

Local man participates in mud run to honor daughter

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(Photo: COURTESY OF THE CDLS FOUNDATION)

On July 11, Shawn Carr participated in the Rugged Maniac 5K obstacle course at Raceway Park in Englishtown in honor of his daughter. Along with his wife, brother and college friend, Carr fundraised for the Cornelia de Lange Syndrome Foundation while training for the race.

"My favorite thing about running for Team CdLS would have to be the fact that we are running for a purpose, and that is to raise money for what I believe to be a great organization: the CdLS Foundation and the work they do with families affected by CdLS," Carr said.

The family has raised more \$12,000 in memory of their daughter, Layla Ann who died from heart disease associated with CdLS three days after her birth in May 2014. For this run, Shawn and his wife Kimberly, of

Somers Point, raised \$3,285.

The family discovered the CdLS Foundation after Layla's passing and Carr immediately signed up for a mud run last year.

"It was a way of dealing with the grief in a positive way," he said.

They hope to continue running for Team CdLS for many years.

The Rugged Maniac is a 5K "mud run" that is held in locations all over the country. Shawn and his family decided to run in this particular race because it was close to home and a different kind of course than they are used to.

Cornelia de Lange Syndrome is rare genetic disorder that occurs in about 1 in 10,000 births. An estimated 20,000 people in the U.S. have CdLS but remain undiagnosed or without support services. Individuals with CdLS range from mildly to severely affected, though most have similar physical characteristics including small size, thin eyebrows, long eyelashes, upturned nose and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms.

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 and their families make informed decisions throughout their lifetime.

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

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