

## **Avon organization accepted into federal rare disease pilot program**

Avon, CT (July 2, 2012)—The Cornelia de Lange Syndrome (CdLS) Foundation is one of just 34 organizations from around the country accepted into the National Institutes of Health’s (NIH) Global Rare Disease Patient Registry and Data Repository (GRDR) pilot program.

The GRDR strives to aid in research, clinical trials, drug developments and therapeutics for people with rare conditions, such as CdLS. The goal of the GRDR is to provide a sustainable resource for the organizations accepted into the program. The program is launching this summer.

“We are thrilled to be part of this important program,” said Acting Executive Director Marie Malloy. “A national registry of CdLS data lets researchers compare and evaluate data among people with CdLS, as well as other similar conditions. In the long-term, the longitudinal data collected through this registry can help doctors understand more about CdLS over a person’s lifetime.”

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](http://www.cdlsusa.org).

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