Dear XX:

I am writing to ask for your financial assistance in providing travel and conference funding so that I *(or my family and I)* may attend the **Cornelia de Lange Syndrome (CdLS) Foundation National Family Conference, June 23-26, 2022 in Tulsa, OK.**

I *(or my son/daughter)* was born with CdLS. Cornelia de Lange Syndrome (CdLS) is a genetic disorder present from birth, usually not inherited. It is usually due to an acquired change (mutation) in one of seven important developmental genes at or shortly after conception. It causes such a broad range of potential physical, cognitive and medical challenges that it is now known as the CdLS spectrum disorder. CdLS does not discriminate— it affects both genders equally and it’s seen in all races and ethnic backgrounds. The occurrence of CdLS is estimated to be 1 in 10,000 live births, but because it is so variable, could remain undiagnosed. In our case, CdLS has affected me *(my child)* in the following ways. *(Insert a description of the physical, behavioral,* *educational challenges encountered and what you/your child have done to overcome them).* (*Hint: try to focus* *on the positive things & not the negative. You aren’t asking for sympathy here; you are asking for funding to* *help you do one more positive thing related to CdLS*.)

Because the syndrome is so rare, the CdLS families are often widely dispersed in each state and most only have an opportunity to meet at these conferences. We also have the opportunity to learn from a wide range of professionals from all over the country who are knowledgeable about CdLS and its medical, educational, social, and developmental challenges. For most people diagnosed with CdLS, Conference represents their only opportunity to interact with peers who cope with similar challenges.

Conference is designed to support my *(our)* entire family. Conference provides families the opportunity to share personal experiences and make connections with others who face similar challenges. Parents and caregivers can attend more than a dozen educational seminars and family workshops, participate in roundtables, and hear from keynote speakers on topics ranging from behavior to special education advocacy. Individuals with CdLS receive free, private, head-to-toe consultations with physicians and allied health professionals who are distinguished in their specialties and who have expertise in the treating of children with CdLS.

The cost for me/our entire family to attend Conference will place a significant financial burden on my family. The detailed costs of attending the National Family Conference are detailed in Attachment 1. I*(/we)* have also applied to *(list other agencies you have contacted)* and have held *(/plan to hold)* the following fundraisers to help defer these costs (*describe the remaining gap between the costs and your resources)* but we will still need and appreciate any help you are able to provide.

You can also view additional information about CdLS and the CdLS Foundation National Family Conference at the CdLS Foundation website, [www.CdLSusa.org](http://www.CdLSusa.org).

My contact information is: XX

Thank you very much for your consideration.

Sincerely,