

aHUS STORIES: ANDREW CHOOSES TRANSITION TO ULTOMIRIS

THIS STORY IS BASED ON A REAL ATYPICAL-HUS PATIENT. TO PROTECT PATIENT PRIVACY, THE PATIENT NAME AND SOME IDENTIFYING DETAILS HAVE BEEN CHANGED, AND PHOTOS ARE FOR ILLUSTRATION ONLY.



INDICATION

What is ULTOMIRIS?

ULTOMIRIS is a prescription medicine used to treat adults and children 1 month of age and older with a disease called atypical Hemolytic Uremic Syndrome (aHUS). ULTOMIRIS is not used in treating people with Shiga toxin E. coli related hemolytic uremic syndrome (STEC-HUS). It is not known if ULTOMIRIS is safe and effective in children younger than 1 month of age.

SELECT IMPORTANT SAFETY INFORMATION

What is the most important information I should know about ULTOMIRIS?

ULTOMIRIS is a medicine that affects your immune system and may lower the ability of your immune system to fight infections.

- **ULTOMIRIS increases your chance of getting serious meningococcal infections that may quickly become life-threatening or cause death if not recognized and treated early.**

1. You must complete or update meningococcal vaccine(s) at least 2 weeks before your first dose of ULTOMIRIS.

- 2.** If you have not completed your meningococcal vaccines and ULTOMIRIS must be started right away, you should receive the required vaccine(s) as soon as possible.
- 3.** If you have not been vaccinated and ULTOMIRIS must be started right away, you should also receive antibiotics for as long as your healthcare provider tells you.
- 4.** If you had a meningococcal vaccine in the past, you might need additional vaccines before starting ULTOMIRIS. Your healthcare provider will decide if you need additional meningococcal vaccines.
- 5.** Meningococcal vaccines do not prevent all meningococcal infections. **Call your healthcare provider or get emergency medical care right away if you get any of these signs and symptoms of a meningococcal infection:** fever, fever with high heart rate, headache and fever, confusion, muscle aches with flu-like symptoms, fever and a rash, headache with nausea or vomiting, headache with a stiff neck or stiff back, or eyes sensitive to light.

Please see additional Important Safety Information throughout and the accompanying full [Prescribing Information \(Ultomiris.com/PI\)](https://www.ultomiris.com/PI) and [Medication Guide \(Ultomiris.com/MedGuide\)](https://www.ultomiris.com/MedGuide) for ULTOMIRIS, including **Boxed WARNING regarding **serious meningococcal infections.****

Remember to speak with your doctor about your symptoms and how to manage atypical-HUS.

This is Andrew. He is a talented musician and songwriter, and he has atypical-HUS.

“LIFE IS UNPREDICTABLE, ESPECIALLY WITH A RARE DISEASE. THROUGH THE ROLLER COASTER, I’VE LEARNED A LOT ABOUT MYSELF AND MY CAPABILITIES.”



Based on an actual patient

Andrew

Age: 48 years old

Height: 6 feet

Weight: 211 lbs

Loves music and meditation

Can you describe how your atypical-HUS journey began?

I was a young man with hopes and dreams of starting a career as a musician.

I definitely didn't think I would find myself in the ER after a gig, hearing that my kidneys were failing.

I was shocked. One day I was healthy and the next I was about to start dialysis.

What happened next?

This was hard on me, but maybe it was harder on my stepmother, seeing me on the dialysis chair.

She called my nephrologist to see if there was anything she could do. She ended up being a match and donated her kidney to me.

Sadly, my body rejected the kidney in just under a year. It was difficult to lose my stepmother's kidney. She made such a brave decision to help me and to have it fail so quickly was discouraging for both of us.

How did you move forward after this setback?

*I wish I could say it was easy, but I was crushed. My life had changed overnight and I simply felt numb to everything. **It wasn't until I accepted my life for how it actually was that I could move forward. This took a lot of inner work.***

At the age of 34, I received a call—another kidney was available. Unfortunately, that kidney lasted just under a year.

I remember my transplant coordinator told me, “This isn't the end of you. I want you to know that they're constantly making strides in medicine. Don't lose hope and we're here to help you get through this.”

Also, my doctor had a possible answer. He told me that I had TTP and that I was not a candidate for another kidney transplant. The news was tough to hear, but I understood. But of course, I was devastated.

When did you feel you needed a second opinion?

I wanted answers, so I researched TTP online frequently. One day, I came across an article about a woman in Maine and our cases were strangely similar. The difference was that she had been diagnosed with atypical-HUS.

*I called my nephrologist and she referred me to see Dr. George, a hematologist and key partner in my atypical-HUS journey. Dr. George conducted a number of tests. My doctors began to collaborate and, finally, after more than 15 years of not knowing what caused my kidneys to fail, **the cause was discovered: I had atypical-HUS. I could begin treatment.***

With a new diagnosis I was put back on the list to receive another kidney. Six years after my second rejected transplant, I received a call and was told to go to the hospital—there was a kidney for me. I was able to receive a third kidney transplant.

TTP=thrombotic thrombocytopenic purpura.

SELECT IMPORTANT SAFETY INFORMATION

Your healthcare provider will give you a Patient Safety Card about the risk of serious meningococcal infection. Carry it with you at all times during treatment and for 8 months after your last ULTOMIRIS dose. Your risk of meningococcal infection may continue for several months after your last dose of ULTOMIRIS. It is important to show this card to any healthcare provider who treats you. This will help them diagnose and treat you quickly.

Please see additional Important Safety Information throughout and the accompanying full Prescribing Information (Ultomiris.com/PI) and Medication Guide (Ultomiris.com/MedGuide) for ULTOMIRIS, including Boxed WARNING regarding serious meningococcal infections.


ULTOMIRIS®
(ravulizumab-cwvz)
injection for intravenous use
300 mg/3 mL vial

AFTER SUCH A LONG JOURNEY, WHAT MADE YOU CHOOSE TO TRANSITION TO ULTOMIRIS?

I was on SOLIRIS when my hematologist told me about ULTOMIRIS.

I'm not a scientist or a medical person by any means, but my doctor took me through how ULTOMIRIS may affect me. I was happy with my experience on SOLIRIS but based on the clinical data provided by my doctor, we felt like ULTOMIRIS may be great for me.

I also thought the dosing schedule would provide me more freedom to live my life without planning it around my infusions.

What is ULTOMIRIS?

- ULTOMIRIS is the first and only FDA-approved long-acting prescription medication for treating atypical-HUS.
- It works by binding and blocking the C5 complement protein to prevent TMA or blood clots.
- ULTOMIRIS was built on the foundation of SOLIRIS, but with modifications that allow it to last longer in the body.

ULTOMIRIS controls C5 immediately

- 100% (70 out of 70) of clinical trial patients on ULTOMIRIS had complete C5 control by the end of their first infusion.

With ULTOMIRIS, C5 control is sustained for up to 8 weeks

- This means that C5 control lasts the full 8 weeks between infusions for adult patients. Depending on body weight, pediatric patients receive infusions every 4 or 8 weeks in order to experience the same sustained C5 control.

WHAT STEPS WERE INVOLVED IN TRANSITIONING?

Before starting ULTOMIRIS I received a meningococcal vaccination.

- Patients must receive the meningococcal vaccination at least 2 weeks prior to administering the first dose of ULTOMIRIS if they have not already had this vaccination. Meningococcal infections have occurred with patients taking ULTOMIRIS and may become life-threatening and cause death if not recognized and treated early.
- Your doctor will give you a **Patient Safety Card** about the risk of meningococcal infection.

Overall, I was able to transition to ULTOMIRIS smoothly. I received my first starting dose of ULTOMIRIS 2 weeks after my last dose of SOLIRIS. **Since then, I've gotten infused every 8 weeks—so, only 6 or 7 times a year.**

- When transitioning from SOLIRIS to ULTOMIRIS, a “starting dose” of ULTOMIRIS is given 2 weeks after the final SOLIRIS infusion.
- Then, beginning 2 weeks after the starting dose, ULTOMIRIS “maintenance doses” are infused once every 4 or 8 weeks depending on age and body weight.
- After each infusion, patients should be monitored for at least 1 hour for infusion-related reactions. Please see **Page 4** for more information about infusion-related reactions.
- The most common side effects of ULTOMIRIS in people with atypical-HUS are upper respiratory tract infection, diarrhea, nausea, vomiting, headache, high blood pressure, and fever.

HAS ULTOMIRIS CHANGED ANYTHING FOR YOU IN TERMS OF HOW YOU LIVE YOUR LIFE WITH ATYPICAL-HUS?

With infusions every 8 weeks, I appreciate that I don't have to plan as much of my life, especially work and travel, around my infusions. I feel like my schedule has opened up a bit more. Of course, this is my experience; it may be different from yours and some people do not respond to therapy. I would encourage you to talk to your physician.

ANY ADVICE FOR PEOPLE NAVIGATING THEIR OWN ATYPICAL-HUS JOURNEY?

My story started in my early 20s. I'm not the same guy anymore. I'm not even the same guy I was 5 years ago. That's the thing about mindfulness. It's an everyday thing. I can't speak to the future, but I hope to keep embracing the present. **Life may not happen in the way I want it to, but I'm so grateful for every day, every moment, that I'm given.**

Also, have a little faith that your medical team and OneSource™ caseworker have your best interests at heart and trust your instincts. You are your best advocate—if you feel something is not quite right, speak up.



SELECT IMPORTANT SAFETY INFORMATION

ULTOMIRIS is only available through a program called the ULTOMIRIS and SOLIRIS Risk Evaluation and Mitigation Strategy (REMS). Before you can receive ULTOMIRIS, your healthcare provider must: enroll in the REMS program; counsel you about the risk of serious meningococcal infections; give you information about the signs and symptoms of serious meningococcal infection; make sure that you are vaccinated against serious infections caused by meningococcal bacteria, and that you receive antibiotics if you need to start ULTOMIRIS right away and are not up to date on your vaccines; give you a **Patient Safety Card** about your risk of meningococcal infection.

ULTOMIRIS may also increase the risk of other types of serious infections, including *Streptococcus pneumoniae*, *Haemophilus influenzae*, and *Neisseria gonorrhoeae*. Your child should receive vaccines against *Streptococcus pneumoniae* and *Haemophilus influenzae* type b (Hib) if treated with ULTOMIRIS. Certain people may be at risk of serious infections with gonorrhea.

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ULTOMIRIS[®]
(ravulizumab-cwvz)
injection for intravenous use
300 mg/3 mL vial



OneSource is a complimentary, personalized support program offered by Alexion. OneSource is staffed by Alexion Patient Navigators, Patient Liaisons, and Patient Education Managers, all of whom have extensive knowledge of atypical-HUS and can assist you every step of the way. They are ready to provide the support and resources you need—wherever you are in your atypical-HUS journey.

Disease Information

Contact OneSource today to receive a free atypical-HUS Patient Resource Kit in the mail.

Or go to aHUSJourney.com to see all the same resources online.

Community Connections

Attend aHUS Together Webinars to hear leading physicians discussing atypical-HUS treatment, and STAR Ambassadors like Andrew sharing their atypical-HUS stories. Visit alexionaHUSevents.com for more information and to register for upcoming events.

Health Insurance Navigation

Get help understanding your insurance coverage, information on external funding resources for out-of-pocket costs, and alternative options for gaps in coverage and funding.

Ongoing Support

Receive personalized support during major life events such as a change in insurance status, travel, or moving—as well as support finding alternative infusion locations while traveling, if applicable.

Don't navigate your atypical-HUS journey alone.

Enroll in OneSource at AlexionOneSource.com by calling 1-888-765-4747, or by scanning below.



Visit aHUSJourney.com or scan below to get your free patient resource kit today!



WHAT ROLE HAS ONESOURCE™ PLAYED IN YOUR JOURNEY?

There has to be a symbiotic relationship between you and the people that care for you, your doctor, transplant coordinator, case manager. It takes a village.

I definitely took advantage of talking with my OneSource case manager to help stay on top of things.

You don't have to do this alone.

SELECT IMPORTANT SAFETY INFORMATION

Who should not receive ULTOMIRIS?

Do not receive ULTOMIRIS if you have a serious meningococcal infection when you are starting ULTOMIRIS.

Before you receive ULTOMIRIS, tell your healthcare provider about all of your medical conditions, including if you: have an infection or fever, are pregnant or plan to become pregnant, and are breastfeeding or plan to breastfeed. It is not known if ULTOMIRIS will harm your unborn baby or if it passes into your breast milk. You should not breastfeed during treatment and for 8 months after your final dose of ULTOMIRIS.

Tell your healthcare provider about all the vaccines you receive and medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements which could affect your treatment.

If you have aHUS, your healthcare provider will need to monitor you closely for at least 12 months after stopping treatment for signs of worsening aHUS or problems related to a type of abnormal clotting and breakdown of your red blood cells called thrombotic microangiopathy (TMA). Symptoms or problems that can happen with TMA may include: confusion or loss of consciousness, seizures, chest pain (angina), difficulty breathing and blood clots or stroke.

What are the possible side effects of ULTOMIRIS?

ULTOMIRIS can cause serious side effects including infusion-related reactions. Symptoms of an infusion-related reaction with ULTOMIRIS may include lower back pain, abdominal pain, muscle spasms, changes in blood pressure, tiredness, feeling faint, shaking chills (rigors), discomfort in your arms or legs, bad taste, or drowsiness. Stop treatment of ULTOMIRIS and tell your healthcare provider right away if you develop these symptoms, or any other symptoms during your ULTOMIRIS infusion that may mean you are having a serious infusion-related reaction, including: chest pain, trouble breathing or shortness of breath, swelling of your face, tongue, or throat, and feel faint or pass out.

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ALEXION'S AHUS TOGETHER WEBINARS CAN HELP YOU FIND INFORMATION ABOUT TOPICS RELEVANT TO LIVING WITH ATYPICAL-HUS

Hear STAR Ambassadors like Andrew as they share their atypical-HUS journeys and discuss topics ranging from mental health and wellness to lifestyle planning and how to work with your healthcare team.



INTERESTED IN SHARING YOUR ATYPICAL-HUS JOURNEY? BECOME A STAR AMBASSADOR!

You can help educate and inspire others living with atypical-HUS by being part of the atypical-HUS STAR Ambassador Program. You can volunteer to share your experiences, participate in educational and promotional activities, and help build community with others living with atypical-HUS, or you can choose to focus more on helping the Alexion team with things like internal training events and creating educational resources like this one.

To learn more about the atypical-HUS star ambassador program, call **1-844-378-2127** or scan below to message us at MyStory@StarsAmbassador.com.



To find upcoming events, visit AlexionaHUSevents.com or scan below.



SELECT IMPORTANT SAFETY INFORMATION

The most common side effects of ULTOMIRIS in people treated for aHUS are upper respiratory tract infection, diarrhea, nausea, vomiting, headache, high blood pressure and fever.

Tell your healthcare provider about any side effect that bothers you or that does not go away. These are not all the possible side effects of ULTOMIRIS. For more information, ask your healthcare provider or pharmacist. Call your healthcare provider right away if you miss an ULTOMIRIS infusion or for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.



Please see additional Important Safety Information throughout and the accompanying full [Prescribing Information \(Ultomiris.com/PI\)](https://Ultomiris.com/PI) and [Medication Guide \(Ultomiris.com/MedGuide\)](https://Ultomiris.com/MedGuide), or scan QR codes for ULTOMIRIS, including **Boxed WARNING** regarding serious meningococcal infections.

