

You, Me, and OTC

A guide to help you learn more about OTC, my experience, and how you can help

Step 1: Learn more about OTC



What is a UCD?

A urea cycle disorder, or UCD, is a rare disease that affects about 1 in 35,000 people born in the United States. UCDs are genetic, which means they are something a person is born with and will have for life. You can't catch a UCD and it is not something that can be outgrown.

Having a UCD means that an enzyme in the liver is missing or is not working. This prevents the liver from turning ammonia, which we get from eating protein, into urea and removing it from the body. If ammonia isn't removed, it can build up to toxic levels in the bloodstream. This can cause behavior changes, serious health problems, and even permanent brain damage or death.



What is OTC?

Ornithine transcarbamylase (OTC) deficiency is the most common type of UCD. More than 60% of people with UCDs have OTC deficiency.

Someone who carries the gene that causes OTC is referred to as an "OTC carrier." Some people don't even know they're OTC carriers until someone else in their family is diagnosed with OTC. This means they may experience symptoms during their lives without knowing the cause.



What are the effects of OTC on a carrier?

People with OTC can experience hyperammonemia, which means too much ammonia in the blood. This can cause the brain to swell, which can result in long-term issues with memory, decision-making, and attention span.

To stay healthy, OTC carriers must try to keep their ammonia levels well controlled. This often means following a management plan recommended by a doctor that includes things like eating a low-protein diet, limiting strenuous activity, staying hydrated, avoiding extreme temperatures, and, for some people, taking medicine.

OTC affects everyone differently and at different times. Someone whose OTC is being well managed may have long periods of time without a health issue. However, it's important to know that OTC symptoms can happen any time and that people with OTC are always at risk for a medical emergency if something triggers a rise in their ammonia levels.

Learn more about me

My OTC experience

I learned that I was an OTC carrier when: _____

The symptoms I typically experience are: _____

The things I do to help manage my OTC are: _____

Help and support

My OTC symptoms and management plan may affect my social life and work life in the following ways:

It's helpful for me to have support in the areas of: _____

I may need help accommodating my OTC needs in the following ways: _____

Usually my symptoms are well managed, so it can be hard to remember that OTC can lead to a medical emergency. I don't expect this to happen, but I want to make sure you have all the information you need in case it does. By the time I appear to be sick, it usually means that help or medical attention is required. If you notice any of the symptoms listed above, or any unusual or out-of-character behavior, this is what you should do:

Emergency contact information

Emergency contact number: _____

Details: _____

Emergency contact number: _____

Details: _____

To learn more about UCDs and OTC and to find helpful resources, visit UCDinCommon.com.