

## A Closer Look at Nutritional Struggles

*By Alicia Mangiafico, Family Service  
Intern, CdLS Foundation*

As many parents of a child with CdLS know, feeding and ensuring proper nutrition can be a lifelong struggle. A significant portion of the CdLS population has, or has had at one time, issues with getting the necessary nutrition to maintain health.

Learning more about these issues was the purpose of a nutrition survey sent to families this past summer.

According to survey respondents, nearly half (48 percent) of their children currently receive, or have needed, some type of oral motor therapy. Julie, mother of Fletcher, age 5, shared her experiences with intensive feeding therapy.

### **Fletcher's Story**

After two failed attempts at feeding programs in 2009 and 2010, the family was referred to the Penn State Institute in Hershey, PA. The staff structured the sessions to fit Fletcher's specific needs, and during the final weeks of therapy, staff directly involved Julie and her husband, Darian, in the feedings.

This, Julie believes, was key to Fletcher's success. Since Julie and Darian were going to be the ones feeding Fletcher at home, it was important to be included in the therapy. Not only does Julie say this was pivotal to his success in therapy, she says it was immensely important for her and Darian to learn the same techniques.

Before attending the clinic, Fletcher was drinking one to two milliliters of liquid by spoon. These days, he drinks more than two ounces and eats upwards of one ounce of pureed food at meal time.

The road to nutritional stability is a rocky one, and getting Fletcher to the point he is now was not easy, says Julie. It took a lot of time and a healthy dose of patience to bring him to his current level of eating.

### **Payson's Story**

One-year-old Payson has dealt with several nutritional issues in his short life. In the Neonatal Intensive Care Unit, Payson was projectile vomiting and had blisters on his buttocks, says his mother, Christie. These are common signs of a milk protein allergy.



Based on the survey, a quarter of the respondents said their children have some kind of milk allergy or intolerance. Sixteen percent have been diagnosed with food allergies. In order to find the cause of Payson's problems, his doctor administered acid reflux medicine and then switched him to a different milk-based formula. When neither of those solutions worked, his formula was switched to Neocate, a hypoallergenic and dairy-free formula. After this switch, Payson's symptoms dissolved quickly. The recent issue Christie is facing is Payson's increasing lack of interest in eating. He had a g-tube inserted, then a Mic-Key button this past summer, and although the button has made feeding time easier, Payson never seems hungry, Christie says. For example, even if he gets three ounces at 10 p.m., he wakes up at 7:30 a.m. without showing any signs of hunger. Christie says she is beginning to think Payson he doesn't have a sense of hunger. This has prompted her to consider putting Payson on an appetite stimulant.

### **Cathy's Story**

For 38-year-old Cathy, maintaining a healthy weight has been an intense battle and even a life-threatening issue, says her mother, Pat. Born with a cleft palate, Cathy was never able to breastfeed or drink from a bottle.

Even though she is able to eat regular meals, Cathy struggles intensely to maintain a healthy weight, says her mother. Two years ago, Cathy, who stands four feet tall, suddenly dropped from 48 pounds to 38.

Pat consulted a nutritionist, who suggested that Cathy, who was consuming between 1,200 and 1,400 calories per day, was not getting enough calories. Pat added Ensure (350 calories per bottle), which boosted her back up to 48 pounds. But recently, Cathy has been refusing to drink her formula, which resulted in a five pound weight loss.

Pat has not considered a feeding tube, saying that she was sure it would be "more of a burden than a helping hand," since Cathy is "incredibly adept at pulling things like bandages off of her body."

The majority of children with CdLS (75 percent according to the survey) have not experienced normal growth. However, a diagnosis of CdLS does not always mean a child will be underweight. Nearly 35 percent of the survey respondents report that their children have experienced excessive weight gain.

Regardless of Cathy's struggles, Pat remains optimistic about her daughter's future. A positive outlook seems to be a great comfort for many families who struggle with getting the proper nutrition for their children.

