Local company rallies for awareness of rare genetic disorder

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PRESS RELEASE

Luanna "Lu" Fielder, and her husband, Bill, are the owners of Fielder Electric Supply Company out of Houston. They also have a daughter, Jaclyn, 23, who has a rare genetic disorder, called Cornelia de Lange Syndrome (CdLS). In honor of National CdLS Awareness Day, employees of Fielder Electric Supply Company will be hosting a special day on Friday, May 15.

"In June of 1991, our daughter, Jaclyn, was born with CdLS. We were at a loss. She was diagnosed at birth and we were told there wasn't much information about CdLS in the American Journal of Medical Genetics except two small paragraphs and a picture. During her first months in the hospital, I kept asking to see this book and the two small paragraphs and photo. They finally showed me, and really all I remember is the picture of a face with hair on it. Having extra hair is a characteristic of CdLS, but not like the picture in the book. Not long after she was born we found the CdLS Foundation and were introduced to other parents and it was a comfort knowing we weren't alone."

National CdLS Awareness Day is observed the second Saturday of May each year in order to shed light on this often misdiagnosed, little-known genetic syndrome. Since CdLS is unfamiliar to many, including professionals in the medical community, Awareness Day—celebrated since 1989—is an opportunity to educate all segments of the population.

"This is Fielder Electric Supply's third annual Dress Down Day fundraiser for the CdLS Foundation," said Lu. "Since we dress down pretty much every day we decided to 'theme' out this event each year. The employees really show their enthusiasm by going all out in their decorations for their work area, it's so amazing!

This year, Fielder Electric's Dress Down Day fundraiser theme: Disney characters.

"The employees look forward to this event each year and boy are all of them creative," said Lu. "We expect nothing less than spectacular this year as it has been our last two years. It really means a lot to my husband and I to see how much support through the acts of kindness our employees give to us, to our child with CdLS and to the Foundation."

"Jaclyn's first couple years were filled with hospital stays and surgeries and figuring out how this syndrome affected her, and it took a real toll on us all," said Lu. "We almost lost her to double pneumonia, but she fought back just like she did when she developed sepsis due to a twisted bowel...Jaclyn is well aware of her surroundings, her wants and needs, and loved her school years before she graduated in 2011 and fully participating in the graduation ceremonies with the rest of her class. She

continues to enjoy her weekly physical and speech and music therapies. She knows some sign language and uses gestures to communicate. She is incredibly complicated, but she also gives so much love unconditionally and she shows that every day with her beautiful smile and giggling. God truly blessed us by trusting us with His gift."

For more information about the Cornelia de Lange Syndrome, the CdLS Foundation or to make a donation, call 800-753-2357 or visit www.cdlsusa.org.

About CdLS

Cornelia de Lange Syndrome occurs in about 1 in 10,000 births. An estimated 20,000 people in the U.S. have CdLS but remain undiagnosed and/or without support services. Individuals with CdLS range from mildly to severely affected, though most have similar physical characteristics including small size, hands and feet; thin eyebrows that meet; long eyelashes; upturned nose; and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms.

About the CdLS Foundation

Founded in 1981, the Cornelia de Lange Syndrome 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.