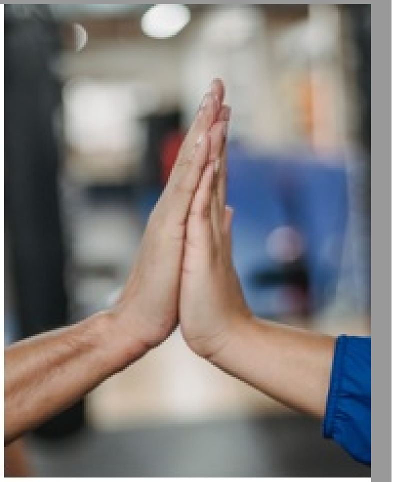
dada2 FOUNDATION



DRIVING TOWARD CONSENSUS

October 2022

Dear DADA2 Community,

This month, I am struck by how we are leaving our mark on the progress of medicine and research to cure this disease! Around the world, we are continually humbled by the way DADA2 affects patients and families, and equally as amazed at the ways this community is doing something about it. From research to fundraising, the DADA2 Community is being heard. Well done!

And why do we do this? Because hundreds of kids deal with DADA2, and so many don't even know it. That's why the work of our clinicians to bring attention to DADA2 as a pediatric cause for mysterious symptoms like stroke, rash or fever is so important. In the meantime, we invite you – especially parents – to get a few practical tips from one of our community members who is both a nurse and a DADA2 mom (we know the injection pain has been a hot topic on our Facebook DADA2 Friends & Family page!).

I do want to share that we are in the very beginning phases of putting together a 2023 conference. It will be so good to be together in person, though we will also offer an online option for those not able to travel. Stay tuned for details soon.

Do you want to share something for the newsletter? Email us at info@dada2.org. We'd love to chat about how you're making a difference for the greater DADA2 community.

Sincerely,

Chip

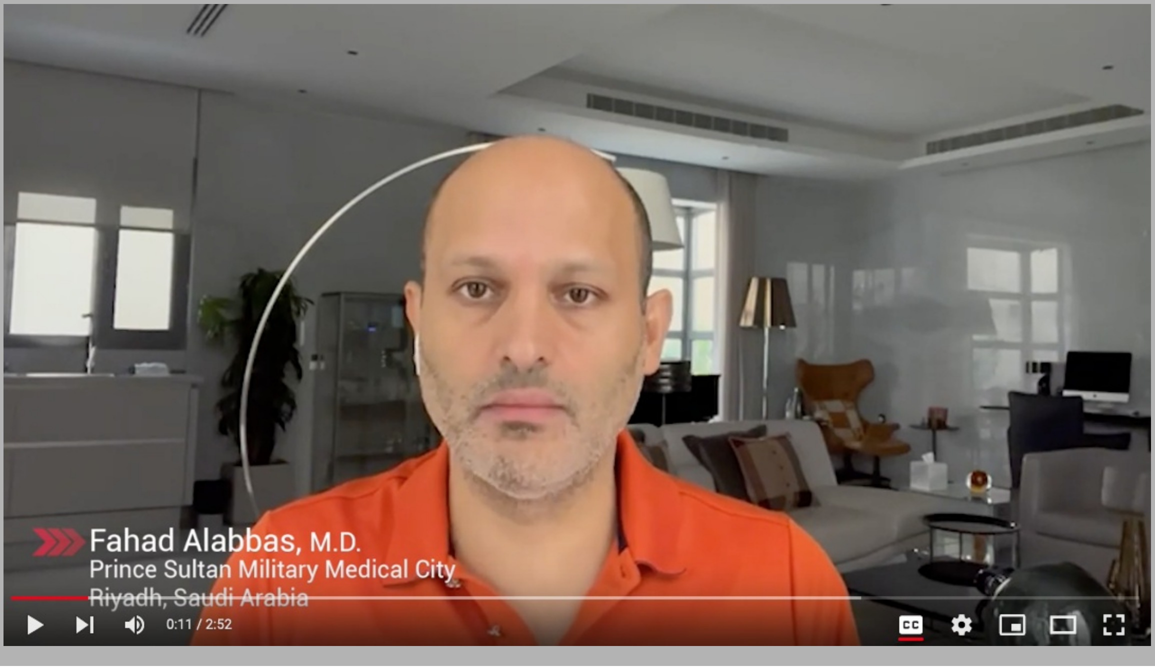
Chip Chambers, M.D.
Founder and President, DADA2 Foundation

Global updates

Consensus Update: A global team of researchers and clinicians continue to work on a consensus statement for how to identify and how to treat DADA2. We are thrilled to report that the team is very close to achieving a unified view of the most critical aspects of DADA2; and while some questions remain, we are confident that this statement will give clarity we have never had before on a universal scale.

We are in the process of analyzing the response from the international team of experts and expect to draft the consensus article in the near future. Many thanks to our incredible team! Worth noting: The White House (US) Office of Science and Technology announced last month that all federally funded research should be made available free of charge. Access to the public should be updated in the coming months through the middle of next year, with every agency complying by the end of 2025. [You can read more here.]()

Saudi Arabian Cohort: In a recently released study, Dr. Fahad Alabbas, M.D., a Pediatric Hematologist at Prince Sultan Military Medial City discusses his finding from his research of the 21 DADA2 patients in Saudi Arabia. It is amazing to see how our community is growing as more doctors know about the disease and how to diagnose it. **Watch our video with Arabic closed captions here**.



Pediatrics

Facebook Group: Did you know about the **DADA2 Families and Friends Facebook Group**? It's a closed group where patients contribute their everyday tips and questions about managing life with DADA2. Recently, discussions on tips to make the Enbrel injections easier given the new formula took up some discussion, with a few ideas for those who are struggling.

Checking with your doctor is ALWAYS the best way to go when it comes to care, but we hope this group helps with a starting point of sharing and learning more info to bring to your next appointment.

What happens when a lifelong dream collides with your own diagnosis of DADA2? Well, med school, of course.

Tara Peterson, a resident of California in the USA, lived years of her life not knowing what her symptoms meant, just like so many DADA2 patients. When she was finally diagnosed and got her disease under control, Tara pursued what it seems had been ready and waiting for her all along. In her late 30s, she applied and was accepted to medical school and began her journey this past month to becoming a doctor!

In a recent update she sent to the DADA2 Foundation, Tara said: "We are doing genetics presentations next week - I got my group to do DADA2! So 70 future physicians will be educated on the topic!" Cheers to you, Tara, and best wishes as you pursue cures for you and for every patient you encounter!

Other publications of note

- Early fast track genetic testing
- Development of ELISA Assays to test ADA2 levels
- Approaches, Obstacles and Special Considerations for hematopoietic cell transplantation
- Innate and Adaptive Immunity in DADA2 Patients

DONATE to The DADA2 Foundation

We would love to be a part of your annual 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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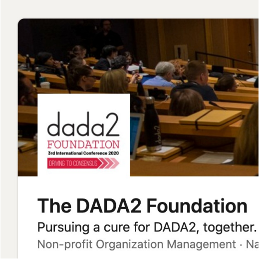

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