



April 27, 2021

The Honorable Larry Bagley
Chair
House Committee on Health and Welfare
900 North 3rd Street
Baton Rouge, LA 70804

Re: Support for House Bill 460

Dear Chairman Bagley and Members of the House Committee on Health and Welfare:

My name is Libby Airhart, and I am the Louisiana Rare Action Network Volunteer State Ambassador for the National Organization for Rare Disorders (NORD). NORD is a unique federation of voluntary health organizations dedicated to helping the 25-30 million Americans living with a rare disease.

In 2013, we were blessed with the arrival of my youngest daughter, Amelie. At first everything seemed normal, but as the months went on, it became evident that Amelie was falling behind and not meeting her appropriate developmental milestones. We were told that she may need more time to develop. This continued until she was eventually referred to a gastroenterology specialist in Baton Rouge. After that meeting, it was recommended that we travel to New Orleans to start genetic testing. The specialist knew right away what she thought her diagnosis was simply because she had treated a patient with this condition before in another country. After one round of genetic testing, the doctor told us the news that no parent ever wants to hear. Amelie was diagnosed with Cardio Facio Cutaneous Syndrome (CFC Syndrome) and we quickly found out just how rare CFC Syndrome is, with a total of 800 diagnoses worldwide and only 11 within Louisiana.

Sadly, our story is not that unique among the rare disease community, as many families and patients go through numerous misdiagnoses and testing before receiving answers. I was on a mission to find what I thought was going to be the cure for CFC Syndrome. Our journey has taken us from a dual income household down to a single income simply to allow us to care for our daughter and her medical needs. Insurance assists with covering some claims, but the expenses from Amelie's multiple hospital stays, medication, therapies, equipment, and even the cost of travel can leave us feeling overwhelmed and at times feeling like we are drowning financially.

A Rare Disease Advisory Council (RDAC) in Louisiana is vital to removing barriers that exist not only with identifying and diagnosing rare diseases, but also with having the ability to access treatments and therapies. This can be extremely challenging in our state, given that we have a shortage of geneticists and specialists. Often accessing services requires a trip to New Orleans, where the highest level of care is available for ill children in Louisiana.



NORD[®]
National Organization
for Rare Disorders



Today, Amelie is almost 8 years old, and still, we encounter many barriers in her health care and therapy care. An RDAC in Louisiana will be instrumental in tackling the barriers so many rare disease families face by bringing the needs of the rare disease community in Louisiana front and center. As Louisiana's Volunteer State Ambassador and a mom to a rare disease patient, I urge you to vote in support of House Bill 460 and help Louisiana become the 18th state to enact an RDAC.

Sincerely,

Libby Airhart
Volunteer State Ambassador
Louisiana Rare Action Network