

Dennis Shares His MDR HIV Treatment Journey

Learn how support from family and friends, along with an optimized medication regimen, helped one patient navigate the challenges of living with MDR HIV

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Please note: The content in this testimonial is from a person living with HIV-1 sharing his personal experience about his diagnosis and his treatment with RUKOBIA (fostemsavir). Individual results may vary.

Courtesy of ViiV Healthcare.

What is RUKOBIA?

RUKOBIA is a prescription medicine used with other human immunodeficiency virus-1 (HIV-1) medicines to treat HIV-1 infection in adults who have received several HIV-1 medicines in the past, and have HIV-1 virus that is resistant to many HIV-1 medicines, and are failing their current HIV-1

medicines because the medicines are not working, you are not able to tolerate the side effects, or there are other safety reasons.

IMPORTANT SAFETY INFORMATION

Do not take RUKOBIA if you:

- are allergic to fostemsavir or any of the ingredients in RUKOBIA.
- take certain medicines, including enzalutamide, carbamazepine, phenytoin, rifampin, mitotane,

St. John's wort (Hypericum perforatum).

Please see additional Important Safety Information for RUKOBIA below. Please use the link on this page to read the <u>Patient Information for RUKOBIA</u>.

Dennis's Story

It's been nearly 33 years since Dennis received the news that would alter the course of his life forever. "When I received my diagnosis, I wasn't totally surprised, but I was scared. "I used the one-mile walk back from the testing site to decide how I was going to tell the people I love," he recalls.

To celebrate the resilience and strength of patients like Dennis, who contracted HIV before highly effective treatments became widely available, we recognize June 5th as HIV Long-Term Survivors Awareness Day. This group of patients makes up 25% of those 1.2 million living with HIV and AIDS, or 300,000 people.

"I was told, 'if you can just hang on until the arrival of these new medications in clinical trials, you might be able to make it,'" Dennis recounted. "I remember thinking that I would be surprised if I made it past the millennium ... but here we are."

Jon Cospito Photography

A clinical trial in Florida was Dennis's first exposure to antiretroviral treatment (ART). As he would discover, adherence was his major challenge. "I wasn't totally adherent," he admits. "These pills gave me the worst hangover of my life. The stigma at that time didn't help, either." When he completed the study, his viral load remained high, and he landed in the hospital with an AIDS- associated illness during a lapse in insurance that left him without any ART coverage.

After being discharged, Dennis had a revelation. Staring into the mirror, he thought, "'Wow, you look like hell. You're going to take these medications as prescribed ... otherwise, you'll have to do this again...'" His roommate organized his daily medications into paper cups and Dennis promised to start taking his health as seriously as the people in his life did.

Thanks to his support system, Dennis was able to stay adherent to an ever-changing carousel of antiretrovirals. But this didn't prevent his viral load from creeping up every 18 months.

Dennis decided the best way for him to spend his life was by becoming an advocate for people living with HIV, just like his friends and family had done for him.

"I became a program manager for Ryan White/AIDS Drug Assistance Program (ADAP)," Dennis recalls. "I remember smiling after the third day."

While working as a program manager, Dennis continued to see his viral load increase despite being adherent to his regimen. As his viral load had been increasing for some time, Dennis enrolled in a clinical trial for RUKOBIA, a novel attachment inhibitor.

Jon Cospito Photography

"On a RUKOBIA-based regimen, I became undetectable and have remained there ever since," Dennis shares proudly. He appreciates that RUKOBIA does not have to be taken with food and does not have any cumbersome refrigeration requirements. Given Dennis's MDR HIV, it was also important to him that RUKOBIA had a different mechanism of action. RUKOBIA works differently from other HIV-1 treatments by stopping the virus from attaching to your CD4+ T-cells.

"It's just working great, and that gives me confidence," Dennis says.

Looking Towards the Future

These professional and personal successes gave Dennis the confidence he needed to take control of his diagnosis—and his life.

Looking back, Dennis can't believe how far HIV treatment has come. "Compared to the past, today's ART is more effective and easier to take" he says. "If you can just get past that stigma and take your medications, you can be confident." You should always talk with your doctor before starting or stopping any medications. Consult with your doctor to see if RUKOBIA may be right for you.

After so many years plagued by uncertainty, Dennis is concentrating on more fulfilling areas of his life, including his work and his personal relationships.

"Once I turned 50, I realized how blessed I was," he recollects. "Many other people didn't have the capacity or access to treatment they needed to take care of themselves."

From the lens of a program manager with over 30 years on his HIV journey, Dennis would like to see 3 major challenges addressed.

"First, isolation and loneliness are major considerations for older people, including those with HIV," he shares.

Dennis recommends leveraging case managers to help engage people with their local communities. Every person in a support network can look out for signs of depression that may impact medication adherence. If you or someone you know is struggling with HIV, consider reaching out to an HIV advocacy community or patient assistance program for additional support.

Dennis also notes that access to HIV specialists presents a real barrier, especially for individuals living outside of major metropolitan areas.

"This is another place to leverage case managers," Dennis observed, as he recalled a program in his hometown that arranged transportation for people with HIV who live in rural areas to get to their appointments.

Finally, he said stable housing represents an ongoing challenge in both rural and urban areas.

"Ryan White and other programs can help people pay for housing," Dennis advised. "You've just got to take advantage of these opportunities offered by your case manager." Jon Cospito Photography

Do you want to hear more about living with MDR HIV? <u>Click here to listen to Dennis's story about</u> <u>RUKOBIA.</u>

If you're interested in sharing your experience on RUKOBIA, please visit <u>myRUKOBIAexperience.com</u>.

IMPORTANT SAFETY INFORMATION (cont'd)

What are the possible side effects of RUKOBIA?

RUKOBIA can cause serious side effects including:

- Changes in your immune system. Your immune system may get stronger and begin to fight infections that have been hidden in your body for a long time. Tell your healthcare provider right away if you start having new symptoms after you start taking RUKOBIA.
- Heart rhythm problems (QTc prolongation). RUKOBIA may cause a heart rhythm problem called QTc prolongation. QTc prolongation causes an irregular heartbeat. If you are elderly, you may be at a greater risk for developing this heart problem with RUKOBIA. Tell your healthcare

provider right away if you feel dizzy, lightheaded, feel changes in your heartbeat, or you faint (lose consciousness).

- Changes in liver function blood tests results. People with HIV-1 who take RUKOBIA and who also have hepatitis B or C virus infections may be more likely to develop new or worsening changes in certain liver function blood tests during treatment with RUKOBIA.
 - If you stop your anti-hepatitis B treatment, this could mean that your hepatitis B may become active again (reactivated). Your healthcare provider may do blood tests to check your liver function.
 - Take any anti-hepatitis B or anti-hepatitis C medicines as prescribed by your healthcare provider during treatment with RUKOBIA.

The most common side effect of RUKOBIA is nausea.

These are not all of the possible side effects of RUKOBIA. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

Before taking RUKOBIA, tell your healthcare provider about all of your medical conditions, including if you:

- have or have had a heart problem, including a heart rhythm problem called QTc prolongation (irregular heartbeat).
- have or have had liver problems, including hepatitis B or C infection.
- are pregnant or plan to become pregnant. It is not known if RUKOBIA will harm your unborn baby. Tell your healthcare provider if you become pregnant during treatment with RUKOBIA.
- are breastfeeding or plan to breastfeed. RUKOBIA may pass into your breast milk. Talk with your healthcare provider about the risks to your baby from breastfeeding during treatment with RUKOBIA.

Tell your healthcare provider about all the medicines you take, including prescription and over-thecounter medicines, vitamins, and herbal supplements. Some medicines interact with RUKOBIA.

Especially tell your healthcare provider if you take birth control pills (oral contraceptives) that contain ethinyl estradiol. The amount of ethinyl estradiol can become increased in your blood during treatment with RUKOBIA. Talk to your healthcare provider about which oral contraceptives may be right for you during treatment with RUKOBIA. Keep a list of your medicines and show it to your healthcare provider and pharmacist when you get a new medicine.

- You can ask your healthcare provider or pharmacist for a list of medicines that interact with RUKOBIA.
- Do not start taking a new medicine without telling your healthcare provider. Your healthcare provider can tell you if it is safe to take RUKOBIA with other medicines.

How should I take RUKOBIA?

- Take RUKOBIA exactly as your healthcare provider tells you to take it.
- Take RUKOBIA tablets whole. Do not chew, crush, or split RUKOBIA tablets before swallowing.
- Take RUKOBIA with or without food.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit <u>www.fda.gov/medwatch</u>, or call <u>1-800-FDA-1088</u>.

Please read the <u>Patient Information</u> for RUKOBIA and discuss it with your healthcare provider.

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https://www.poz.com/article/dennis-shares-his-mdr-hiv-treatment-journey

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