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Walk event raises funds in honor of New Hampshire boy with genetic syndrome

Seabrook, NH (May 24, 2010) – Hoof-it 4 Hunter, a two-mile walk event to benefit the Cornelia de Lange Syndrome (CdLS) Foundation, is Saturday, June 12, at Seabrook Elementary School on Walton Road.



Marcia and Jason Knowles of Seabrook started Hoof-it 4 Hunter in honor of their four-year-old son, Hunter, who was diagnosed with CdLS

when he was 10 months old. CdLS is a little-known genetic disorder that causes a variety of physical, cognitive and developmental disabilities. When Hunter was diagnosed with CdLS, Marcia and Jason found comfort in the CdLS Foundation. “Words cannot express how we feel about the Foundation. They have answered every question we’ve ever had and been there for us emotionally through it all,” says Marcia Knowles.

“There are three things we hope to accomplish through Hoof-it 4 Hunter,” she says. “The first is to help people understand CdLS, and to allow other children to be properly diagnosed if they have CdLS. The second is to raise money for the Foundation because they have been so amazing to us. And the third is to educate our community to help Hunter as he grows up.”

The two-mile walk begins at 10 a.m., and refreshments are served following the event. For more information contact Marcia Knowles at 603-474-1966.

About CdLS

CdLS is a genetic syndrome that 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. Although individuals with CdLS range from mildly to severely affected, most have similar physical characteristics: small size, hands and feet; thin eyebrows that meet in the middle; long eyelashes; upturned nose; and thin,

downturned lips. Some individuals have limb differences, including missing fingers or arms, and partial joining of the toes. Common medical problems include gastroesophageal reflux, bowel obstruction, hearing loss, and congenital heart defects.

About the 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 make informed decisions throughout their lifetime. For more information, call 800-753-2357 or go to www.cdlsusa.org.

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