

# FAMILIES SHARE COPING SKILLS

## A Mauston couple helps families diagnose children with Cornelia de Lange Syndrome

By Gail Boehm

Star-Times

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LC 16856

**K**arla and Mike Postell do not give half-heartedly when attempting to help children and families. The couple, who has been married for 25 years, feel they have a mission to accomplish. Karla said, "Our son Colin, 19, was not diagnosed with Cornelia de Lange Syndrome (CdLS) until he was 10 years old.

"The endocrinologist also found that his pituitary gland did not work. In 1997 the doctor tested Colin's genes to find he also had CdLS."

The syndrome is due to mutated genes and not known to be hereditary. Individuals with the syndrome resemble each other and have common characteristics such as: low birthweight, slow growth, small stature, small head size, thin eyebrows which meet midline, long eyelashes, short upturned noses and thin down-turned lips, small hands and feet, partial joining of the second and third toes, missing limbs and fingers, a cleft palate, gastroesophageal reflux, seizures, feeding difficulties, vision and hearing problems, behavioral issues and developmental delays.

Karla said because Colin had mild symptoms of CdLS, the family pursued some information about it, but did not really get involved until the family got a computer and went online to find out more. They joined an online support group in 2003.

She said through the support group she found Shepherd's Crook, Cincinnati, which helps place special needs children for adoption, had received a letter from American missionaries about Sam. The letter had been

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Colin and Sam Postell, of Mauston, share the same syndrome. Cornelia de Lange syndrome (CdLS) is a syndrome of multiple congenital anomalies characterized by a distinctive facial appearance, prenatal and postnatal growth deficiency, feeding difficulties, psychomotor delay, behavioral problems, and associated malformations that mainly involve the upper extremities.

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