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PEDIATRIC NUTRITION ISSUES

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# Feeding Changes in Children With Trisomy 18

## Longitudinal Data on Primary Feeding Method and Reflux Identification and Treatment

**Deborah A. Bruns, PhD; Stacey A. Springer, BS**

Research indicates that approximately 40% to 70% of children with disabilities are identified and treated for feeding difficulties such as reflux. The available literature on children with trisomy 18 does not describe feeding needs or treatment. The results described here address primary feeding method along with identification and longitudinal treatment of gastroesophageal reflux in 10 children with trisomy 18. Data indicate videofluoroscopic swallowing study as the primary diagnostic procedure and treatment with medication as largely effective. The majority of the sample also moved to tube feedings to address feeding difficulties. It is hoped that this information is an initial step to further understanding the nutritional needs of this unique population. Implications for practice and a need for further research are recommended. **Key words:** *diagnostic testing, reflux, reflux treatment, trisomy 18*

**M**ANY CHILDREN WITH disabilities experience feeding difficulties. Approximately 40% to 70% of children with conditions such as cerebral palsy and autism have problems with food intake, especially food selectivity, as well as digestion.<sup>1-3</sup> The basis for these difficulties is related to a child's neurological status, anatomical issues, respiratory difficulties, and/or oral motor issues. One or more of these issues may interact with

developmental delays or disorders and to further contribute to feeding difficulties. For example, an infant with respiratory difficulties may experience problems with several formulas before identifying of the most appropriate mode throughout infancy and early toddlerhood. Another example is a 3-year-old boy with hypertonia (high muscle tone) in his arms and torso and limited voluntary upper body movement who may experience difficulties holding and bringing bite-sized pieces of food to his mouth. In addition, he may also have problems swallowing textured foods (dysphagia).<sup>4</sup>

A group that is not covered in the feeding literature is children with a rare trisomy condition such as trisomy 18 (t18 or Edward syndrome). Children with t18 often present with cardiac anomalies such as ventricular septal defect as well as compromised respiratory status and feeding difficulties.<sup>5</sup> Low muscle tone is an additional characteristic of the condition that can also adversely affect feeding.

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**Author Affiliation:** Department of Educational Psychology and Special Education, Southern Illinois University Carbondale, MC 4618, Carbondale, Illinois.

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**Correspondence:** Deborah A. Bruns, PhD, Department of Educational Psychology and Special Education, Southern Illinois University Carbondale, MC 4618, Carbondale, IL 62901 ([dabrun@sui.edu](mailto:dabrun@sui.edu)).

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However, there is little detail about feeding difficulties and their resolution in the literature due, in large part, to the dire prognosis this diagnosis carries.<sup>6-8</sup>

Much of the existent literature provides the statistic that only 10% of children affected by t18 survive to their first birthday, with many deaths before an infant reaches 2 or 3 months of age.<sup>7,8</sup> Yet, in recent years, more intensive treatments have been provided, and survival is increasing with more children reaching 12 months of age and living into the early childhood years.<sup>9-13</sup> Although difficult to determine exact survival rates because some studies are geographically specific and population based with a focus on mortality, feeding difficulties are a problem, especially when complicated by apnea, gastroesophageal reflux (GER), and/or swallowing difficulties.<sup>14,15</sup> At present, there are no studies explicitly examining oral intake and treatment of GER in children with t18.

#### **DIAGNOSIS OF FEEDING PROBLEMS IN INFANTS AND YOUNG CHILDREN**

Feeding difficulties are identified through multiple assessment methods including observation of the child during a meal, interviewing parents and other caregivers, and completion of questionnaires and rating scales.<sup>16-19</sup> Selecting the assessment methods depends on the suspected etiology and finding individuals who can provide information about the child's feeding history and current eating habits.<sup>17</sup> Diagnostic testing may also be necessary to elucidate feeding difficulties.<sup>20</sup> Often for diagnosis, a team of professionals (pediatrician, speech and language pathologist, and dietitian) is required to conduct assessments and evaluate their findings.

Besides the issues described previously, approximately 40% to 50% of infants younger than 4 months experience at least 1 episode of GER per day defined as the movement of stomach contents upward into the esophagus.<sup>21</sup> By age 1, many infants no longer experience GER episodes because of improved neuromuscular

control, maturation of the digestive system, and reduced oral intake after the first year.<sup>22,23</sup> However, other young children with disabilities or developmental delays do not outgrow GER.

Gastroesophageal reflux disease (GERD) is the clinical manifestations of GER. Specifically, the National Institutes of Health defines GERD as when the lower esophageal sphincter opens spontaneously or does not close properly and stomach contents rise up into the esophagus causing irritation to the esophagus as well as the mouth or nose making mealtimes unpleasant (see <http://digestive.niddk.nih.gov/ddiseases/pubs/gerd/>). Reflux past the first birthday may be GERD. This condition can present as repeated regurgitation, nausea, heartburn, coughing, laryngitis, or chronic respiratory problems including wheezing or pneumonia. Infants and young children may be irritable during or immediately after feedings or may refuse to feed (eg, bottle, spoon). Dysphagia may also be present and further impact feeding.<sup>24</sup> This condition impacts consumption of liquids and foods, especially to problems with the swallowing process, including the swallowing response and related structures such as the tongue (see <http://www.nidcd.nih.gov/health/voice/pages/dysph.aspx>).

A common diagnostic test for GER and dysphagia is a videofluoroscopic swallowing study (VFSS), also known as a modified barium swallow or cookie swallow. A VFSS is a video x-ray imaging study that examines a child's oral structures to analyze swallowing and the passage of liquids and food boluses into the esophagus and the stomach.<sup>25-29</sup> A VFSS can be repeated to verify the presence or absence of a problem. Results can assist in developing a plan to ensure safe feeding.

An alternative to VFSS is a flexible endoscopic evaluation of swallowing. This procedure assesses the structure of the airway through insertion of a fiberoptic scope attached to a camera. After application of topical anesthesia, the scope is passed through each nostril to the pharynx. As a brief, in-office procedure, the flexible endoscopic evaluation

of swallowing is performed in a more familiar setting than in the examination room for a VFSS.<sup>16,28</sup> An upper gastrointestinal (GI) series is a radiologic study to evaluate the anatomy and functioning of the esophagus, stomach, and duodenum (first part of the small intestine). Each type of diagnostic testing has advantages and disadvantages.<sup>17</sup> Selection of a procedure will vary on the basis of the symptoms as well as an individual child's tolerance and presence of respiratory difficulties or cardiac condition. For example, similar to the VFSS, a pH probe requires the insertion of a tube through the nose and into the esophagus. With this procedure, data are collected over a period of 24 hours in a hospital setting rather than in a brief in-office or clinic visit. Regardless of the presence of a disability, a young child may pull the tube out. Furthermore, a toddler or preschooler requiring oxygen may experience compromised flow because of placement of the tube for a pH probe.

The use of one or more of these diagnostic methods provides a complete picture of a child's feeding strengths, emerging skills, and needs. Treatment can begin only when the assessment results are compiled and prioritized by a feeding team.<sup>16,17,30,31</sup> Decisions include the type and amount of feeding such as oral intake supplemented with enteral formula feeding to ensure adequate caloric intake. A specialized formula may be necessary for infants or older children with specific feeding difficulties such as aspiration or GER.

Treatment of GERD can take several approaches. Changes to diet can reduce GERD. Wenzl and colleagues<sup>32</sup> recommend thickening feedings for infants and foods for toddlers and preschoolers to assist with GER. Yet, Carroll et al<sup>33</sup> counter that thickened formulas may not reduce GER appreciably. Positioning to facilitate the alignment of the trunk to facilitate passage of food and liquids through the mouth and throat can also lessen the impact of this condition.<sup>34</sup> Some infants and older children require medication. When medication is indicated, it must be monitored by a feeding team to determine the appropriate

dosage as well as necessary food restrictions or positioning recommendations.<sup>35</sup> Results have been mixed depending on the specific medication and child's age such as use of Prevacid (lansoprazole) in infants.<sup>36-39</sup>

There is a need to increase awareness and understanding of the unique needs of children to help parents with feeding problems, particularly those with t18.<sup>30</sup> When a child with t18 is unable to adequately accept and digest fluids and food items, the appropriate methods must be identified to support the child's overall health and development. In addition, information needs to be gathered and shared regarding effective identification as well as long-term treatment and management of GER.

This study is an exploratory investigation as part of the Tracking Rare Incidence Syndromes (TRIS) project. The goals of the project are to increase knowledge about children and adults with rare trisomy conditions such as t18 through several online surveys. The TRIS project is an international project focusing on collecting data directly from parents and caregivers and sharing the results with families and professionals including clinical geneticists, neonatal nurses, and early childhood specialists. This study is a subset of TRIS project, exploring information on feeding needs and GER over time in a sample of children with t18 in the current literature. Results from the parent-completed surveys (TRIS Feeding Protocol) have given a preliminary knowledge base for this group clinically and for future comparison.

## METHODS

Tracking Rare Incidence Syndromes project began in 2007. Surveys with closed and open-ended questions collect data from parents on a range of rare trisomy-related topics. The Full TRIS survey of children living more than 2 months, or "long-term survivors," gathers information on birth history, family support, daily care needs, and medical conditions. An annual TRIS follow-up survey is sent to parents with surviving children on

the anniversary of their completion of the full survey. An abbreviated version of the TRIS full survey is available for parents of infants living up to 60 days (TRIS modified survey). All surveys were developed from the existing literature and combine print and online resource materials specific to this subgroup (eg, tri-med listserv, materials from the Support Organization for Trisomy 18, 13 and related disorders [SOFT]).

Funding was not used for initial development of the TRIS surveys. Once data collection began, financial support was requested and received from SOFT, Noah's Never Ending Rainbow (NNER) and Hope for Trisomy 13 and 18 for recruitment of participants, data analyses, and dissemination of survey results. These groups are parent-led organization focusing on family support, information sharing, and advocacy.

### **Instrument development**

The TRIS feeding protocol was developed using feeding-related items from the TRIS full survey and a review of the literature focusing on young children with GER and other feeding difficulties. The TRIS feeding protocol asked parents to recall feeding experiences with their child during infancy and at the current time. Most items are forced choice (yes/no) and allow for elaboration of participant responses in each section (eg, list child's preferred foods, additional feeding challenges).

The TRIS feeding protocol comprises 23 multipart items. The first section focuses on birth to 1 month of age. The second set of items emphasizes the same topics during 2 additional time periods (2-6 months, 7 months to 1 year). The last section requests information concerning the current feeding status of the child. Within each section, items request responses to feeding preferences, accepted and preferred foods, and feeding challenges. In addition, there are a total of 10 questions on the TRIS feeding protocol that specifically address GER and GERD. These questions are grouped within the same age ranges and query on identification of GER, types of diagnostic testing, and effectiveness of medications.

### **Procedure**

The first author developed the TRIS feeding protocol and submitted materials for human subjects review. Upon approval, recruitment of participants was initiated on the basis of completed surveys.

The TRIS database was used as the source for demographic information since all study participants had completed the TRIS full survey between February 2007 and September 2009. The TRIS full survey collects information including mother's age at the time the child was conceived, marital status, highest level of education, and socioeconomic status. Additional information is available about the TRIS full survey.<sup>9</sup>

### **Participants**

Based on completion of a total of 121 TRIS full surveys by October 2009, 52 parents with children with t18 were contacted in January 2010 about participating in a feeding study. Additional invitations were sent to 25 parents of children with t9 and to 44 parents of children with t13. A reminder notice was sent in mid-March. Nineteen parents with a child with t18 (37%) responded positively and were sent a letter of consent and the TRIS feeding protocol. Ten completed protocols were returned, representing children diagnosed with t18 ( $n = 30$ , 33%). Specifically, 6 children were diagnosed with full t18 ( $n = 6$ , 60%), 2 with t18 mosaic (20%), and 2 with partial t18 (20%). (Data related to t13 and t9 are available from the first author.)

The ages of the children at the time of protocol completion ranged from 6 months to 182 months. For the 8 living children, the average age was 71.5 months ( $\pm 55.67$  months). The 2 children who passed away were aged 6 months and 9 months, respectively. Correspondingly, for infants who died, responses to the TRIS feeding protocol items reflect only feeding experiences during their infancy.

All parents were married. The average age of the mothers at their child's birth was 35.6 years ( $\pm 5.68$  years). Parental ages ranged from 24 to 42 years. Eight of the

10 parents (80%) completed at least some post-secondary education. Five parents (50%) reported a high-income level: four (40%) reported medium income and the remaining one (10%) reported low income. The income levels are categorized as described because of the international scope of the project.

### Data analysis

After receiving the completed protocols, data were systematically organized according to the participant and the stages of their ages. The responses from the protocols were then converted into a numerical system so that they could be scored. Responses for each forced choice item were tallied. The open-ended items were read a minimum of 3 times by each author to generate relevant categories. The authors then discussed and reached consensus on categories.<sup>40</sup> SPSS 16.0 (IBM Corp, Armonk, New York)<sup>41</sup> was used to run descriptive statistical analyses of demographic information. Frequency counts were conducted to determine the occurrence of GER and medications prescribed for each age range on the TRIS feeding protocol.

### FINDINGS

The results of the TRIS feeding protocol are presented by primary feeding method along with diagnostic testing, effectiveness of med-

ication for the treatment of GER during the first year and at time of completion of the protocol.

### Birth to 1 month of age

For the immediate postbirth period (birth to 1 month of age), the most common feeding method reported by 9 of 10 parents was by bottle. Two infants also received gavage feeds and 1 an orogastric tube (feeding tube connecting the mouth and the stomach) (OG tube) feedings. Six infants required a nasogastric feeding tube (feeding tube connecting the nose and the stomach) (NG tube) feedings. A gastrostomy tube (feeding tube surgically inserted into the stomach) (G-tube) was placed in 1 infant (Table 1).

Breast milk, directly from the breast or expressed and presented in a bottle, was given to 7 infants. Six infants fed with a bottle received breast milk. Three infants were fed only formula. One infant in the sample received a combination of breast milk and formula for the purpose of increasing overall caloric intake.

### Two to 6 months of age

Between the ages of 2 to 6 months, 6 infants were fed by bottle. Three were also fed via an NG tube. Two infants continued to receive gavage feedings. In addition, the following 3 feeding methods were each used with 1 infant

**Table 1.** Primary Methods of Feeding

	Postbirth to 1 mo (n = 10) n (%)	Two to 6 mo (n = 10) n (%)	Seven mo to 1 y (n = 9) n (%)	Current Status (n = 8) n (%)
Breast fed	2 (20)	1 (10)	0 (0)	0 (0)
Breast milk (pumped or expressed)	7 (70)	5 (50)	4 (44.4)	0 (0)
Gavage	2 (20)	2(20)	2 (22.2)	1 (12.5)
Bottle	9 (90)	6 (60)	5 (55.6)	0 (0)
Nasogastric tube	6 (60)	3 (30)	2 (22.2)	1 (12.5)
Gastrostomy tube	1 (10)	1 (10)	3 (33.3)	5 (62.5)
Orogastric tube	2 (20)	1 (10)	1 (10)	0 (0)
Purees, soft foods, and/or table foods	0 (0)	1 (10)	2 (22.2)	6 (75)

in the sample: breast-feeding, OG tube, and G-tube feedings. Expressed breast milk was fed to 5 infants during this time period. In addition, of the 6 fed with a bottle, 2 received breast milk and 4 were given formula (refer to Table 1 for additional data).

Diagnostic tests for GER and associated medications are described below. From birth to 6 months of age, 6 parents listed reflux as a feeding-related complication for their child. Several diagnostic tests were used to identify GER. An upper GI series and VFSS procedure was performed on 2 infants each at the ages of 2 months and 4 months.

A range of medications was prescribed to treat reflux in the 6 infants. Three infants were prescribed 1 medicine to treat the condition (Zantac [ranitidine], Propulsid [cisapride], and Prilosec [omeprazole], respectively). Several took a combination such as Propulsid and Zantac to treat reflux symptoms. Overall, parents reported that the medications were effective in treating their infants' reflux symptoms.

### Seven months to 1 year of age

The following results are based on 9 infants. One infant passed away at the age of 6 months. Importantly, an additional infant passed away at the age of 9 months, but the parent pro-

vided information for this entire section of the protocol.

Parents continued to use different methods to feed their infants. Bottle-feeding was the most common method for 5 infants. Gavage feeding was used with 2 infants. During this time period, an NG tube was placed in 2 infants and G-tube in 3 infants. Altogether, by 1 year of age, over half of the group relied on tube feeding for most, if not all, of their nutritional needs. One infant was exclusively fed breast milk. Three infants were given a combination of breast milk and formula. Formula only was given to the remainder of the group. Rice cereal mixed with formula was given to 1 infant starting at the age of 4 months.

During the 7 months to 1-year period, 2 infants who were not previously identified with reflux were tested with an upper GI series at 8 months and 11 months, respectively. The VFSS procedure was carried out with 3 infants. One infant had the VFSS procedure performed 2 times (8 months old and 12 months). A barium swallow was used in 3 infants. A total of 5 participants indicated reflux as a feeding-related complication for their infant.

To treat the condition, 3 infants were prescribed 1 medication: 1 Propulsid, 1 Zantac, and 1 Prilosec. Two infants required a combination of medications to treat the condition (Table 2). Similar to the earlier time period,

**Table 2.** Reflux Testing and Medications

	Two to 6 mo (n = 10) n (%)	Seven mo to 1 y (n = 9) n (%)	Current Status (n = 8) n (%)
<b>Reflux testing</b>			
Videofluoroscopic swallow study	2 (20)	3 (33.3)	4 (50)
Upper gastrointestinal series	2 (20)	2 (22.2)	2 (25)
<b>Medications</b>			
Gaviscon	1 (10)	1 (11.1)	0 (0)
Motilium	1 (10)	1 (11.1)	0 (0)
Prevacid	1 (10)	1 (11.1)	1 (12.5)
Prilosec	1 (10)	1 (11.1)	1 (12.5)
Propulsid	2 (20)	2 (22.2)	0 (0)
Reglan	1 (10)	0 (0)	0 (0)
Zantac	3 (30)	2 (22.2)	0 (0)

the medications successfully treated the reflux symptoms.

### Current status

Current feeding status is available for 8 children (refer to Table 3), with several feeding methods identified. Six children were fed orally for at least 1 daily meal. One child used an NG tube in place of up to 2 meals a day. Five children were also fed through a G-tube. Specifically, 3 children received all of their nutrition through the G-tube and 2 tubes were placed for supplemental nutrition.

Two of the 8 children fed themselves table food on a daily basis. Data on 2 protocols describe children with t18 eating “soft, mashed foods and purees.” One of the 8 children reportedly ate twice a day, using a baby safe feeder. Another participant, who was still very young, was beginning to eat stage 1 baby food.

Several participants provided data indicating further testing for reflux but did not specify the age of their child when the testing was conducted. A VFSS was completed on 4 children. An upper GI series was performed on 1 child. Of the 8 participants, 2 continued to experience GER. One child was given Prevacid

and the other Prilosec. Parents reported that the medications were effective.

### DISCUSSION

Data indicated a range of feeding methods during infancy for children with t18. Breast milk and formula were offered with varying success. Some infants required enteral feeding (eg, nasogastric tube). Current status indicated that most children in the sample relied on tube feeding for most or all of their nutrition. Six of the 8 children were able to accept oral foods in various consistencies (puree, soft foods, or table foods). At present, there is no literature to compare these results with other studies, which only assess mortality<sup>6-8</sup> or cover specialized interventions.<sup>11-13</sup>

In addition, a majority of infants were identified with GER through VFSS or upper GI series and received medications that effectively controlled GER symptoms. It is important to note that only Prevacid and Prilosec were consistently identified for effective treatment. Current feeding status indicated that the majority of children with t18 received at least 1 meal through tube feeding. Identification of GER was less prevalent than in the first 6

**Table 3.** Demographic Characteristics (n = 10)

Characteristic	Mean (± SD)
Child age: Living at the time of participation (n = 8)	71.5 mo (± 55.67 mo); range: 3-146 mo
Child age: Not living at the time of participation (n = 2)	7.5 mo (± 0.71 mo); range: 7-8 mo
Mother's age at conception	35.6 y (± 5.68 y); range: 24-42 y n (%)
Marital status	
Married	10 (100)
Education level	
10-12 y	2 (20)
13-16 y	5 (50)
17-20 y	3 (30)
Income level <sup>a</sup>	
Low	1 (10)
Medium	4 (40)
High	5 (50)

<sup>a</sup>Income level is not presented in dollar figures because of the international scope of the project. Participants represented the United States (n = 8), Canada (n = 1), and Scotland (n = 1).

months, but testing continued for most of the children in the sample.

Videofluoroscopic swallowing study was the most frequently identified method used to identify GER in this sample as well as in the literature.<sup>25-29</sup> The use of medications to treat GER symptoms is also confirmed.<sup>36-39</sup> Further confirmation of the existing literature is problematic for 2 reasons. First, the parental reports provided here are longitudinal while published studies primarily focus on one period of time.<sup>32</sup> Second, this sample of children with t18 is the first one described in the feeding literature. Since minimal attention given to studies of this nature, it is important to draw attention to the unique sample described here and the need for further investigation of feeding difficulties and their resolution in long-term survivors with t18.

### Limitations

The findings cannot be generalized because of the following limitations. The TRIS feeding protocol collected largely retrospective data. Parental recollections of early feeding-related events of infants in their child's life may not be fully accurate due to the passage of time. Parent-reported data, in general, are an additional consideration. For example, parents may not fully understand some terminology on the data collection instrument or, if appropriate, the review of medical reports related to their child's feeding needs. In addition, since the data analyses reported here were carried out approximately 2 years after data collection, it was decided by the authors that it was inappropriate to contact participants to finish incomplete items, especially for parents who lost a child.

Another limitation of this study is the small sample size. The return rate was lower than expected, with data from only 10 children with t18 available for analysis. Yet, this sample is the largest one to be reported on related to the identification and treatment of GER for this condition. The TRIS project continues to expand and provide opportunities to enlarge the sample.

In addition, each child with t18 shares a genotype. However, the severity and physical manifestations of GER as well as treatment outcomes can vary because of the child's phenotype (observable characteristics influenced by the environment). This must be taken into account when examining data presented here and for children with other genetic conditions such as Down syndrome and CHARGE syndrome (coloboma of the eye, heart defects, atresia of the choanae [back of the nasal passage], retardation of growth and/or development, genital and/or urinary abnormalities, and ear defects).

### Future research

Additional research is necessary to increase our understanding of feeding and approaches to care for children with t18 as well as children with other trisomy types such as trisomy 13 and trisomy 9. For these groups, data can be collected and analyzed about the identification, prevalence, and treatment of GER. This information can then be shared with families with infants and older children with t18 and the professionals involved in feeding interventions. Dietitians are in a key position to assist with collecting data and translating results into functional feeding plans.

The rise in the use of enteral feeding is another area for research. A larger, longitudinal data set can be used to search for possible correlations between identification and treatment of reflux and primary feeding method for this clinical subgroup. The majority of the 8 survivors received G-tube feedings as either their primary or supplemental source of nutrition. It is also important to note the high percentage of children with t18 diagnosed and treated for GERD. Correlations between tube feeding and reflux need to be explored by research. This type of investigation has the potential to raise awareness and improve treatment decisions in the short and long term.

It is critical to examine potential differences between the identification and treatment of feeding conditions on the basis of trisomy type. Comparing and contrasting GER

in children with t18 with children with Down syndrome, CHARGE syndrome, or velocardiofacial syndrome would expand the literature. For example, feeding tends to be a concern for children with velocardiofacial syndrome, and the existing literature provides recommendations in this area.<sup>42</sup>

Additional aspects of feeding could be examined within the trisomy 18 population, such as experiences of oral feeders and tolerance of oral stimulation for children with G-tubes. These areas could be examined over time to provide a more complete picture of feeding needs and guidance for nutritionists and other feeding team members including parents, caregivers, speech-language pathologists, and physical therapists. Children who have reflux as their primary intake issue, or as one of a constellation of feeding difficulties, must receive appropriate feeding support to grow and thrive.

### Implications

It is hoped that our findings will inform clinicians of feeding needs and conditions of children with t18. While limited in scope to 10 cases, it is a beginning point for understanding feeding methods over time, GER identification and treatment, and related dysphagia concerns. This exploration is intended to encourage discussion and further study.

As described for treatments of reflux,<sup>21,33-38,43-45</sup> research on children with t18 and other rare trisomy conditions will increase the awareness of professionals and parents and, in turn, lead to improved therapeutic interventions. Furthermore, with increased awareness of the needs of this population related to cardiac defects and respiratory support,<sup>11-13</sup> additional knowledge of feeding needs is necessary. Anecdotally, parents with children with t18 also reported improvement of feeding after treatment of heart and breathing difficulties on the TRIS feeding protocol (D. A. Bruns, PhD, unpub-

lished data, 2010). Based on the need for further data analysis and confirmation with a larger sample, it is too early for definitive results, but it appears that changes in core bodily functioning positively impacts oral intake for some children with t18.

As the life span for some children with t18 improves,<sup>14,15</sup> it becomes critical to provide treatment recommendations on the basis of sound research for commonly diagnosed conditions such as GER. It is clear from the data that G-tube placement is regarded as a means to assist with GER, but studies indicate mixed responses to this intervention.<sup>46,47</sup> Specifically, parents report weight gain for their children, but problems with tube feedings and dysphagia remain.<sup>24</sup>

### IMPLICATIONS FOR PRACTICE

Efforts should be made to increase understanding of feeding needs of children with t18 along with opportunities for input on treatment in both the short term and the long term for GER and other conditions such as dysphagia. As more becomes known about this population, associated feeding needs warrant attention on both an individual and group level. As the results suggest, each child encountered feeding challenges that were reduced or resolved via a combination of interventions and monitoring. Additional data from the TRIS survey address cardiac defects and respiratory difficulties that can impact oral intake and treatment of GER.

Clinicians with an understanding of GER and its treatment are vital to the successful resolution or reduction in symptoms of this condition in children with t18. Among the multiple health and medical needs characteristic of this population, it is imperative that treatment decisions are recommended, implemented, and reviewed by the child's care team. Appropriate nutrition for growth and optimal development is a critical outcome.

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