dada2 FOUNDATION

In This Issue:

DRIVING TOWARD CONSENSUS

June 3, 2021

CONSENSUS KICKOFF IS ON!

Consensus Kickoff has begun! And we are humbled to have begun this road so that our patients, who can experience a delay in diagnosis and therefore a longer diagnostic journey, can get treatment faster.

In early May, our Consensus Committee gathered to discuss the critical milestone of writing a consensus statement for diagnosing and treating DADA2. As we know, coming to this conclusion will help patients who present to their physicians with the many phenotypes that signify a possible DADA2 diagnosis. Likewise, this framework will help physicians better recognize the disease. As the DADA2 Foundation, we are committed to doing all we can to raise awareness of this consensus statement among physicians who might be on the front lines of making a diagnosis, so that more patients can be identified and cared for.

It will take the work of this Committee as well as others to make this consensus statement as accurate and thoughtful as possible. This is truly a group effort that will change the lives of so many patients.

IT'S GOOD TO BE TOGETHER

Patient & Family Gathering Convenes Virtual Crowd of 175

It was so good to see so many faces at our 2021 Virtual Patient & Family Gathering. Over the course of 4.5 hours in two days, positioned convenient to timezones from California, U.S.A, to Mumbai, India, nearly 175 patients, family members and presenters gathered to hear the latest of disease understanding, treatment opportunities, big questions to resolve and genetic implications. We could have spent to much more time together; but the overwhelming majority of attendees cherished the time and learning.

A special thanks to our patients who shared on panels, about how to manage clinical care, and in Q&A times. We know it takes bravery to share your story, but we also know that each of our stories is what encourages one another. Of course, we are grateful for Dr. Pui Lee, Dr. Mandy Ombrello and Natalie Deuitch, genetic counselor, for their insight!

Every talk is available on our YouTube channel. So take a look! The talks are meant to reach a patient level, so they may be helpful in sharing with loved ones who are curious about DADA2.

Family Spotlight: Anna Maria Beretta

Anna Maria and Veronica, twins who live in Italy, were teens when they were diagnosed with DADA2. While they are so genetically similar, their paths with DADA2 have taken different routes, with Anna Maria needing a bone marrow transplant and Veronica not. They are active in their home country to share the news of rare disease awareness and the benefits of bone marrow transplant, and even raise funds for their local hospital! Anna Maria's story is just one example of taking action on behalf of DADA2, and our Foundation will engage with families who want to take a road like theirs. Read Anna Maria's story, in her own words, here.

OF NOTE

- **LASID hosted a half-day conference on DADA2 for immunology experts across Latin America. Dr. Chambers, Dr. Amanda Ombrello, Dr. Marco Gattorno, Dr. Isabelle Myets, Dr. Ignacio Uriarte, Dr. Leonardo Oliveira & Dr. Liliana Bezrodnik each presented on the disease and the discussion helped the audience understand the disease even more. You can view the recording in English or Spanish here.**
- **In the last month, The Foundation has added more than 100 researchers and clinicians who are interested in DADA2, adding more countries to our footprint of clinicians and scientists who are learning about DADA2 to better care for patients in their country.**

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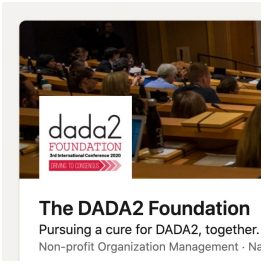

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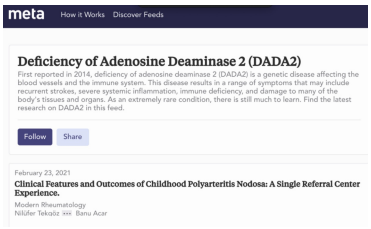

LATEST DADA2 PAPERS
We're partnering with Meta to bring the latest papers.