

# OPINION

## May is cystic fibrosis awareness month

For the past couple of months, Minnesotans have been practicing social distancing measures to prevent the spread of COVID-19.

Minnesotans have stayed at home, kept 6 feet apart from one another, worn face masks, vigorously and frequently washed our hands with soap and water for 20 seconds while singing “Happy Birthday,” used hand sanitizer and kept frequently used surfaces clean. While people have been extra careful about routinely practicing these healthy habits since the pandemic started, cystic fibrosis patients have used these skills their entire lives.

According to the Cystic Fibrosis Foundation, cystic fibrosis is a progressive, genetic disease that causes persistent lung infections and limits the ability to breathe over time.

According to the Mayo Clinic, cystic fibrosis affects the cells that produce mucus, sweat and diges-

### WRITER'S BLACK



Paige Kieffer  
Staff Writer

tive juices. These secreted fluids are normally thin and slippery, but in people with cystic fibrosis, a defective gene causes the secretions to become sticky and thick.

Cystic fibrosis causes a person's lungs and airways to become clogged with mucus that traps germs and leads to infections, inflammation, respiratory failure and other complications. The thick mucus can also block tubes that carry digestive enzymes from your pancreas to your small intestine.

Common complications from cystic fibrosis includes damaged airways, chronic infections, nasal polyps, coughing up

blood, pneumothorax, respiratory failure, clubbed fingers, reduced fertility in women, infertility in men, nutritional deficiencies, diabetes, liver disease, intestinal obstructions, osteoporosis, dehydration, electrolyte imbalances and mental health problems.

According to the Cystic Fibrosis Foundation, more than 30,000 people in the United States, and 70,000 worldwide, live with cystic fibrosis. Approximately 1,000 new cases of cystic fibrosis are diagnosed every year with more than 75% of people being diagnosed by age 2.

There's no cure for cystic fibrosis. The average life expectancy ranges

from 40-50 years old, but it's improving.

Last year, a new treatment called Trikafta came on the market, and it has literally been a life-saving drug for people with cystic fibrosis who have seen an average improvement of 10-13% in lung function.

People with cystic fibrosis also have to follow an extensive daily treatment regimen, which can include 20-40 pills, a day, enzymes, a high calorie diet, vest therapy, nebulizer therapies, physical exercise and more.

People with cystic fibrosis are also required to practice social distancing to avoid infections. This is especially important now for people with cystic fibrosis during a pandemic.

Most people with cystic fibrosis will require a lung transplant sometime in their life. New lungs give them five to 10 years or more of life but don't cure them of cystic fibrosis.

I recently saw a film

called “Five Feet Apart” (2019), which follows two young cystic fibrosis patients (Haley Lu Richardson and Cole Sprouse) who fall in love despite needing to avoid close contact due to the risk of cross infections.

The film is inspired by cystic fibrosis activist and author Claire Wineland, from Austin, Texas, who founded the nonprofit Claire's Place Foundation. Wineland raised awareness about her disease, cystic fibrosis, through her YouTube channel, TEDx talks and in her book “Every Breath I Take, Surviving and Thriving with Cystic Fibrosis.”

Wineland died from a stroke one week after a double lung transplant at the age of 21.

After seeing the film “Five Feet Apart,” I started listing the Claire Wineland's old YouTube videos. In them she has important messages not only for cystic fibrosis patients and people with chronic dis-

eases but for everyone.

“I have lived a life of a lot of pain, and I'm not pretending that I haven't,” she said in one video. “I've had to deal with death; I've had to deal with painful surgeries; I've had to deal with being alone and scared in the hospital. But I have had a beautiful life — and one that I am so incredibly proud of. And that is not in spite of having cystic fibrosis. ... That's because of it.”

To watch Claire Wineland's YouTube channel visit [tinyurl.com/ycac5atz](https://tinyurl.com/ycac5atz) or visit the Claire's Place Foundation at [clairesplacefoundation.org](https://clairesplacefoundation.org). If you'd like to learn more about cystic fibrosis, a few suggested YouTube channels are The Frey Life at [tinyurl.com/ya4ft9l8](https://tinyurl.com/ya4ft9l8), Stephi Lee at [tinyurl.com/ybdpqh5](https://tinyurl.com/ybdpqh5) and Ben Mudge at [tinyurl.com/yccretld](https://tinyurl.com/yccretld).

To learn more about cystic fibrosis, visit the Cystic Fibrosis Foundation's website at [cff.org](https://cff.org).

[paige.kieffer@apgecm.com](mailto:paige.kieffer@apgecm.com)

## Parenting

Continued from 4

about how hard it is to not be with friends, to miss some of the events that are big in their lives such as dances, sports, concerts and graduation. Listen and empathize. Even as adults we feel anxious and upset about what is happening — and we have more tools than they do to cope.

It's not an easy time. But if we try to stay calm, love and support our children, take one day at a time, and connect to others, we will get through this. Parenting was never easy, and now it's really hard. Know that there are free classes, videos, resources and support groups through NAMI Minnesota. Sometimes it helps just to hear that you are not the only one struggling.

Sue Abderholden is executive director of NAMI Minnesota (National Alliance on Mental Illness). For more information, go to [namimn.org](https://namimn.org) or call 651-645-2948.

