

Event hosted for Texas families connected by rare genetic disorder

Brenda Shepard, Star Local Media contributor | Posted: Saturday, November 8, 2014 11:44 am

More than 120 people from around Texas gathered together Oct. 25 for one reason: Cornelia de Lange Syndrome (CdLS).

Among those in attendance at the Dove Park South Pavilion were parents, relatives, friends and individuals with CdLS, a rare genetic disorder.

“We appreciated the opportunity provided by the CdLS Foundation to meet other Texas families affected by CdLS,” said Glenda Albright, grandmother of Andre, 15, who has CdLS. “Andre was happy to see previous friends and meet new ones.”

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; long eyelashes; upturned nose; and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms.

“I’m always touched by the love and acceptance families have for one another’s children and each other’s situation,” said Mary Opitz, mom to Katie, 27, who has CdLS. “Experienced families put new families at ease, help answer questions and let them know they are not alone. One new father told me the experience exceeded his expectation and well worth the drive from San Antonio.”

For many families, this event was a rare chance for them to interact and meet other families and individuals with CdLS.

“For every individual with CdLS, there were an average of four other people with them,” Opitz said. “We met siblings, aunts, uncles and grandparents all there to provide much needed support to their loved one – support which I’m sure extends well beyond our day in the sun.”

For more information about the CdLS Foundation or to make a donation, call 800-753-2357 or visit cdlsusa.org.



CdLS Day

Katie, 27, right, who has Cornelia de Lange Syndrome, and CdLS Foundation Executive Director Marie at the Oct. 25 event.