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Families host motorcycle ride to benefit children with rare genetic disorder

Minneapolis/St. Paul, MN (May 27, 2010) – The first-ever Motorcycle Ride for Cornelia de Lange Syndrome (CdLS) is Saturday, June 12, starting at Hitching Post MotorSports in Hopkins. The event was organized by three area families with the hopes of raising \$5,000.

Motorcycle ride organizer David Viland is the grandfather to five-year-old Audrey, who has CdLS, a little-known genetic disorder that causes a variety of physical, cognitive and developmental disabilities. All proceeds benefit the CdLS Foundation, a national family support organization. Viland became a CdLS Foundation board member after attending a CdLS family conference when Audrey was five months old.

“After we found out about the CdLS Foundation, my wife and I decided that we wanted to be a part of it. When the previous director recognized my background in healthcare and asked me to join the board, I knew that I had to for my daughter and family, and for Audrey,” said Viland, who lives not far from Audrey and her family in Minnetonka.

Viland was inspired to start a motorcycle ride fundraising event because he is a biker himself, and saw it as a new way to raise money for the cause. Viland is joined by the Watzak family of Eagan and the Drach family of Arden Hills. Both families have children with the syndrome.

“The major resources of revenue for the CdLS Foundation are from donations and fundraising activities. Being a biker myself, I know motorcyclists do benefit rides all the time, so “why not?” ” said Viland.

“We also want to develop a template for this event for other regions of the country. We hope other bikers will see what we’ve done and want to start a CdLS benefit ride near them.

Motorcycle events like this around the country will go a long way to increase awareness of CdLS.”

The motorcycle event begins at 9:30 a.m. with registration and a continental breakfast, followed by the start of the motorcycle ride at 10 a.m. There is a mid-point stop and lunch break at 12 p.m. at the Lake Ridge Care and Rehab Center in Buffalo. The ride ends back at Hitching Post Motorsports at 2 p.m., where there will be an awards ceremony, a 50/50 drawing, poker run, and the chance to win prizes.

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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