

## Torrington residents recognized for work with foundation centered around genetic disorder

**Genetic syndrome causes debilitating medical problems; 1 in 10,000 affected**

*By Ben Lambert, The Register Citizen*

Friday, July 15, 2016



TORRINGTON >> A Torrington couple has been recognized for their longtime work with the Cornelia de Lange Syndrome Foundation, and were recently inducted as members of the de Lange society. The organization issued a statement regarding the honor earlier this week.

Linda and Ron Berger of Torrington have been involved with the foundation since 1975, after they became friends with a couple whose daughter had the syndrome.

“Linda has helped coordinate with consultations at the CdLS Foundation National Family Conference for the past several years, directing and welcoming families during the event,” foundation representatives said in a statement.

“Ron has served on the Clinical Advisory Board for the foundation since 2003. He has written numerous articles for foundation publications regarding eyes and eye-care in CdLS. Ron has also attended numerous CdLS national and international conferences and through consultations, provided countless families with

valuable information to bring back to their medical care team.”

Ron Berger holds an M.D., as described in the release.

According to the foundation, 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 in the middle; long eyelashes; an upturned nose; and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms. Common medical problems include GERD, bowel obstruction, hearing loss, and congenital heart defects.

The Avon-based [Cornelia de Lange Syndrome Foundation](#) was founded in 1981, according to its website, and is named after the physician who brought the existence of the syndrome into common knowledge.

The organization “provides a host of services that educate and unite families touched by this little-known genetic syndrome,” as described on its website, and “(enlists) the support of hundreds of dedicated volunteers throughout the United States, as well as the expertise of professionals from the fields of genetics, medicine,

education, psychiatry, and more, in our effort toward advancing both societal and scientific understanding of CdLS.”

---

URL: <http://www.registercitizen.com/lifestyle/20160715/torrington-residents-recognized-for-work-with-foundation-centered-around-genetic-disorder>

© 2016 The Register Citizen (<http://www.registercitizen.com>)