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**Grandfather sets off on cross-country motorcycle ride, from Manchester to San Francisco, in honor of his grandson and others with rare genetic syndrome**

*100 Harleys and dozens of families gather at Saint Anselm College to send him off, May 14*

**Manchester, NH (April 12, 2011)** – What would make a 70-year-old man ride his Harley-Davidson 3,800 miles across America? Simple: To help his grandson and other children born with Cornelia de Lange Syndrome (CdLS), a little known genetic syndrome that causes a range of medical, physical and cognitive challenges for those born with it.

Ken Fouts, a retired Emmy-award winning sports director, loves his 2008 Harley-Davidson Softail Heritage and his 16-year-old grandson, Adrian, a Manchester resident, so what better way to honor both than by riding across the country

*Adrian's Ride 2011* aims to raise money for the national CdLS Foundation and awareness of the syndrome. An estimated 20,000 men, women and children have CdLS but remain undiagnosed and/or without support services.

Fouts plans to start his three-week, 20-state trek from Saint Anselm College on national CdLS Awareness Day, May 14. It's also the day after Adrian's 17<sup>th</sup> birthday. CdLS families from the New England region and upwards of 100 members of the Manchester Harley-Davidson chapter will be on hand to celebrate Awareness Day and send Fouts off. A

representative of the college will bless Fout's bike. New Hampshire Governor John Lynch has been invited.

The festivities are from 11 a.m. to 3 p.m., with the bikers arriving at 11:30 a.m. and leaving at 1 p.m. to head to Portsmouth, where Fouts will collect water from the Atlantic Ocean to pour into the Pacific.

Motorcycle riders are encouraged to join him along his cross-country ride, whether for a few miles or a few hundred. Anyone interested in joining *Adrian's Ride 2011*, or donating to the cause, can call the CdLS Foundation at 800-223-8355 or email [events@CdLSusa.org](mailto:events@CdLSusa.org).

Updates on Fouts' ride will be posted on the CdLS Foundation's blog, found at [www.CdLSus.org](http://www.CdLSus.org).

### **About CdLS**

CdLS is a genetic syndrome that occurs in about 1 in 10,000 births. Common medical problems include gastroesophageal reflux, bowel obstruction, hearing loss, and congenital heart defects. 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.

### **About the CdLS Foundation**

Founded in 1981, the CdLS 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](http://www.CdLSusa.org).

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