

# FACES OF AMR PROFILE STORIES

## Nicole Kohr



***“I qualified for a lung transplant under end-stage cystic fibrosis and complete antibiotic resistance. It was the first time that we were told I was dying.”***

Nicole Kohr has always loved the theater. Her best performance, however, came off-stage by keeping her illness a secret until she couldn't hide it anymore. Kohr was diagnosed with cystic fibrosis as a child. Cystic fibrosis is a chronic disease that impacts multiple organs and carries a lifelong risk of infection.

For a number of years, she was able to manage her disease with regular “tune-ups” – two-week hospital stays to receive IV antibiotics – but once her lung function declined to below 11% and she became completely resistant to antibiotics, she qualified for a lung transplant.

That's when she decided that she could no longer keep her disease a secret and started to share her story.

With cystic fibrosis, mucus builds up in the lungs, clogging airways and trapping bacteria, which can lead to infection, inflammation and other complications, including developing antibiotic-resistant bacteria in the lungs. These bacteria foster infections that come with fever, increased cough, aches, pains, fatigue, shortness of breath and, over time, a steady loss of lung function.

These are all symptoms and challenges that Kohr has faced – as a young child, a high schooler, a college student and even at her first job out of college where she self-administered IV antibiotics. In the process of managing her cystic fibrosis, Kohr has also endured throat surgery, hearing loss and concerns of kidney and liver disease. Despite these challenges, coupled with her declining lung function and increasing hospital stays, Kohr was determined not to allow her disease to derail her dreams.

After being told officially that there were no more antibiotics available to address her frequent infections and being unable to make it through a short walk due to low lung function, Kohr was going to get a new set of lungs. She was 26 years old and had just gotten married 13 days before receiving her new lungs. That was three years ago.

But her story doesn't end there. Her new lungs also breathed life into her new role as a patient advocate.

Today, she is a volunteer engagement chair of the Cystic Fibrosis Foundation's Central/Eastern Carolinas Chapter. And while she is still concerned with getting infections, she has been able to take on some new opportunities. In her spare time, she writes a blog, musicals and children's books. Her theater background also plays a role in her commitment to using the power of storytelling – including her own – to raise awareness of the need for antibiotic innovation to curb the growing antibiotic resistance health crisis.

