

## Nutritional Survey Results

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Nutrition plays a vital role in the growth and development of children. For children with CdLS, obtaining proper nutrition may be an obstacle due to challenges associated with the syndrome.

To better understand the nutritional issues associated with CdLS, the Foundation surveyed parents about nutritional complications and challenges.

The questions addressed issues found to be more prevalent in people with CdLS when compared to those unaffected by the syndrome. The areas addressed by the study included growth concerns, feeding issues, food allergies/intolerances, and gastrointestinal issues. Two hundred and two parents/caregivers completed the online survey in the summer of 2011. This article reviews some of the results from the survey.

### **Growth Concerns**

For those with CdLS, specific growth curves are available to determine if a child's growth is appropriate when compared to others with CdLS. These CdLS gender-specific growth charts are based on research and data collected over many years.

When asked about the growth of their child, approximately 75 percent indicated that their child's growth was not normal. Comments from parents showed that many of their children were smaller than their peers in both weight and height, but were appropriate when plotted on the CdLS curve.

Many indicated that their child's weight gain was slow during early years but picked up as he/she got older, even resulting in excessive weight gain.

A follow-up question asking about weight gain showed that 35 percent of individuals experienced periods of excessive weight gain. Overeating, medication and lack of physical activity played a large role in contributing to this weight gain. Most reported that the initial period of weight gain occurred during adolescence.



### **Feeding Issues**

The majority of people with CdLS are able to consume at least part of their nutritional requirements by mouth. Out of those surveyed, nine percent of children could not eat anything by mouth, 17 percent had limited oral intakes and 43 percent required tube feedings (either ongoing or at one point in the past).

Tube feeding was required due to gastroesophageal reflux, poor weight gain, small jaw and other anatomical difficulties, swallowing dysfunction, cleft palate, or a combination of factors.

For those who required a feeding tube due to gastroesophageal reflux, 60 percent received a Nissen fundoplication (surgical procedure used to treat reflux).

Most children on tube feedings were able to tolerate a milk-based intact formula, but others required semi-elemental or free amino acid-based specialty formulas due to poor tolerance to intact proteins. For those that did not require tube feeds, 36 percent required oral nutritional supplements and/or additional vitamin/mineral supplements to meet nutritional needs.

At least half of those surveyed indicated feeding issues and/or food aversions that prevented appropriate oral intakes for growth. Those surveyed reported that 46 percent of their children had sensory or texture issues associated with eating; 51 percent required some type of oral motor therapy or other feeding therapy; and 32 percent had issues with food storage in the mouth.

### **Food allergies/intolerances**

Food allergies were reported by 16 percent of those who responded. Twenty six percent indicated the child had either a milk protein allergy or lactose intolerance. Other food allergies listed were corn, rye, seafood, peanuts, tree nuts, soy, berries, egg, citrus, and wheat.

For those whose children had lactose intolerance, most reported limiting dairy intake or using lactaid pills when dairy products were consumed.

### **Gastrointestinal Issues**

Diarrhea, constipation and gastroesophageal reflux are common issues in people with CdLS. Of those who answered the survey, 69 percent indicated their child deals with constipation either frequently or sometimes; 49 percent indicated their child experiences diarrhea.



Many parents whose children deal with constipation use Miralax, a stool softener or Milk of Magnesia to aid bowel regularity, while others use more natural methods such as increasing fiber and fluid intake or by giving prunes daily. Still others improve constipation by increasing physical activity or doing a combination of methods.

Out of those who reported diarrhea, 10 percent indicated it occurred frequently. Many use Imodium to control symptoms.

Although a specific question on reflux was not included in the study, about one third of caregivers whose child ruminated (brings food back up into the mouth after swallowing) believed the rumination was due to reflux.

Parents reported that these symptoms improved with surgery (Nissen fundoplication) or with acid- blocking medication. Others modified the child's diet by avoiding spicy, acidic and fatty foods, chocolate, and caffeine to prevent symptoms of reflux and rumination.

If you have concerns about your child's nutrition, speak with his/her doctor or contact the CdLS Foundation at 800-753-2357 or through the *Ask the Expert* service at [www.CdLSusa.org](http://www.CdLSusa.org).

