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# A multidisciplinary program to wean infants and toddlers from long-term tube feeding: Lessons learned from a retrospective study

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## Abstract

**Objectives:** Children maintain growth and development by ingesting adequate calories and nutrients, typically achieved via oral intake of food and liquids. When unable to eat and drink orally, they need temporary or permanent enteral nutritional support via nasogastric, nasoduodenal, gastrostomy, or jejunostomy tubes. The objectives of this retrospective study are to describe lessons learned from operating a weaning program at ALYN Hospital for over a decade, the characteristics of the patient population (gender, age, medical condition, and type of tube feeding and hospitalization), and which of these characteristics correlate with successful weaning.

**Methods:** Data were obtained from the hospital's secure database of 82 infants and toddlers, 37 boys (45.4%) and 45 girls (54.9%) aged 3 months to 10.8 years who took part in a tube feeding intervention from 2011 to 2020. Descriptive and correlational analyses were performed to characterize the participants and their responses to the program.

**Results:** Fifty-one children (62.2%) were less than 2 years, 26 children (31.7%) were 2–4.11 years, and only 5 children were aged 5 years (6.1%) and older. Fifty-six children were successfully weaned from tube feeding, 9 children were eventually successful, but the process took longer than anticipated, 11 children were partially weaned and 6 were not successfully weaned.

**Conclusions:** These results are discussed within the context of a successful weaning program related to participant characteristics (medical condition, age, gender, and weight), and subsequent recommendations are offered related to the intervention setting, duration, and intensity; redefining success in weaning and the need for long-term follow-up.

**KEYWORDS**

children, enteral nutritional support, nasogastric tubes, tube feeding, weaning

## 1 | INTRODUCTION

The use of tube feeding to enable children to receive enteral nutrition is an accepted practice for children who are unable to eat orally. These tubes may be temporary or permanent. Weaning off tube feeding is a complex challenge that requires a multidisciplinary approach including medical and nutritional management, speech and language therapy, and psychological support.

Among the conditions that require tube feeding are complications of prematurity, neurodevelopmental disorders, congenital malformations, and metabolic disorders.[1] Some children require tube feeding due to food refusal secondary to autism or avoidant restrictive food intake

disorder.[2] Feeding Tube Dependency, defined as "the reliance on a feeding tube to provide nutrition support to ensure growth and/or sustenance to aid recovery and/or maintain developmental trajectory despite being able to eat orally,"[3,p.1] is a growing concern as tube feeding prevalence increases.

Common approaches of tube weaning interventions have been described.[2,4,5] An intensive, inpatient multidisciplinary program involving decreased tube feeding and enhanced oral feeding under multidisciplinary supervision was found to be effective.[6] Children significantly increased their oral intake over a 3-week program, with a high success rate in discontinuing tube feeding post-discharge and maintaining these results at a 1-year follow-up. A multidisciplinary clinical hunger provocation program has also been shown to be effective in quickly resuming oral feeding in children who are fully tube-fed.[7] These programs utilize a structured approach to decrease tube feeding and induce hunger, which assists in the transition to oral feeding, showing a high success rate in both short-term and 6-month follow-ups. Long-term efficacy and follow-up studies also highlight the importance of long-term follow-up to ensure sustained success and address any emerging challenges postweaning.[8] Long-term efficacy of clinical hunger provocation was demonstrated with most children remaining tube-free and exhibiting beneficial feeding outcomes years after the intervention. Finally, the effectiveness of an outpatient multidisciplinary intervention that combine behavioral, nutritional, and oral-motor therapies has been demonstrated.[9] Such programs have shown success in weaning children from tube feeding while improving their oral intake and overall growth.

The objective of this paper is to present the characteristics of the patient population such as gender, age, medical condition, and type of tube feeding and hospitalization to identify which of these characteristics are relevant to successful weaning.

**What is Known**

- Children whose growth and development are hampered by inability to feed orally need enteral nutritional support by tube feeding.
- Weaning from tube dependence is a complex process requiring medical, nutritional, behavioral, and functional support.
- Children who need a comprehensive feeding rehabilitation program often include complex care and multiple-problem patients.

**What is New**

- Gender, age, diagnosis, and treatment setting (in- or outpatient) do not influence the effectiveness of tube weaning.
- Medical complexity influences the length but not necessarily the results of the weaning process.
- The process should be considered successful even if additional nutritional or hydration tube support is provided during periodic medical or metabolic setbacks.
- Follow-up of tube weaning alumni is essential to improve feeding skills as the child grows.

## 2 | METHODS

ALYN's Child Centred Weaning program is a three-phase behavioral intervention with hunger-driven oral feeding cycles.[10] As depicted in Table 1, the first Preparatory phase includes assessments that address gaps in weaning preparedness in the child's functional, nutritional, medical, behavioral, and environmental aspects. The second phase is a 3-week intervention which includes withdrawal of the tube feeding together with intensive clinical intervention to promote the acquisition of oral feeding skills. This part was provided in an inpatient setting for the first few years and later in an outpatient framework. The third phase includes follow-up visits and fine-tuning of the recommendations for at least a year to ensure the child's success in maintaining growth and continuing improvement of oral skills.

### 2.1 | Study design and participants

A retrospective, single center study was conducted at the ALYN Hospital Pediatric and Adolescent Rehabilitation Center in Jerusalem. Data were obtained from the secure medical database of 82 infants and toddlers, aged 3 months to 10.8 years (mean age = 1.6 years, standard deviation [SD] = 1.9), who took part in ALYN's tube feeding intervention from 2011 to 2020. Participants included all children whose tube feeding continued longer than medically required (i.e., since birth or for more than three consecutive months); children had to be medically stable (i.e., no cardiac failure, metabolic instability, brittle diabetes, or intractable epilepsy); chronic but stable conditions did not preclude initiation of treatment. This study was approved by the hospital's Committee for Research Ethics (protocol 034-20) in accordance with the requirements of the Declaration of Helsinki.

### 2.2 | Outcome measures

Data included type of tube nutrition (nasogastric tube [NGT] or gastronomy tube [GT]), age, sex, pre- and postweaning program weight recorded on first and last days of weaning program, in- or outpatient hospitalization, medical conditions: (prematurity; metabolic

**TABLE 1** Components of 6- to 12-month tube weaning program.

| Phase | Focus of activities | Timing and location |
|---|---|---|
| Preparatory | • Medical workup to diagnose and treat conditions like esophageal reflux, vomiting, and constipation.<br>• Rule out metabolic, cardiac, or epileptic instability.<br>• Swallow studies, clinical assessments, and nutritional evaluation to support children with expected weight loss during transition.<br>• Optimize seating, head support, and feeding utensils.<br>• Introduce therapy sessions to improve feeding skills, exposure to a variety of textures and tastes.<br>• Coordination with primary care teams and postponement of elective medical interventions. | Outpatient evaluation 2–4 months |
| Transition from tube feeding → oral feeding | • A focused 3-week intervention where tube feeding starts with a 30% reduction in Week 1, aiming for complete cessation by Week 3.<br>• Encourages experiencing hunger and learning that oral food results in satiety.<br>• Increases oral feeding quantities and motivates efficient, self-motivated oral feeding. | 3 weeks (or longer) of intensive tube weaning while child in an inpatient or day-patient |

syndrome; heart, respiratory tract and/or lung disease; cerebral palsy; congenital hyperinsulinemia; developmental delay; genetic syndrome; cleft palate or lip; gastrointestinal tract malformation or disease; esophageal reflux; autism spectrum disorder; tracheostomy), previous consistent (if minimal) oral intake of food or liquids, type of eating disorder including medical, functional (e.g., oral and pharyngeal issues in mastication and swallowing) and/or behavioral (e.g., food refusal, disruptive mealtime behavior, rigid food preferences), pre- and post-program growth percentile, year participated in the program, number of times participated in the program.

The standard duration of the weaning program's second stage was 3 weeks, except for eight children with planned weaning over a longer period due to specific medical conditions or social factors. All results are reported together.

We recognized four end categories: (i) Successful: no tube support by the end of the weaning program; (ii) Prolonged successful: Oral feeding with an extended period of partial tube support and eventual complete cessation; (iii) Partial Success: Significant reduction in the amount of caloric intake by tube; (iv) Unsuccessful: Complete dependence on tube feeding at the end of the intensive intervention.

## 2.3 | Data analysis

The descriptive analysis of the patient outcome measures and frequency distribution for nominal data and mean (M) and median values with SDs and interquartile ranges (IQRs) for continuous variables were performed. Univariate associations between the variables related to the child's personal, medical, and feeding tube characteristics as well as responses to the weaning program were tested by Pearson chi-square test, Fisher exact test, or independent samples *t* test, as appropriate using the Statistical Package for Social Sciences version 21 (SPSS Inc.). $p$ Values of ≤0.05 were considered to be statistically significant. Study hypotheses and the analytic plan for analysis were specified before the data were collected.

# 3 | RESULTS

Table 2 shows data from 82 children (including 4 children who participated two times), 37 boys (45.4%) and 45 girls (54.9%) with a mean age of 1.6 years (SD = 1.9, median = 1.0). Forty-seven (57.3%) participated as inpatients and 35 (42.7%) as outpatients. Most had prior experience of oral intake of liquids or solids (82.9%). Twenty-seven (32.9%) of the participants were born preterm (13 boys and 14 girls), spread equally between gender ($p = 0.440$) and age groups ($p = 0.755$).

Reasons for initial eating difficulties varied between medical problems (96.3%), functional problems (98.8%) and behavioral issues (65.9%). We identified 11 medical conditions associated with the need for alternate feeding (Figure 1). The most frequent condition was heart, respiratory tract and/or lung disease

**TABLE 2** Frequency counts for all participants including gender, type of feeding assistance, type of hospitalization and if previously had at least minimal, consistent oral intake of food or liquids.

| | | Gender | | | Previously had at least minimal, consistent oral intake of food or liquids | | Type of hospitalization | | Type of feeding assistance | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Female | Male | | Yes | No | Outpatient | Inpatient | GT | NGT |
| All participants | $N = 82$ | 45 | 37 | # | 68 | 14 | 35 | 47 | 52 | 30 |
| | | 54.9 | 45.1 | % | 82.9 | 17.1 | 42.7 | 57.3 | 63.4 | 36.6 |
| Less than 5% weight loss by end of program | $N = 65$ | 36 | 29 | # | 57 | 12 | 27 | 42 | 43 | 26 |
| | | 55.4 | 44.6 | % | 82.6 | 17.4 | 39.1 | 60.9 | 62.3 | 37.7 |

Abbreviations: GT, gastronomy tube; NGT, nasogastric tube.

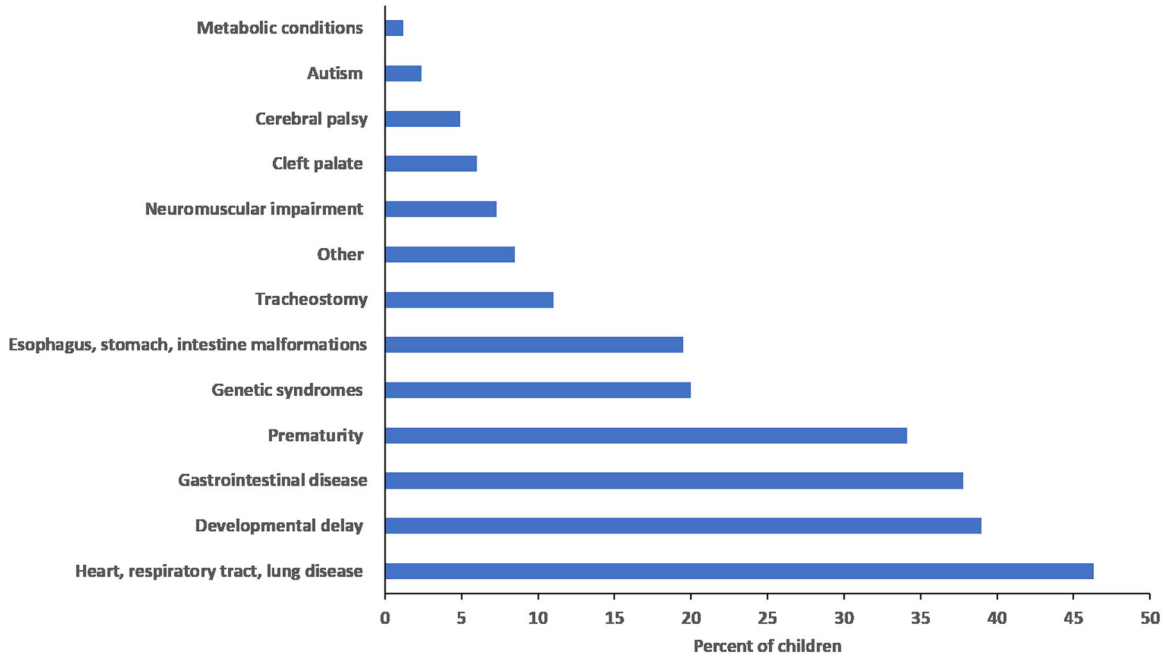


**FIGURE 1** Percent of children having condition associated with the need for alternate feeding. The categories, listed from least frequent to most frequent, are: metabolic conditions (1.2%), autism (2.4%), cerebral palsy (4.9%), cleft palate (6.0%), disturbances of the neuromuscular system (7.3%), malformation of esophagus, stomach or intestine (19.5%), genetic syndromes (20.0%), diseases of the gastrointestinal tract (37.8%), global developmental delay (39.0%), prematurity (34.1%) and heart, respiratory tract and/or lung disease (46.3%).

(46.3%), prematurity (34.1%), global developmental delay (39.0%), diseases of the gastrointestinal tract (37.8%). Other conditions accounted for a further (8.5%) of the sample and (11%) had a tracheostomy. Almost all children had two to four different medical conditions. Thirty children (36.6%) had an NGT at the start of the weaning program, whereas 52 (63.4%) had a GT.

Since feeding skills are age-dependent, we examined three age groups: 51 children (62.2%) were younger than 2 years at the time of weaning, 26 children (31.7%) were 2–4.11 years, and only 5 children (6.1%) were ≥5 years. There were statistically significant differences in the ratio between the use of NGT and GT for each age group. In the younger group, the ratio was close to 1:1 (NGT:GT –52.9% vs. 47.1%). As expected, NGT was used far less frequently than GT in both of the other age groups (middle group NGT = 11.5% vs. GT = 88.5%, older group (0% vs. 100%; $\chi 2 = 15.79$, $p = 0.000$).

Significantly more boys were treated with GT compared to NGT, whereas the percent of NGT and GT was about evenly divided for girls ($\chi 2 = 9.07$, $p = 0.003$). The frequency of GT use for the youngest boys did not differ from the older boys. However, the youngest girls used NGT more frequently than older girls ($\chi 2 = 12.12$, $p = 0.001$). For both genders in the middle-aged group, GT was more frequent than NG.

Fifty-six (68.3%) were successfully weaned from tube feeding, 9 (11%) were in the prolonged category (eventually successful but took longer than

anticipated), 11 (13.4%) were partially weaned, and 6 (7%) were not successfully weaned. Age at weaning was close to being statistically significant ($p = 0.066$), with a higher weaning success rate in children under 5 years. Gender ($p = 0.262$), type of feeding assistance ($p = 0.490$), type of hospitalization ($p = 0.131$), and whether children had previous oral intake of food or liquids ($p = 0.514$) were not significant factors in weaning success.

Table 2 also shows that 57.3% were inpatients and 42.7% were outpatients. A large percentage of inpatients were weaned successfully within the duration of the 3-week intensive weaning phase of program (67.9% vs. 32.1%), whereas a larger percentage of outpatients were successfully weaned over a somewhat longer term (77.8% vs. 22.2%). There were also more partial successful and fewer unsuccessful cases for outpatients. These differences were not statistically significant.

Table 3 shows that the mean *z* score of the participants' weight-for-age before the start of the Intensive weaning phases was −1.87 (SD = 1.26). The mean percent weight loss by the end of the Intensive weaning phase for all participants was 2.87% with changes in weight varying from −12.5% to +14.9%. By the end of the Intensive weaning phase of the program, the youngest children (<2 years) had a mean weight loss of 1.82% (SD = 5.5) and children aged 2–4.11 years had a mean weight loss of 4.34% (SD = 3.55); age-related differences in percent weight loss were not statistically significant ($p = 0.277$). Moreover, there were no gender-related statistically significant differences in weight loss ($p = 0.449$). Many children were below the third percentile before weaning, and did not surpass that value following the Intensive weaning phase, even up to 1 year later.

The above analyses were repeated for a large subset of the participants (65 out of 82) to exclude "outliers," that is, children whose weight *gain* exceeded 5% or who, due to the complexity of their condition, participated in the tube weaning program for a much longer period (up to several months). There were no significant differences in the results.

Finally, we report on six (five girls and one boy) children, aged 4 months to 7 years, who were not weaned despite participation in the program. Their medical conditions included autism, intellectual disabilities, seizures, metabolic difficulties, medical instability, cognitive impairment, kidney failure, unresolved postprandial vomiting and behavioral issues; only one was premature. Three had an NGT and three had a GT. Five children participated in the program as inpatients and one as an outpatient. All participants had previously at least minimal, consistent oral intake of food or liquids. These children presented with a range of difficulties including medical instability unrelated to the weaning process, family incompliance, and severe autism which impeded the behavioral engagement and/or led to failure to induce hunger-led motivation.

## 4 | DISCUSSION

This retrospective analysis provided an opportunity to reflect on a long-running, comprehensive, and complex intervention. Eating is a basic skill which naturally evolves from a congenital reflex into a voluntary, developmental and social behavior that differs from child to child. The key biological factors that have been shown to predict the time taken to wean a child from tube dependency include the child's age, the type and duration of tube feeding, and the fragility of the child due to medical complexity.[1]

### 4.1 | Complexity of population

Many children who require tube feeding face primary and secondary medical, nutritional, developmental, and emotional issues[11]; it was challenging to assess an intervention that entails so many shifting parameters. Indeed, almost all the current study's population presented with both medical and functional feeding challenges, and about two thirds also had behavioral issues that influenced the weaning process. Furthermore, unstable medical conditions (e.g., spasticity, epilepsy, upper airway obstruction and esophageal

**TABLE 3** Means and SDs for participants' weight, *z* scores, and percent weight lost from the start and to the end of the intensive weaning stage.

| | | Start of intensive weaning stage | | End of intensive weaning stage | | | |
|---|---|---|---|---|---|---|---|
| | | Weight (kg) | Weight-for-age *z* score | Weight (kg) | Percent weight loss (%)[a] | | |
| | Age | All age groups | All age groups | All age groups | All age groups | Age group: <2 years | Age group: 2–4.11 years |
| Mean | 1.6 | 9.46 | −1.87 | 9.02 | 2.87 | 1.82 | 4.34 |
| SD | 1.93 | 4.45 | 1.26 | 3.51 | 5.04 | 5.5 | 3.55 |

Abbreviation: SD, standard deviation.

[a]Compared to the weight at the beginning of the intensive weaning phase.

reflux, constipation) also frequently interfere with the planned weaning protocol.

## 4.2 | Prematurity

A significant patient subgroup was born prematurely (32.9%); their characteristics (e.g., gender, type of tube feeding) did not differ statistically from the total population. This is a rate similar to other reports such as Wilken et al.[3] who found that 27% infants with feeding tube dependency were premature. Pahsini et al.[12] did not find differences between preterm and full-term infants in tube weaning outcomes. Further research is needed to determine whether earlier intervention would reduce the number of neonatal intensive care graduates who require tube feeding, shorten the period of alternative feeding, or reduce later food refusal.

## 4.3 | Age

Most research has focused on weaning programs for children who are 5 years and younger.[5,10,13] Ishizaki et al.[14] showed that children older than 5 tend to experience slow or failed weaning. The results from the current study also showed that weaning success was higher for young children. This may be accounted for by the shorter time of psychological and physical dependency on tube feeding or it may be related to young children's ability to adapt their behavior. On the other hand, it may be attributed to the younger child's feeding skill acquisition process which is still within the range of typical developmental milestones. Finally, when children are older at the start of the weaning program, they likely have had prolonged and significant medical issues necessitating tube feeding; this is perhaps an indication of their generally fragile health. Other issues that could have influenced the results of older children are learned behavioral issues and psychological challenges.[11]

## 4.4 | Gender

We found no widely accepted explanation for the differences between boys and girls regarding the type of alternative feeding. As reported above for the entire sample, significantly more boys were treated with GT compared to NGT, whereas the percent of NGT and GT was evenly divided for girls. However, when the youngest age group is examined, most of the boys were treated with GT compared to girls who were significantly fed more frequently via NGT. This finding was unrelated to other factors such as prematurity or medical complexity and may reflect culturally related parental perceptions of girls compared to boys. In contrast to NGT, GT entails a surgical procedure that leaves a scar. The literature does not provide any specific support for the notion that gender-based differences in parental perceptions of their very young child's body schema influence decision-making of invasive medical procedures. There is, however, some evidence from Morawska's[15] review of 45 articles that examined gender-related differences in parenting from a very young age, primarily in vocalization, socialization and play. For instance, parents warned girls more frequently about safety and injury risk,[16] suggesting a differential attitude to their bodily integrity. Additional research is needed to investigate gender-related issues related to types of alternative feeding.

## 4.5 | Weight loss considerations during tube feeding reduction

Most of the children lost less than 5% of their weight by the end of the Intensive phase of the program. For the children participating in the 3-week intervention,[10] this decrease was particularly marked during the second week, corresponding to the period when the children were already off tube feeding, and beginning to acquire eating and swallowing skills, but not yet achieving daily nutritional intake goals. Clinically, we observed that during the third week, weight began to stabilize as the hunger-satiety cycle became regulated, eating and swallowing skills matured and became more efficient. Moreover, mealtimes became easier and less stressful, and parental anxiety decreased.

## 4.6 | Redefining success

We consider functional and efficient oral feeding, even if supplemented by a small portion of tube nutrition or hydration, to be a successful result. Indeed, we categorized these children as “Successful Prolonged.” Therefore, we follow these patients over longer periods until they reach complete reliance on oral feeding, which may take a year or longer. This is in keeping with many of the studies reviewed by Taylor et al.[5]

## 4.7 | Intervention setting, duration, and intensity

When the ALYN program was first launched, it was assumed that the children would require careful monitoring in an inpatient setting. However, careful preparation of the patients resulted in the prevention of dehydration and decompensation and outpatient care sufficed. We recognize that this planned change had additional implications for the program; an outpatient

program required more flexibility in managing patient complexity, with the understanding that some children needed a more personally tailored weaning program, including slower progress over a longer period with fluctuations in tube intake. Moreover, the change allowed the team to oversee and manage parental ability to handle mealtimes at home as their child progressed. Previously, children experienced home meals only after being discharged, and some children had trouble in transferring their newly acquired feeding behaviors from hospital to home mealtime. Switching the program to an intermittent, outpatient framework helped the parents be more available to the overall daily life of the family. This is in accordance with the current trends of caring for a patient as close to their home environment as possible. The ALYN program did allow inpatient care for the occasional medically fragile child or anxious family.

### 4.8 | Timing of GT removal

Since the current study population included many children with complex medical issues, we acknowledge our hesitation in removing the tube, even when the child achieved full oral feeding and the stoma had not been in use for a while. In complex cases, when the possibility of medical instability or seasonal susceptibility to illness are present or when medical interventions are anticipated, we suggest keeping the tube in place for periodic fluid and nutritional access.

### 4.9 | Growth curves

We note the limited usefulness of growth curves for results such as those presented here. The expected growth of children with known genetic mutations or syndromes is different than the general population.[17] For years, it was acceptable to place children on diagnosis-specific charts. Since some of these populations are small, the growth curves may not represent the actual growth potential given current medical treatment. In addition, there have been questions regarding the use of the Gross Motor Function Classification System based growth curves for children with cerebral palsy. These are based on a population that is relatively small and may have been skewed by lack of appropriate nutrition at the time of the cerebral palsy specific growth curve publication.[18] As an alternative, we considered using body mass index (BMI) scores of the population wide growth curves and attempted to use as a reference point the *z* scores of the BMI.[10] However, we found that these are not widely accepted under 2 years of age, so we could not compare preweaning data with the children's current BMI. In the end, we used the accepted percentage weight and gain results but acknowledge that their usefulness for a particular child is limited.

## 5 | CONCLUSIONS AND LIMITATIONS

Tube weaning is a complex process requiring ongoing assessments of many shifting parameters. A successful weaning program is not intrinsically related to the physical removal of the tube. Weaning may be considered successful even if additional nutritional or hydration tube support is intermittently provided due to ongoing medical or metabolic determinant. This 11-year retrospective analysis of a weaning program provided to a heterogeneous sample of children with varying medical and behavioral conditions. As our experience in weaning protocols progressed, the setting and number of therapies during the second Intensive phase of the program changed. Nevertheless, outcomes remained similar so data from all patients were included in the analysis. A larger sample of children who received the same protocol is anticipated in a future report. Cultural differences may have affected environmental and nutritional factors.

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### CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

### DATA AVAILABILITY STATEMENT

All data used in the study are available. The lead author has full access to the data reported in the manuscript.

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