



Samantha Manns has gone above and beyond for the CdLS Foundation, participating in a 40-mile bicycle ride fundraiser with just three weeks' notice. (Photo by Matthew DaCorte/The Courier | Buy This Photo ([http://shorepublishingwest.mycapture.com/mycapture/remotimage.asp?backtext=Click here to return to the Photo&backurl=http%3A%2F%2Fwww.shorepublishing.com%2Fapps%2Fpbcs.dll%2Farticle%3Favis%3DZ6%26date%3D2017\\_1.jpg](http://shorepublishingwest.mycapture.com/mycapture/remotimage.asp?backtext=Click+here+to+return+to+the+Photo&backurl=http%3A%2F%2Fwww.shorepublishing.com%2Fapps%2Fpbcs.dll%2Farticle%3Favis%3DZ6%26date%3D2017_1.jpg)))

## Samantha Manns: Raising Funds While Riding a Bike

By Matthew DaCorte, Staff Reporter (</apps/pbcs.dll/personalia?ID=m.dacorte>) • Contact Reporter (<mailto:m.dacorte@shorepublishing.com>)

Published May 24, 2017. Last updated 10:36 a.m., May 24, 2017

[www.facebook.com/sharer/sharer.php?](http://www.facebook.com/sharer/sharer.php?)

[vw.zip06.com/profile/20170524/samantha-manns-raising-funds-while-riding-a-bike\)](http://www.zip06.com/profile/20170524/samantha-manns-raising-funds-while-riding-a-bike)

[twitter.com/share?url=http://www.zip06.com/profile/20170524/samantha-manns-raising-funds-while-riding-a-bike&text=Samantha Manns: Raising Funds While Riding a Bike -](https://twitter.com/sharer/sharer.php?url=http://www.zip06.com/profile/20170524/samantha-manns-raising-funds-while-riding-a-bike&text=Samantha+Manns:+Raising+Funds+While+Riding+a+Bike)  
[\) !\[\]\(faf942dc3e59ce8eb64b4ac481eca7e0\_img.jpg\) \(/apps/pbcs.dll/article?](/apps/pbcs.dll/article?)

[ate=20170524&category=NWS10&lopenr=170529880&Ref=AR&template=printart\)](http://www.zip06.com/profile/20170524/samantha-manns-raising-funds-while-riding-a-bike)

Samantha Manns says that it is in her nature to help people, and she did just that by helping raise funds that will benefit those with a rare disorder.

After graduating from Emerson College in three years with a degree in journalism, she earned her master's degree in public relations from Quinnipiac University.

“After completing my thesis, I was looking for my first big job, and I came across the CdLS Foundation,” says Samantha, who is now communications coordinator for the foundation.

The Cornelia de Lange Syndrome (CdLS) Foundation is a family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS and their families make informed decisions throughout their lifetime.

“It’s a rare, genetic syndrome that affects one in 10,000 births,” Samantha says.

According to a press release, an estimated 20,000 people in the U.S. have CdLS but remain undiagnosed and/or without support services.

Samantha says that the disorder is usually diagnosed at birth, but is sometimes initially misdiagnosed as Down syndrome.

“There’s a lack of knowledge in the general public and especially in the medical community, where they don’t know what it is until they happen to meet someone that is familiar with the syndrome,” she says.

Characteristics include a short, upturned nose, long eyelashes, and eyebrows that meet in the middle. The disorder exists on a spectrum, so children who are more severely affected can have limb differences, and may never walk or talk.

However, Samantha says that some kids who have a mild form of CdLS have gone to college.

“It’s kind of hard to pinpoint a person with CdLS just because you want to accurately represent the whole spectrum,” she says.

The CdLS Foundation is a non-profit organization, and Samantha says that 50 percent of the organization's revenue comes from special events and fundraising. The organization's program for marathons, bike tours, and other athletic events is called Team CdLS.

This year marked the organization's inaugural year as an official charity partner for the TD Five Boro Bike Tour, which took place on May 7 in New York City. Samantha participated in that ride, but was hesitant to do so initially.

She says that her supervisor, who is the charity manager, put her name in to secure the final spot of the 10 the organization was given.

"I ended up training for only three weeks, and went to New York City to ride 40 miles," she says.

Samantha finished the ride in less than four hours, which she thought was pretty good, especially since she had never gone on a real bike, and only trained on the stationary bike at the gym.

"I'm pretty dedicated to the foundation, and the families I work with and work for, so I definitely felt determined to finish even though I had to walk some of the bridges," Samantha says with a laugh.

She says she and the rest of her team got to have a nice weekend in New York City. That included a pre-race luncheon and celebrating at a ceremony after the race.

Every team member on Samantha's team had to raise a minimum of \$750, with the total fundraising goal being \$7,500. Samantha ended up raising \$2,200.

"Actually, all of my team members went above the minimum," she says.

She says that the last time she checked, that total amount that was raised was about \$9,000, which is about 123 percent of what the organization had hoped to raise.

Samantha says that some of the services the CdLS Foundation offers include family gatherings, a biennial conference, and clinics. All of the services are free of charge.