



Buying more Breaths with ShamRockin'

I will always remember the moment I was ShamRocked. The instance when I saw a music venue become a garden of twinkling lights, and green hair, and 1,500 people dancing to 80's tunes. And crying and writing checks as two dear boys and their parents told their story of their journey with Cystic Fibrosis, an incurable genetic disease.

That was six years ago, and I know for sure that every dollar raised at this event has bought more science to find the cure. In the six years I've been involved, I've been to two first dose parties, where new drugs are being introduced that help control the destructive path of this disease. And I've watched this precious medicine help 5% of the CF population, then 20%, and now in Nov. 2019 a new med that can help 90% of the genetic variations. No cure...just extra time, healthier patients, less time in the hospital. I've also watched as precious friends have suffered through lung transplants, hospitalizations, oxygen canisters, depression, and death. I've watched the moms and dads who first get the diagnosis for their child struggle to understand and cope.

This cause has changed my life. I know for sure that dollars are all that is holding back the cure. That we are so close and have to keep fighting. And I can see the difference. So when I ask you to buy a ticket, to donate, to come to a ShamRockstar neighborhood party, it's not just because I love to dance and dress up and partake of an adult beverage in March every year.

As I write this, I'm fighting a bout of bronchitis. Miserable. Elephant on the chest misery. But it's a quick short term state. With CF, I'd be facing hospitalization, lung damage, and knowing it was going to happen again and again. As an old friend said, it's gonna happen. The cure is coming. And those precious breaths will come easier. www.shamrockin.com



CF Warrior has been on the new drug Trikafta for 16 days as of 12-9-19. Here are his life changing words....

[Andy Lipman to CF Warrior Project](#)

It's Day 16 of Trikafta. I've never been one who likes change but I think this might be the exception. I feel like I'm turning almost superhuman. I can still tell that I have cystic fibrosis but it's just different. It's hard to explain but I'll try. I'm barely coughing.

I'm noticing now when I squirt my nasal spray that I feel it go all the way to my sinuses. Usually it just stops inside my nostrils because I'm so congested. I'm starting to smell things. Foods even taste a little different.

I am up 5 to 7 pounds up. We usually have trouble keeping our weight up and have been told to devour as many calories as possible. **Imagine being in one body years and trading it in and having a totally new body within 2 weeks. It's like dying and going to heaven.** I feel like it's an adjustment with regards to eating, breathing & exercising. But I'm ready for change...

I've never wanted anything more! [#day16Trikafta](#) [#changing#cfwarriorproject](#) [#cfwarrior](#) [#humorprevails](#)