



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

A Closer Look: Families Consider Intensive Feeding Programs

It's only natural for parents to want the best for their children. For parents of children with CdLS, it can be difficult to decide whether to enroll their children in intensive feeding programs if they are tube fed. Below are the stories of two families currently facing this decision.

Julie and Darian of Maryland recently completed an intensive feeding program with their two-year-old son Fletcher. "The main reason we wanted to do this program was the desire for normalcy," Julie says. "We want Fletcher to live as normal a life as possible, and eating through your mouth is a big part of that."

Fletcher attended the feeding program at Mt. Washington Pediatric Hospital in Baltimore. His regiment consisted of three half-hour feedings per day Monday through Friday for seven weeks. By the end of the program, Fletcher readily accepted a half ounce of pureed food per meal.

Fletcher's oral motor skills also improved. "By the end of the program, if he didn't open his mouth automatically when he saw the spoon, he would open it if you asked him," says Julie. "And not all but some of the food stayed in his mouth. This was a huge development."

Julie and Darian haven't stopped their efforts to help Fletcher eat. "We are so convinced that Fletcher needs to eat, that we are willing to do absolutely anything to get him there," Julie says. Fletcher is currently on a waiting list for a more aggressive feeding program at the Kennedy Krieger Institute in Baltimore.

For Jennifer and Brent, parents of Isabelle (pictured on the cover), who will be three years old in May, the decision to enroll their daughter in an intensive feeding program has been difficult. Isabelle is on the waiting list for a program that consists of five feedings per day, five days per week for eight weeks. In the meantime, the Michigan couple has gone back and forth between different forms of feeding. After gagging spells and Isabelle's frustration with bolus (all at once) tube feeds, the family is focused on drip feeding while Isabelle sleeps.

"The drip feedings while sleeping seems to fit well with Isabelle. She is healthy and happy," Jennifer says. "It seems that the less pressure I put on her to eat, the more she eats on her own. I'm worried that we may take a step in the wrong direction if we put her in the intensive program and try to force her to eat. I think she will resist even more," she says. "We are still weighing our options ... and we will continue to encourage eating and weekly feeding therapy, just not in an aggressive manner."

Jennifer and Brent would like to speak to families whose children have had success in an intensive feeding program. Contact the Foundation at 800-753-2357 or familysupport@cdlsusa.org and we'll share your contact information with the family.