

Tips for navigating education with Danon

Children with Danon Disease have different intellectual, behavioral, and educational needs. While there is no one-sized-fits all approach to education, below are tips to help you navigate your child's educational path and potential support services.



Get a neuropsychological* evaluation

This test will evaluate your child for potential learning differences or disability, and can help you understand the educational support your child needs. To get started:

- Talk to your child's primary doctor about referral for this evaluation
- Ask how the evaluation works
- Discuss what the results may mean and how best to use them

* **Neuropsychological exam** – a test that is performed by a neuropsychologist, an expert in diagnosing and treating issues with behavior, mood and thinking skills



Develop an education plan

Based on the results of the evaluation, and recommendations from your child's doctor, consider your child's education plan:

- Assess pros / cons of public, private and homeschool
- Learn about IEPs and 504s
- Start a conversation with the school's administration about special education services

What is an IEP?

An individualized education plan (IEP) is a blueprint for a child's special education experience at school; a child must qualify based on eligibility review with the school

What is a 504?

A plan for how the school will provide changes to the learning environment to enable students to learn alongside peers; available to any student with a disability that limits daily activities in a major way

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Speak with teachers / support staff

Many educators may be unfamiliar with Danon Disease, so it's important to be proactive. You may want to:

- Write a letter to your child's teacher(s), describing the way Danon impacts your child
- Provide the school nurse / counselors with information about Danon
- Have a conversation with specialists – such as PE instructors – about your child's condition, their strengths, and limitations



For more resources about Danon Disease, visit DanonFoundation.org



Support your child's conversations

Children may be faced with the challenge of describing Danon to their peers. To show support, you can:

- Talk to your child about what they feel comfortable sharing about Danon
- Choose specific phrases that describe your child's experience, such as ***"I can go to school and play, but I get tired and need to take breaks"*** or ***"My heart is sick, so I go to the doctor sometimes"***

Support along the way

The Danon Foundation boldly empowers people living with Danon Disease, providing trusted information, resources and support to help navigate life, from diagnosis to treatment. As you navigate your child's education, we can help share **templates for IEPs, 504 plans and school letters**, as well as **FAQs for school staff**.