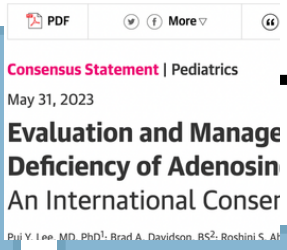
2018, 2020, 2023

Researchers and clinicians continue to gather for international scientific conferences hosted by the Foundation - including a virtual gathering during the global COVID-19 pandemic. Genetic therapy was first discussed at the 2018 meeting, pursued within 18 months at two global research sites.

PREVALENCE STUDY

2021

With the Broad Institute at Massachusetts Institute of Technology (MIT), the Foundation publishes a prevalence study revealing the possibility of 35,000 patients worldwide and a carrier frequency of 1 in 237. As of 2026, 800+ patients are known.



CONSENSUS STATEMENT

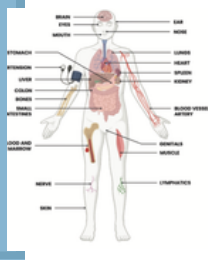
2023

A result of the 2020 conference, the DADA2 Consensus Statement publishes in the Journal of the American Medical Association, offering guidelines for diagnosis, treatment, and next steps in discovery with collaboration from 35 researchers, 3 patient families, and the Foundation.

PEG-ADA2 ACQUIRED

2023

Through a gifted acquisition, the DADA2 Foundation takes ownership of the PEG-ADA2 enzyme for future development into a treatment. As of 2026, the Foundation holds patents in 31 countries.



ADA2 NOW METER



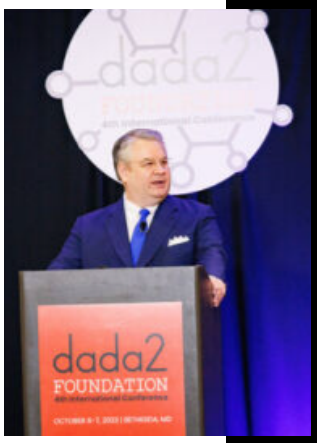
2023-2025

The Foundation co-develops a prototype, point-of-care test which would allow DADA2 diagnosis in 15 minutes with a simple finger prick blood sample.

A Letter from our Founder

DIAGNOSTIC ODYSSEY TO GLOBAL MOVEMENT

A parent doesn't stop - especially one whose professional background aligns with their child's greatest challenge.



Since 2016, our quest for a cure for DADA2 has unfolded to an inflection point that will determine the future of every family and patient facing this disease.

Over the last ten years, partners have helped us progress toward a cure for DADA2 - **establishing the DADA2 Foundation as a central hub of a worldwide community including:**

- A network of 30+ labs around the globe who relentlessly study all aspects of DADA2 including diagnosis, mechanism, and treatments, publishing 20% of all DADA2 papers to date.
- Hundreds of physicians diagnosing DADA2 in the 800+ known patients. We are also always keeping an eye out for the remaining 34,000 patients that prevalence studies say are undiagnosed.
- Patients raising awareness and funds to support the Foundation in our daily effort to counsel patients and physicians on disease next steps, bring researchers together at conferences, and communicate to a global audience.

Today, we believe it is only a matter of time before we find the right partners and support to identify a cure specifically for DADA2 - both a treatment now and a genetic therapy in the future.

As I look forward, **I can see the path ahead - the Path to Possibility that will answer questions and create solutions.** Partnership - in both cases - has been and will continue to be the lynchpin to curing DADA2. So I thank you for the past ten years and invite you into the next ten years.

With gratitude,

Chip Chambers, M.D., Founder & President, The DADA2 Foundation

THE PATH TO POSSIBILITY

FASTER DIAGNOSIS

The **ADA2 Now Meter** is in development. Coupled with greater awareness, the Meter enables diagnosis in as little as 15 minutes by measuring a blood enzyme level.

NEW TREATMENT

The DADA2 Foundation owns the **PEG-ADA2** enzyme and is pursuing a new therapeutic to replace missing ADA2 enzyme in patients. At the same time, **genetic therapy** is being researched.

CONTINUED DISCOVERY

A Patient Registry, scientific conferences and collaboration, and **patient support** will continue across the world to push the limits of discovery.

OUR VISION

To see a world cured of DADA2

OUR MISSION

The DADA2 Foundation aims to find innovative ways for patients and families, physicians, researchers, non-profits, government, academia, biotech and pharma, to work together to accelerate research into the rare disease Deficiency of Adenosine Deaminase 2, to raise awareness about the condition, and to improve the lives of DADA2 patients around the world.

WHAT IS DADA2?

Deficiency of Adenosine Deaminase 2 (DADA2) is a rare autosomal recessive genetic disease caused by mutations in the ADA2 gene.

There are three phenotypes. The disease can affect blood vessels, the immune system, and bone marrow. In addition to daily pain and symptoms, patients may experience severe inflammation, recurrent infections, stroke, anemia, and bone marrow failure.

DIAGNOSIS GAP & PREVALENCE

In 2021, the DADA2 Foundation and Dr. Pui Lee published a study with the MIT Broad Institute that estimates nearly 35,000 patients may exist. As of 2026, **we know of only 800+ of those patients based on published literature.**
Carrier frequency - a measure of how many individuals simply carry the genetic deficiency - is estimated at 1 in 237 people globally. Researchers are actively studying the symptomatic impact of being a carrier.

AN INCOMPLETE TREATMENT

There is no one treatment for all DADA2 phenotypes. The treatments we do have only treat symptoms, not the root cause.

Today, patients often wait more than one year for their disease to be recognized and confirmed, enduring pain, fevers, and the potential for adverse events like stroke and bone marrow failure.

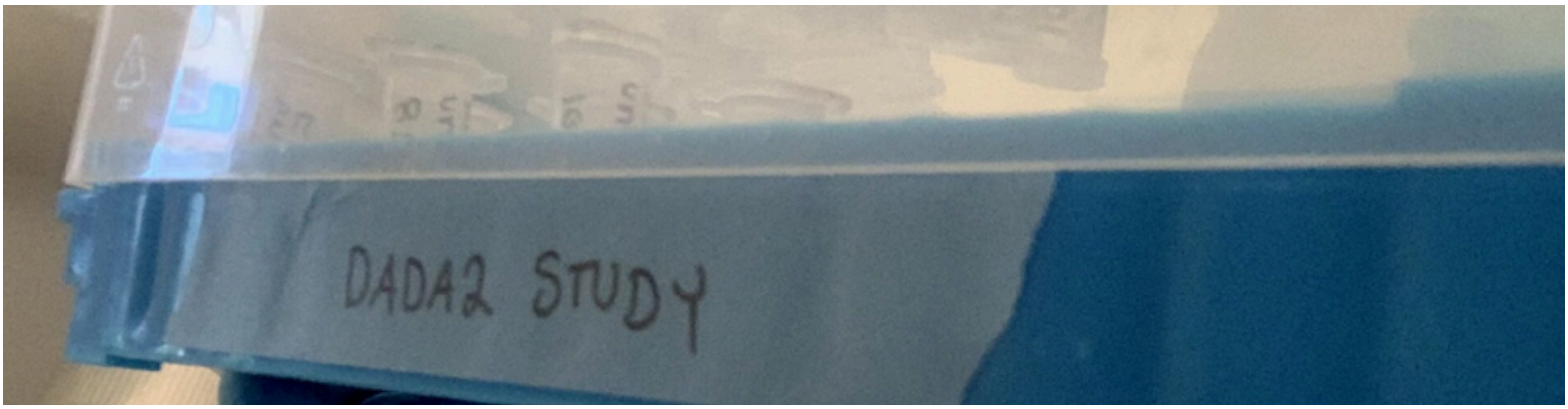
TNF inhibitors, when finally prescribed, lead to management of the inflammation that results from DADA2 but are not a true treatment or a cure. Further, it is only effective for one of the three phenotypes.



Every undiagnosed patient - symbolically in red above - represents the opportunity to prevent irreversible complications and improve outcomes and quality of life.

IMPACT FOCUS #1

CONNECTING THE RESEARCH NETWORK THAT WILL FIND A CURE



The DADA2 Foundation is the hub of the world's only research network focused on this disease, serving as a convener, connector, and collaborator.

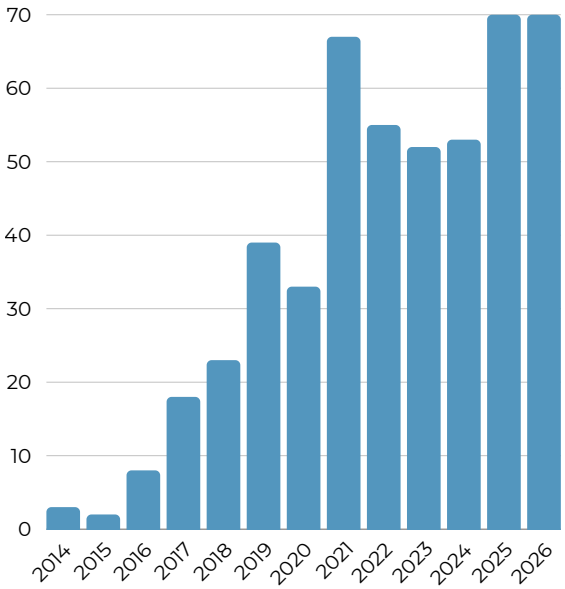
Our approach to research has never been linear. Instead, we see scientific discovery best accomplished in a web format, where one point of inquiry or one discovery is shared among many experts, who then pursue avenues of understanding and share that knowledge.

This approach has led us to:

- Host four international conferences
- Invest in global research meetings
- Keep in constant communication with global researchers
- Make connections among researchers representing
- Talk to patients on a weekly basis who need guidance

Published Paper Growth

Source: PubMed, 2026 = annualized estimate



Total: 475+

READ EVERY PUBLISHED DADA2 PAPER

Source: Google Scholar

View How Discovery Happens in the DADA2 Network

Scan or click

Dr. Chambers talks about the "web" approach to discovery
Global Health Innovators Conference
Nashville, TN, USA 2025

Essential talks about DADA2
Featuring global researchers.







In 2016, we hosted the first conference alongside support from Dan Kastner, M.D., Ph.D. who served as Scientific Director of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH) in Washington, DC. Since then, researchers have come to anticipate meetings organized by the DADA2 Foundation.

Through these global conferences, the DADA2 research community has advanced its understanding of critical aspects of the disease, leading to further discovery on disease presentation, carrier status, genetic therapy, and other critical topics.

Webinar meetings and collaboration continue to take place, engaging the widest possible research community while also hosting focused meetings on specific topics.

WHAT'S POSSIBLE:

The DADA2 Foundation will:

- Continue to **host meetings** that bring the global community together
- Build a **patient registry platform** that informs clinicians, researchers, and pharma on patient experience living with DADA2
- Set scientific agendas for future collaborative discovery
- Pursue **updated prevalence understanding** of the disease

Across four International Conferences, 250+ attendees have represented...

24	89	142	100+	93
COUNTRIES	NON-US PHYSICIANS & SCIENTISTS	US PHYSICIANS & SCIENTISTS	WORLDWIDE CITIES	WORLDWIDE INSTITUTIONS

IMPACT FOCUS #2

GROWING RESOURCES & AWARENESS SO PHYSICIANS CAN DIAGNOSE FASTER



Knowledgeable physicians are critical for quick diagnosis. They are the key to finding the 34,000 estimated undiagnosed patients around the world.

Our goal is to reach the specialties who would most likely encounter an undiagnosed DADA2 patient or a diagnosed patient who needs updated care:

- Rheumatologist
- Pediatrician
- Hematologist
- Immunologist
- Neurologist
- Emergency Room

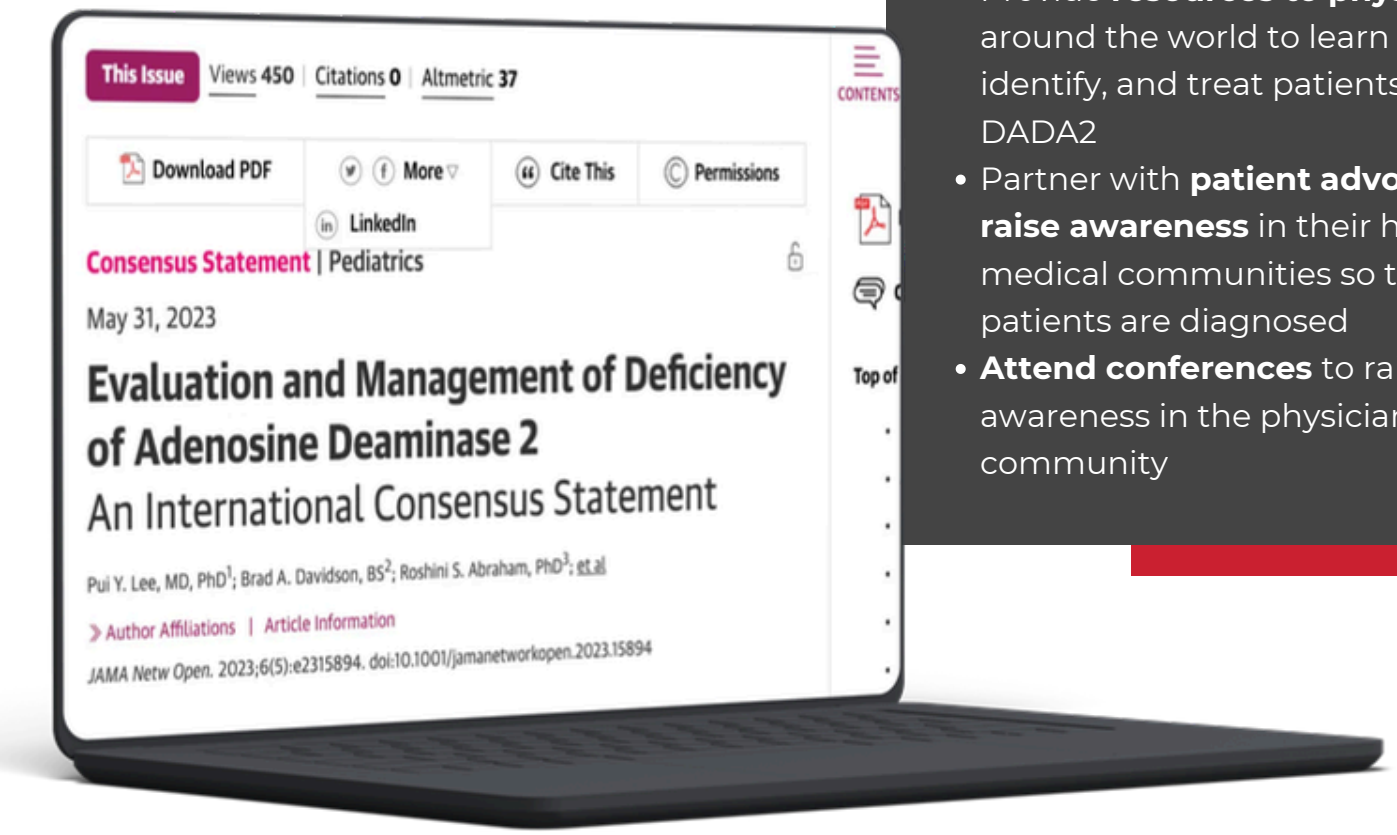
We will continue to share about DADA2 through Grand Rounds presentations throughout the world. Email us to invite a live or recorded speaker.

Increased Diagnosis will Fuel a Patient Registry

A Patient Registry is in our sights - which fuels further discovery on disease manifestations and provides patients an outlet to be a critical part of disease discovery.

Learn more about the status of our patient registry efforts:

Scan or click



WHAT'S POSSIBLE:

The DADA2 Foundation will:

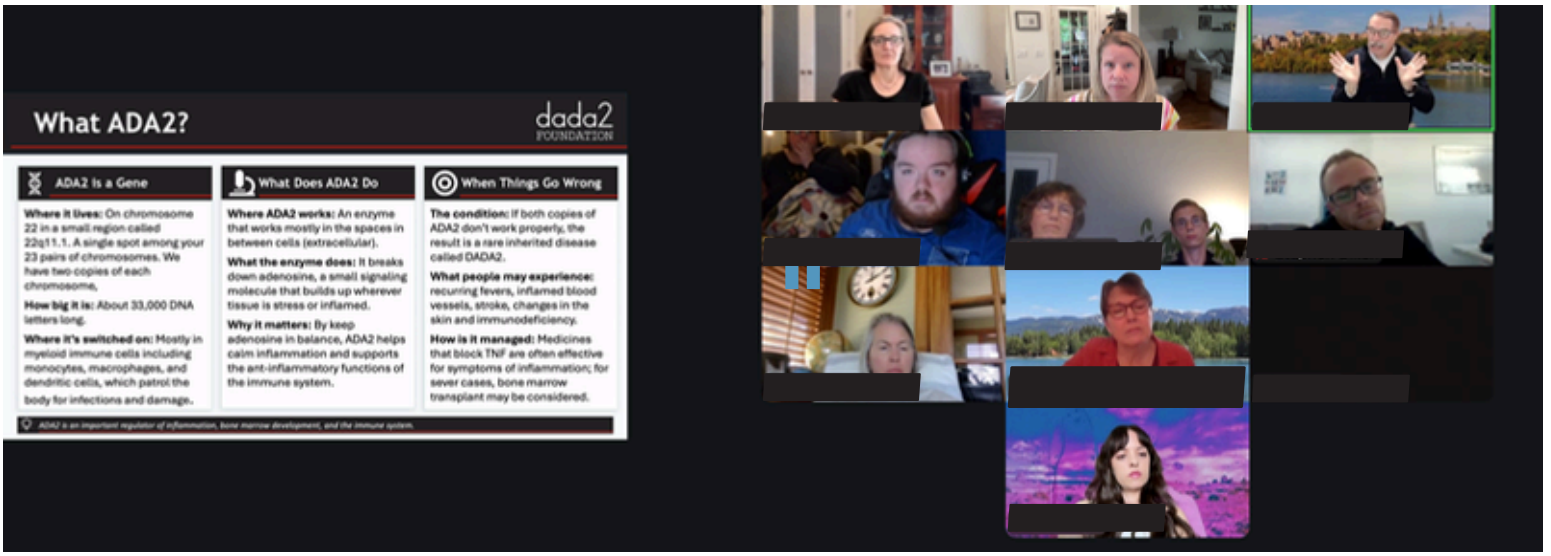
- Provide **resources to physicians** around the world to learn about, identify, and treat patients with DADA2
- Partner with **patient advocates to raise awareness** in their home medical communities so that more patients are diagnosed
- **Attend conferences** to raise awareness in the physician community

RESOURCES AVAILABLE TO PHYSICIANS

- Diagnostic resources connecting clinics to global labs
- Online symptom tracker to understand disease process on entire body
- Online info available in all global languages, with printed brochures available in 7 languages
- Info line for emergent and ongoing consult via info@dada2.org

IMPACT FOCUS #3

SUPPORTING PATIENTS SO LIFE HAS MORE ANSWERS



Patients are the reason we exist.

For many, the path to diagnosis is months to years long. It is arduous, and with every month that passes, the disease damages tissue and can threaten stroke.

Hear about their stories in their own words:



@dada2foundation

While scientific discovery and clinical care take place, the DADA2 Foundation engages with patients every day to help them understand their disease, connect them with resources, and empower them to advocate for their own care and for the care of others who are not yet diagnosed.

MEET PATIENTS



Scan or click

*As a child, **Andy** grew up in pain with few answers. When he was finally diagnosed in 2021, and started on TNF inhibitors, he was able to live life more fully. Andy is now married, a father, and a trusted agronomist in his community. He is also an avid advocate for the rare disease community, having shared his story online, on the radio, and with local groups.*

REGULAR WEBINARS

We host quarterly webinars for patients featuring disease experts on specific topics. On any given webinar, 15+ countries are represented by patients and families curious to know more about DADA2.

ON CALL

The Foundation answers patient emails nearly weekly - from newly diagnosed patients to those seeking a next idea for their care. With advice to always consult their medical team, we offer ideas to consider.

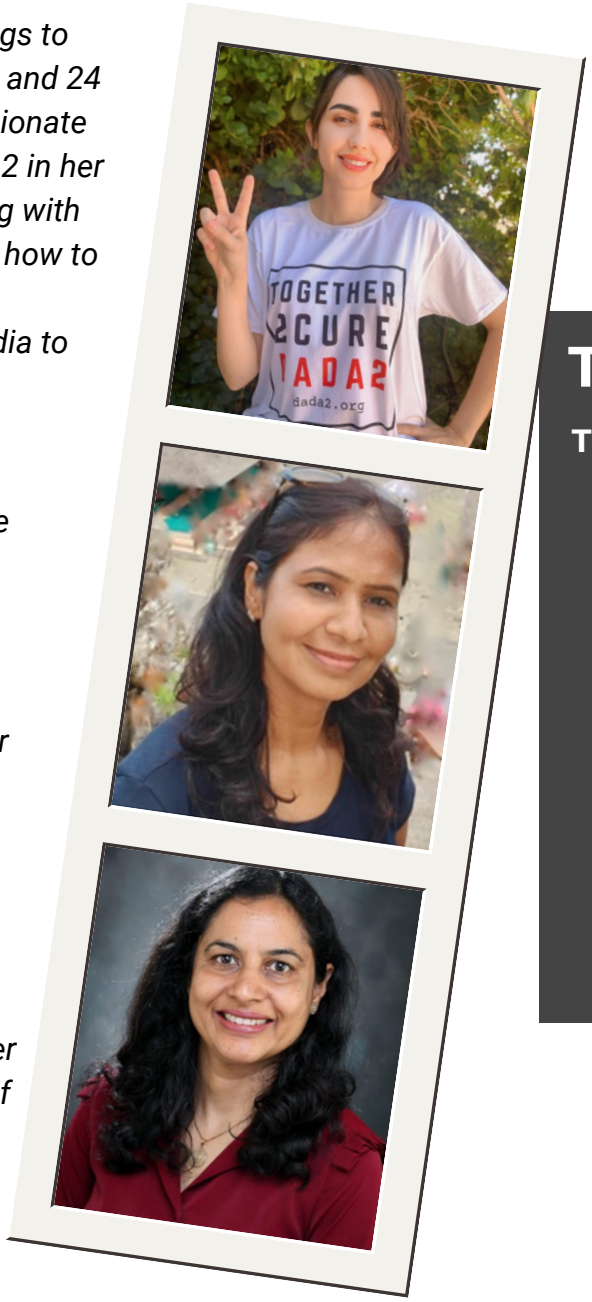
FAMILY GROUP

Patients connect with one another on our 500+ person Family & Friends Facebook Group - a closed group where support, questions about daily life and disease management can be asked.

Elnaz *lost two of her siblings to DADA2 when they were 20 and 24 years old. She is now passionate about sharing about DADA2 in her home community, speaking with physicians regularly about how to spot DADA2. She also collaborates on social media to raise awareness.*

Pooja G. *is a patient living with DADA2 in India, where DADA2 seems to be more prevalent in certain communities. She has advocated for medication coverage in her country for DADA2 treatment.*

Also in India, ***Pooja G.*** *founded the Vasculitis Society and partners with physician groups to host testing days in honor of her son who died as a result of DADA2 complications.*



THE FUTURE

The DADA2 Foundation will:

- Connect with **patients as they reach out** to help them take a next step in their care
- Provide **regular webinars** and resources through online communication
- Organize active **patients to support the mission** of the Foundation with their talents

WHAT'S NEXT

PURSUING WHAT'S POSSIBLE: DADA2 IN 2026–2030



> My daughter was diagnosed with DADA2 soon after it was discovered, after she'd had two massive strokes at two years old. The progress the DADA2 Foundation and global researchers have made in the last few years is extraordinary.
>
> **But families like ours need more treatment options.** With the right support, the foundation will be able to work a lot faster and get us closer to a cure.
>
> *Katherine Bell, DADA2 Parent & Board Member*

WE ARE CLOSER THAN EVER

Imagine a time in the not-too-distant future when a patient can present with symptoms and a physician has the knowledge to suspect DADA2. That physician can complete a point-of-care ADA2 enzyme level test in 15 minutes, confirm with genetic testing, and prescribe a treatment specifically for DADA2. That scenario is within reach.

THE PATH TO POSSIBILITY



UNDERSTAND MORE:
The DADA2 Registry

Building on 10+ years of patient connection, we will build on our phase I patient registry to create a full-fledged natural history study of medical care.

Collaborators:
- Patients & Physicians
- Tech Platform

Cost: $200,000 annually
Timeline: 2029

DIAGNOSE FASTER:
ADA2 Now Meter

We will pursue final meter development that is the foundation for prototype production and clinical trials.

Collaborators:
- Existing development partner
- Go-to-market partner

Cost: $600,000
Timeline: 2028

TREAT THE DISEASE:
PEG-ADA2

Rooted in our proof-of-concept plan, we will partner with a pharmaceutical company who can fully develop the enzyme replacement therapy.

Collaborators:
- Capital Investors
- Pharma Partner

Cost: $900,000
Timeline: mid-2028

A SUSTAINABLE FUTURE

Full clinical trials & FDA approval of PEG-ADA2 as the only treatment of DADA2 .

Point-of-care testing device with results in 15 minutes.

Engaged patients contributing continuous data that offers more full understanding of DADA2.

Collaboration with global researchers & pharma partners on gene therapy development.

REMEMBERING OUR PIONEER
DR. DAN KASTNER, THE HUMAN SCIENTIST



Dr. Dan Kastner, M.D., Ph.D., is a co-discoverer of DADA2. His research while serving as Scientific Director of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH) in Washington, DC, USA, surged DADA2 into a global research spotlight.

But we, as patients and families who benefited so deeply from his discovery, have to speak of him by his first name for a moment. **That is who Dan was: the human scientist.**

Across more than ten years, Dan never failed to ask about families. He was far more than a researcher; he possessed a rare depth of humanity, and understood, in a way few do, that while science matters profoundly, it exists to serve human beings.

Few know that Dan began his career with a Bachelor of Arts in philosophy. Perhaps this foundation nurtured the intellectual curiosity that would later define his career in medical research. A true Renaissance man, Dan went on to investigate a wide range of autoinflammatory diseases, traveling the world in pursuit of answers.

It was a fortuitous connection with Dan at the NIH that inspired Dr. Chambers to form the Foundation and host the first global scientific meeting on DADA2 - alongside receiving the right treatment for his children. Dr. Chambers arranged a meeting with Dan's team to discuss hosting a conference, but the entire lab arrived prepared to discuss the science of DADA2 at length. In the final minutes, Dan explained that his team could neither fund nor host the meeting. Dr. Chambers replied, "That's just fine — I have that covered. So let's set a date." He agreed without hesitation, the date was set, and Dr. Chambers then went home to start the Foundation and raise the funds.

Dan's sustained presence helped turn the early DADA2 meetings into a global research community. It was this investment — reflected, in part, in his continued moderation of those meetings — that likely helped grow the DADA2 research community into one of the most notable of its kind. His dedication and considerable intellect drew many researchers to those early gatherings, and his sustained engagement helped keep them involved, encouraging a number to establish laboratories of their own. While Dan remains DADA2's founding researcher, the disease is now fortunate to be studied by laboratories around the world, each pursuing treatments and, ultimately, a cure.

Dan also welcomed a good question, from wherever it came. He entertained countless lines of inquiry — about patient experiences and needs as well as science. No question struck him as too unlikely to merit real conversation. His researcher's mind moved easily between the clinical and the scientific, and that fluency likely drove progress toward understanding both the patients and the disease itself.

Yet amid the rigorous science, the searching conversations, and the sheer intellect, Dan always made time for his patients. DADA2's devastating toll on children, including the strokes it can cause, may have been what drew him to invest so deeply in the disease.

Dr. Kastner — Dan — is missed. He always will be. So, we thank Dan. We thank his family for sharing him with the scientific community, and with the countless individuals whose lives have been touched by rare disease. His impact will extend further than any of ours — until a cure is found.

CONNECT WITH US:

Get the monthly newsletter with updates on research, patient stories, and Foundation growth:



FOLLOW US:

@dada2foundation

@dada2-foundation

SUPPORT US:

We would love to share more about the Foundation's future and talk about your partnership capacity with the DADA2 Foundation. Please reach out to us at info@dada2.org to start a conversation.

EIN: 81-2686038

Make a donation through:

- **One-time**
- **Recurring**
- **Stock**
- **Legacy planning**

PHONE :
(615) 647-8790

WEBSITE :
www.dada2.org

ADDRESS :
7051 Hwy 70 South #353, Nashville, TN 37221

EMAIL :
info@dada2.org


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FOUNDATION
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THE PATH TO POSSIBILITY
ADVANCEMENTS THRU 2030

As of 2026, the DADA2 Foundation is at an inflection point. With significant possible pursuits on our horizon, we are in need of a new wave of partners to carry us through the next four years of discovery. We have the assets, we have the staff, and we have the network. Now, we need the partners - advisory and financial - to help us make it happen.

NEXT STOP: 2027

PEG-ADA2 Pharma partnership to conduct studies $80K
ADA2 Now Meter hardware, application & test strip $200K
Foundation Programmatic & Overhead Support $200K/year
(Chief Science, Executive Director, Comms & Strategy)

- *Patient Registry Recruitment & Surveys*
- *Virtual Researcher Conference*
- *Physician Awareness*
- *Patient Engagement*

NEXT STOP: 2028

PEG-ADA2 pre-clinical studies / proof of concept plan $800K
ADA2 Now Meter Production and clinical trial prep $400K
Foundation Programmatic & Overhead Support $300K/year
(adds Registry Staff, Development Director)

- *Phase II Patient Registry Development & Launch*
- *Research Roadmap from 2027 Virtual Conference Outcomes*
- *Publishing: Registry Surveys*
- *Patient Engagement*

NEXT STOP: 2029

PEG-ADA2 manufacture & pre-clinical development $1M
ADA2 Now Meter Cinical Trials $600K
Researcher Conference $60K
Foundation Programmatic & Overhead Support $400K/year

- Patient Registry Maintenance & Recruitment
- *Publishing: Consensus Statement Update, Prevalence Study Update*
- *Patient Engagement*

NEXT STOP: 2030

PEG-ADA2 production $1M
ADA2 Now Meter Production and Promotion $400K
Patient Registry Maintenance & Recruitment $200K
(platform, director, 2 part-time assistants)
Foundation Overhead Support $400K/year