

GALLAGHER: After decades, bonds forged over rare disease still strong



10 HOURS AGO • [TIM GALLAGHER](#)
TGALLAGHER@SIOUXCITYJOURNAL.COM

SPIRIT LAKE, Iowa | Four decades later, Bob Shaw talks about the preciousness in the photo. Pausing, he thinks of two babes he and wife Kathleen lost. Moving ahead, he tells their story.

Son Hudson Shaw was 3 when he died in 1974; a life cut short when a viral infection settled in his heart.

In the photo he clutches baby sister Angela Shaw, who was born in 1973, nine months before her brother's death. Unlike her older brother, Angela wasn't healthy from Day One. She had Cornelia de Lange syndrome, a rare genetic condition that shows in various physical problems among its victims, and some common traits, too, such as connected

eyebrows, small head, thick head of hair.

"It's a very rare genetic imbalance," Bob Shaw says, noting mention of it still sends listeners to Google. "When Angie was born, the medical staff told us to prepare for a funeral as she had a three- to five-year life expectancy."

A funny thing happened on the way to this tragedy. Gordon Gammack of The Des Moines Register wrote a 1974 feature on Angela Shaw and her CdLS diagnosis. Soon after, Bob and Kathleen Shaw heard from a couple in Sitka, Alaska. And another from Seattle. A third from Dexter, Iowa, called.

Remember, this was 1974. No Internet. No email. No social media or Skype. Parents whose children looked conspicuously like a girl in an Iowa news story, it turns out, had the same rare condition. Parents bonded immediately, as immediately, at least, as snail mail and AT&T could offer.

These isolated parents forged the national Cornelia de Lange Syndrome Foundation in 1977. To this day, the organization raises funds for research and family support.

Bob and Kathleen Shaw did their small part 10 years ago, honoring Angela in the year she would have turned 30 by inviting all CdLS families to the Iowa Great Lakes for a weekend of sunshine and moral support. Fourteen de Lange families came from seven states.

"The de Lange children looked alike," Bob Shaw says. "And after all those years it was like we had 14 Angies back."

Bob and Kathleen and their four surviving children gathered for photos with kids who looked like Angie. They wept and celebrated. And pledged to do it again.

Ten years zipped past. The 40th birthday for their Angie came and went quietly earlier this year. The Shaws make some noise for their two angels (Hudson and Angie) this weekend in hosting "Our Angels Concert – A Night to Remember Hud and Angela Shaw and all CdLS Families" at the Sami Center in Spirit Lake.

Todd Shaw, a 2000 graduate of Spirit Lake High School, joins the family celebration by playing classical music on the Sami Center's limited-edition Elton John Signature Red Piano. Todd, who has an odd claim to fame, is one of Bob and Kathleen's four surviving children.

"We have two angels in heaven who keep us going and four devils on Earth who keep us hopping," Bob Shaw says with a laugh.

Todd Shaw is believed to be the last person who ran a snowmobile across an open East Lake Okoboji. He did so on a 92-degree day about a decade ago and has video of the run still making waves on YouTube. Thankfully, a law prohibiting the practice was passed in his wake.

"See what I mean about devils," his dad says, chuckling.

For \$10, you can hear Todd Shaw play on Saturday. He's also a video comic, so there's gotta be entertainment value. Giving won't be limited to \$10. There are various levels of sponsorship for the weekend, Bob Shaw advises.

There's also a CdLS panel discussion from 9:30 a.m to noon Saturday at Cutty's in Spirit Lake. Another Shaw child, Jeff Shaw, a social worker based in Las Vegas will serve on the panel, as will Angie Shaw's former pediatrician, Dr. John C. Justin of Mason City, Iowa, who retired years ago.

"To me, the whole emphasis is on family support," Bob Shaw says. "Fundraising is important. Developing awareness and bringing attention to CdLS is even more important."

"Our Angels Concert"

"Our Angels Concert – A Night to Remember Hud and Angela Shaw and all CdLS Families" takes place at 8 p.m. Saturday at the Sami Center in Spirit Lake, Iowa. Other events Saturday include a panel discussion on CdLS from 9:30 a.m. to noon at Cutty's of Okoboji, a 5 p.m. Mass at St. Mary's Catholic Church in Spirit Lake and a 6 p.m. meal at St. Mary's Parish Hall.

For information, contact Bob Shaw at (712) 330-0751 or see www.cdlsusa.org