Morell Thomsen Family on Living with DADA2 for Nine Years

Tell us about Ida: what does she like to do—favorite school subject, sports, hobbies?

Ida is a happy and curious girl who really likes going to school and learning new things. She does swimming and gymnastics in her free time and often hangs out with friends on the weekends. She's full of ideas and always quick to get something fun started.

How is she managing with her symptoms and with taking medications?

Ida receives both anti-TNF treatment (adalimumab) and subcutaneous immunoglobulin (for her immune deficiency). Currently, her symptoms are well-managed, though fatigue continues to be the most persistent symptom. To help with this, she has a designated rest/stay-at-home day each week. This allows her to keep up with the rest of her peers during the remaining days — a solution that works well for her, and we will continue it for as long as she needs.

She is generally very cooperative with her medication. She often helps prepare the syringes herself and chooses the injection site. It helps a lot to have a set routine — we always give her a heads-up the day before, so she knows what's coming. — this helps her prepare mentally and has significantly reduced the number of times she gets upset about it.

She often says the injections hurt, but if we cool her skin with something like an ice cube beforehand, she feels it helps a lot. If she's feeling unwell or especially tired, injections can be harder on her. In those moments, we talk openly about how frustrating it is and how we all wish DADA2 didn't exist — but since we can't change that, we acknowledge the feeling and carry on.

She's at an age now where we've started gently explaining why the medicine is important. We've talked about DADA2 in child-appropriate terms, though of course there's still much she doesn't fully grasp.

In the summer of 2023, she experienced a flare-up with cerebral vasculitis, which required hospitalization. She received IV treatments, underwent numerous blood tests and MRIs, and was quite unwell for a while. The episode was most likely triggered by a combination of underdosing, anti-tnf, due to weight gain and a prolonged lung infection. It was a terrifying experience — but thankfully, she recovered without any lasting damage and has been completely stable ever since. We now refer to that episode when talking about why the medication matters.

How does Ida talk to her friends about her diagnosis? Does she have any restrictions in what she can do due to her DADA2, and how does she cope with that?

Ida tells openly, that she has a rare disease and often enjoys showing our video, from the DADA2 Foundation's YouTube channel. She actually thinks it's kind of cool to be able to say she's "ultra-rare." Her friends usually don't fully understand and often need us, as parents, to confirm that it's true.

She doesn't go into much detail about the disease itself, but she'll say, "My body doesn't work quite as well as yours, so I need a thousand needles with medicine."

We try to make her life feel as normal as possible and not defined by DADA2. She has no restrictions due to the illness, but sometimes she simply doesn't have the energy to participate in certain activities, and

she has to stay home. That can make her very sad, as she doesn't want to miss out. When this happens, we try not to say it's because of DADA2 — we want to avoid her feeling angry at the disease, if possible.

She usually doesn't recognize her own limits, so it's up to us as parents to know when she needs to rest. Occasionally, she gets an extra day off from school if there's a big event coming up on the weekend. Balancing school and social life is always a fine line. We hope that as she grows older, she'll learn to sense when her body needs rest.

What are the biggest challenges for your family in living with DADA2?

Practically speaking, it requires an enormous amount of planning. We must coordinate Ida's rest days, medication days, hospital appointments for regular bloodwork and doctor consultations, and make sure to order medication and supplies on time. Both parents work full-time, and Ida has two older siblings who also live with chronic conditions, which demands a great deal from the whole family.

Emotionally, it can feel very isolating. No one truly understands what we're going through. People are curious and ask questions, and we're happy to share what we know — but no one can say, "I know exactly how you feel."

Still, the greatest challenge is the fear of what the future holds for Ida. It's frightening not to know what lies ahead or whether she'll continue to do as well as she is now. That's why we are incredibly grateful for the work of the DADA2 Foundation and support it in every way we can. We've witnessed tremendous progress in knowledge and treatment options since her diagnosis in 2017, and we remain hopeful that a cure will be found.

How have your sons coped with having a sibling with a rare disease?

Illness, medications, and doctor visits are an unavoidable part of our family's life, though we try to keep it from dominating. When Ida has needed hospitalization, we split up so that one parent is with her and the other stays home with the boys. We make sure to give them extra attention and time for what they need.

Our middle son, Mathias, was diagnosed with type 1 diabetes in 2020. Of course, we would rather not have to deal with this — but there's no doubt that it helps balance out the attention. He also receives medication through injections, has frequent blood tests, and goes to many medical appointments.

Sometimes, he and Ida have little competitions about who's had the most injections or who has the coolest medical gear. They are great at supporting each other, especially on difficult medication days.

Our oldest son, Andreas, has ADHD and asthma, so he's part of the "medical conversation" too. Thankfully, he's a talented swimmer and regularly competes in tournaments — which our families and friends show interest in.

I believe Ida was the first Danish patient diagnosed, correct? Have you since met/talked with other families?

Yes, that's correct — she was the first and the only one for a long time. Around three years ago, we were contacted by another family whose teenage daughter had just been diagnosed with DADA2. And about three months ago, we were put in touch with a third family through the DADA2 Foundation.

In both cases, we felt we were able to offer help and knowledge that hopefully made their diagnosis, feel a little less overwhelming. It's always a mix of feelings — on one hand, it's really nice to finally talk to someone that is in the same situation, but on the other hand, it's also sad that another family has to deal with DADA2.

We honestly can't imagine what our journey would've looked like without the DADA2 Foundation. Being able to contribute and give others the same support we once needed means a great deal to us.

What is your biggest hope for Ida's future?

We really hope Ida gets to grow up with a life that feels pretty normal — full of good experiences and maybe one day have a family of her own. Of course, a cure would be amazing and is something we really hope for. But if she needs medication for the rest of her life, then we just hope it keeps working and that she can stay as stable as she is now.

What would be your advice to a family with young children newly diagnosed?

One of the most important things we've learned is that you have to become the expert yourself. You can't count on every doctor or nurse you meet to know about DADA2, so staying informed and persistent is key to making sure you or your child gets the right care. It can be overwhelming, if so, reach out to the DADA2 Foundation. Ask your questions, share your concerns — talking to someone who truly understands makes a huge difference. And when things get tough, with injections and hospital visits, try to remember: this is lifesaving, absolutely essential for your child — and most importantly, it works.