

# Kids with Tubes News

A newsletter connecting parents and caregivers of tube-fed children

## Welcome to Kids with Tubes' First Newsletter

Welcome to the first edition of *Kids with Tubes News*. It is our hope that with this newsletter we will be able to connect with many families and caregivers who share the common experience of caring for a tube-fed child.

Kids with Tubes is an organization run by parents that offers a variety of support services. Quarterly Seminars offer speakers on topics of interest to the parents and caregivers of tube-fed children. Regional Support Groups are smaller, geographically-based groups which meet informally, at each group's own initiative, in order to provide a forum for more personal sharing. Our website is a place for parents to start in their quest to find support. And always, a member of Kids with Tubes is available to answer questions by phone and to offer support.

This newsletter is another vehicle for both the sharing of information and of our stories and experiences. Each newsletter will focus on a specific topic. We will ask a physician and other professionals to address that topic from the perspective of their disciplines. And we will ask parents of tube-fed children to share their stories and experiences on the same theme.

In this, the first *Kids with Tubes News*, the focus is on making the decision to place a feeding tube in a child. This decision is often a very emotional and difficult one for the parents (and for the child, depending on the child's age). Inside you will read thoughts from three professionals and the very personal stories about how several children's families made the decision to have a feeding tube placed.

*Kids with Tubes News* is a way for you, the member of Kids with Tubes, to share with other members and to learn from others' experiences. We hope that you will find ideas in this newsletter that help you: with making difficult decisions, with your child's care or just by feeling less alone and more understood. And we encourage you to participate in future newsletters by sharing your stories and experiences with others in hopes that your story might touch and help those who read it as you have been helped by what you read here.

We thank Dr. Athos Bousvaros, Ms. Heidi Quinn and Ms. Arden Hill for their articles in this newsletter. We especially thank the parents who shared their children's stories with all of us.

Sincerely,

Jill Crisman  
Nura Funda  
Sue Gorman  
Irene Walborsky

March 2000

### *The Decision to Place a Feeding Tube*

#### *Our shared principles:*

- *Each child with a feeding tube is unique – what works for one child and family may not work for another.*
- *Always check with your child's doctor(s) and/or therapist(s) before using any information presented in this newsletter for your child's treatment or care.*
- *All information that is learned through any Kids with Tubes forum is to be treated with complete respect and confidentiality.*
- *Some children will outgrow the need for a feeding tube, others will have a tube for their lifetime; we seek to support all parents and caregivers of tube-fed children, whatever their experience will be.*



## Evaluating a Child for Gastrostomy Tube Placement

Athos Bousvaros, M.D., Dept. of Gastroenterology,  
Children's Hospital, Boston, MA

As a physician who specializes in the care of children with feeding difficulties and other intestinal conditions, I am often asked to determine whether a gastrostomy (G-tube, stomach feeding tube) will help a child. Parents often come to see me with anxiety. Many parents view a G-tube as a "necessary evil" which may help their child gain weight, but which may also isolate their child from other children, as well as limit oral intake. In some cases, I recommend a feeding tube be placed promptly, while in other cases I recommend no tube at all. To help me make this decision, I usually ask these questions:

### **1. Is the child malnourished. If so, why?**

While special needs children are all unique individuals with different needs, they all have one thing in common: nutrition is essential for their proper growth and development. Malnourished children are at risk for infections, bone fractures, and anemia. A malnourished child undergoing a surgery has decreased wound healing abilities and may experience more complications. In addition, normal children who are starved have slowed develop-

ment; therefore, while it is not proven, refeeding malnourished special needs children may increase energy, alertness, and possibly improve development.

I usually determine malnutrition by reviewing a child's growth curve, seeing if the weight is appropriate for height, and examining them carefully. Most blood tests are normal except in very severe malnutrition. Most of the time, the baby's underlying disease (cerebral palsy, congenital heart disease, prematurity, chronic lung disease, etc.) is the only cause of the poor growth. Babies with cerebral palsy often grow normally in the first six months, but as they get older, their suck and swallow may not keep up with their needs, and they stop gaining weight. Babies with congenital heart disease or lung disease feed normally at the beginning of a feeding, but tire out by the end of the feeding. Babies with behavioral feeding resistance (oral aversion) tend to turn away from the bottle before it even gets put in the mouth.

Sometimes, I find a treatable cause of malnutrition, such as pneumonia, urinary infection, gastroesophageal reflux with esophagitis, food

allergy, or incorrect preparation of formula. In these cases, treatment with the appropriate formula or medication may increase oral intake. Unfortunately, only a few patients have an easily correctable cause of malnutrition.

### **2. Is the child safe to eat by mouth?**

Some children may not be malnourished, but are referred because of respiratory symptoms. These children usually have a neurologic disorder, such as cerebral palsy or muscular dystrophy. When they eat or drink by mouth, food enters not only the esophagus and stomach, but also the lungs (aspiration), and nasal passages (nasopharyngeal reflux). Typically, these children have been hospitalized for pneumonia and may also have recurrent "bronchitis", "asthma" or "sinusitis".

The aspiration is usually diagnosed with a test called a "barium swallow" or "modified barium swallow". While the test may demonstrate aspiration, the decision to place a G-tube should not be made on the basis of the test alone, but rather based on the child's symptoms. At this point, I often consult with a respiratory specialist (pulmonologist) to determine

## A Gastroenterologist's Perspective ...

the severity of a patient's lung disease.

### 3. Does the child need the tube for medications?

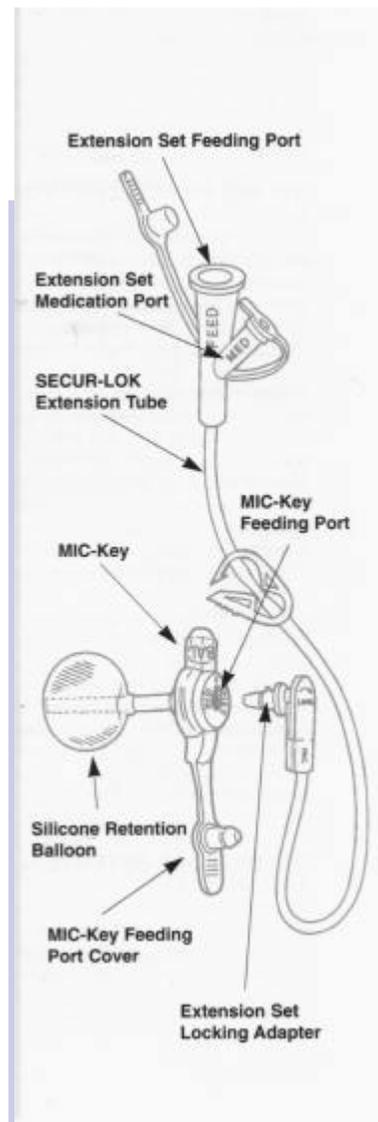
Certain children with intractable epilepsy or other conditions may require a large number of medications. If a child with epilepsy starts having seizures, he/she may be unable to take their medications by mouth. Lack of medications in turn leads to worse seizures. In these situations, a G-tube may provide a useful "safety valve" by which special needs children can receive their medications under just about any conditions.

### 4. Do the benefits of a tube outweigh the risks?

In the year 2000, the surgical risks of placing a feeding tube are relatively low. At Children's the tube is placed under general anesthesia, with a gastroenterologist and surgeon performing the procedure. The risk of a serious surgical complication of G-tube placement (bowel perforation, bleeding) is less than 1:100, and the procedure takes under an hour. Nevertheless, there are some children (between 10-20%) who may have problems after the tube is placed. These problems include vomiting and

skin infections around the G-tube site. Because of these risks, I tend to recommend feeding tubes only to these children who I feel will really benefit, and who will need supplemental feeding for a long time. I also make sure other ways of improving nutrition (such as thickening feedings or increasing calories) have been tried.

After discussing all these elements with parents, I find most parents are prepared for having a feeding tube placed, assuming their child really needs it. If parents are not ready, I recommend further discussion between them, and ask for a return clinic visit so that I can answer any questions. Since a G-tube involves a major family commitment, I feel it is important that a family believe it is in their child's best interest before I recommend the surgery. □



The MIC-Key button. Taken from the Patient Information Guide from Medical Innovations Corporation.

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## Commonly Asked Questions Regarding Tube Placement

Heidi Quinn M.S., RD, Feeding Team Coordinator, Children's Hospital, Boston, MA

### *A Dietitian's Perspective ...*

Parents have so many questions and concerns as they consider G-tube placement for their child. It is a difficult decision often filled with much anxiety. First, let's discuss some of the benefits of G-tube placement, and then address some of the nutrition and feeding questions that we commonly hear from parents.

#### **What are the benefits of having a G-tube placed?**

Supplemental feedings via a G-tube provide:

- Appropriate nutrients for good growth and good health to help fight infections.
- Fluid to meet hydration requirements and ease constipation difficulties.
- A safe feeding alternative for children who cannot safely feed orally.
- Help in reducing stress and anxiety, for both caregivers and child, due to long feedings with often limited volume of intake which are not adequate for growth and good health.
- Reducing the number of hours spent feeding allows more time to do other things with your child which are enjoyable and less stressful.

#### **What about using an NG-tube instead of a G-tube for supplemental feedings?**

In general, NG-tube feedings are recommended only as a short term (i.e., 6-8 weeks) supplemental feeding method. Prolonged NG-tube feedings have been found to contribute significantly to the development of oral aversion which can be a barrier to the progression of oral feeding later on.

#### **Can my child still eat by mouth if he/she has a G-tube?**

If your child does not have safety issues related to oral intake (i.e., Is not at risk for getting food or fluid into their lungs), he/she can and should continue to eat by mouth. It is generally recommended that they continue to eat by mouth to promote both oral-motor and feeding skill development as well as to experience the pleasurable social aspect of sharing mealtimes. For some children, safety considerations need to be addressed, generally by a speech-language pathologist or occupational therapist who specializes in oral-motor feeding issues. Some children may be safe with certain textures of food or fluid, or very small volumes of specific foods or fluids.

#### **What if my child is not allowed to eat by mouth?**

There are many pleasurable activities that you can do with your child to help promote oral motor

development. Your child's speech, occupational, or physical therapist can develop an appropriate oral-motor program for your child.

#### **What do I feed my child through the G-tube?**

There are many types of formulas that can be given to your child through the G-tube to meet your child's nutritional needs. Your child's nutritionist will help you plan an appropriate diet to meet the individual nutrient and fluid needs of your child. Vitamin and mineral supplements may also be incorporated into your child's diet intake.

#### **Can I put food through the G-tube?**

Blenderized foods are available as commercially prepared formulas or can be made at home from baby foods, juices, milk, baby cereal or pureed foods. However, preparation of home blended formulas require careful sanitary measures with regard to foods and equipment used for preparation, and monitoring by a nutritionist for adequacy of calorie and nutrient intake. Your child's nutritionist can help you develop the best diet for your child. □

## Commonly Asked Questions Regarding Tube Placement

Arden Hill, M.S., CCC-SLP, Children's Hospital, Boston, MA

### *A Speech and Language Pathologist's Perspective ...*

#### **Why would my child be considered for tube feedings?**

If your child cannot safely orally feed because food or liquid is going into the trachea and down into the lungs and/or your child cannot meet their nutrition or hydration needs with oral feeding alone, tube feeding might be considered.

#### **How do I know how much food or liquid going into the lungs is too much (referred to as aspiration)?**

The truth is, no one knows. This can be a very frustrating answer to parents as well as therapists. What we do know is that food and liquid does not enter the lungs in a child with a normal swallow and that there are many children who have recurrent difficulties (i.e. upper respiratory infections, pneumonias, fevers, asthma, allergies) when aspiration occurs.

#### **How do I know what tube is best for my child?**

The decision regarding what type of tube is right for your child is really determined by your core medical team. Typically an NG-tube is considered a short-term supplementation system. That can have a negative impact on a child's comfort with their mouth and with oral feeding experiences if it is in

for an extensive period of time. A G-tube is typically the "tube of choice" for a child who can tolerate feedings into the stomach and is considered the preferred tube for a "partnership" with oral feedings when the child is safe and comfortable eating something by mouth. The J-tube is often recommended for the child who cannot tolerate feedings into the stomach (i.e. vomiting with feedings and compromising their health or growth as a result).

#### **Will my child need the tube forever?**

Some children need supplemental tube feedings for fairly short periods of time (i.e. 6 months), while others may need them considerably longer. The determining factors are again safety and ability to meet nutrition and hydration with oral feedings.

#### **How long does it take to wean my child off of tube feedings?**

The time period greatly varies from one child to the next. In addition to safety and nutrition factors, a child's medical status plays a huge role. Often there are interfering factors such as gastroesophageal reflux, necessary medical inter-

vention (i.e. surgery), ability to integrate sensory information, and common childhood illnesses that can interfere in a child's comfort with oral feedings. When there are interfering factors, the weaning process can often last a long time, even years. In many children, as these interfering factors become less pervasive, the process moves ahead at what often feels like slow-but-steady progress. The ultimate goal of a speech language pathologist is to have every child feed orally, but not at the expense of safe oral feedings and/or adequate nutrition and hydration. Our job is to educate and advise, but not to make ultimate decisions about your child's care. Only your family, with the support of your core medical team, can make management decisions for your child. □



## May's Story

We resisted the idea of placing a G-tube in our daughter, May, for as long as we could. Due to pregnancy complications, May was born prematurely and small for gestational age at 29 weeks gestation and only 1 lb 7 oz. She had no congenital problems, but she struggled to survive with respiratory distress, among other typical preemie medical problems which led to chronic lung disease and failure to thrive. As parents, we struggled with many decisions over her care, but the hardest one was the G-tube. It seemed so foreign, invasive and permanent, we hoped against hope that we could come up with a simple solution for a very complicated problem.

In the NICU, May's doctor occasionally floated the idea of placing a G-tube. The nurses disagreed with the idea and assured us that she would bottle-feed and grow better at home. She languished an extra month in the NICU while we tried to get her to take all of her minimum bottle feeds, but she always needed to be supplemented by the NG-tube. Finally, at over 4 months of age she came home without the NG-tube and we had expectations that she would soon improve her bottle feeding.

The first six weeks at home were distressing and exhausting. May showed no improvement in her ability to feed, and had slow growth despite the 32-calorie "rocket fuel" formula of breast milk mixed with formula, polycose and oil. We essentially carried on her NICU schedule at home: every four hours around the clock we fed her, gave her meds, took her temperature and recorded her input and output in a log. She had weekly hospital visits for weight checks and blood draws to monitor her electrolytes. At six months of age, and after six weeks of very slow growth, she weighed in at only seven pounds. We talked more about the G-tube decision, yet our Early Intervention therapist

was negative about it, calling the G-tube "no picnic". We had no contact with anyone in the outside world who had ever heard of a G-tube other than our therapist and medical professionals. We agreed to use the NG-tube again as an interim measure before we had to face the G-tube decision.

May had a terrible aversion to anything going in her mouth. We believe it came partly from her history of a long intubation and use of the NG-tube, partly from having to take the extremely bitter tasting KCl (potassium chloride) supplement by mouth, and partly the thick formula she had to drink. She would only suck consistently on the bottle while she slept. Awake, it was always a struggle. We didn't know it then, but it was an oral aversion that would last for several years.

We started her back on the NG-tube at home and she began to pile on the weight. We put her meds through the tube so she didn't have to taste them. At the same time, however, she began to develop severe gastroesophageal reflux. The vomiting went on day and night. We would estimate the volume vomited and then re-feed that amount with fresh formula. We tried to continue the bottle and soon began trying the cup. She seemed to hate the bottle and preferred the cup. The Early Intervention therapist brought us Haberman nipples, which take less effort to suck. I bought so many different nipples and even ordered a case of the same brand of nipples she used in the hospital, always hoping for a simple solution. But she would not take enough volume by mouth. She became more and more dependent on the NG-tube as her weight increased and her corresponding caloric mini-

num requirement increased.

We took the data from the log and charted it to illustrate to the doctor our concern about how her vomiting was increasing in frequency. The doctor felt the NG-tube should only be a temporary measure, and he started getting us ready for the G-tube decision. After 6 weeks of the NG-tube at home, we could never catch up to that minimum required amount by mouth. It was clear that it was time.

Then May pulled a fast one on us. She yanked out her NG-tube, a common occurrence, two days before her scheduled surgery. The next day, instead of getting the visiting nurse over to drop the tube back in, we thought we'd see how well she'd bottle-feed. She only had one day before her surgery, so we thought it wouldn't hurt to try it. Of course, she bottle-fed very well that day. We gave her regular strength formula, which at 20 calories per ounce was nice and watery and thirst-quenching. She drank almost all of her volume requirement for the day. We were ecstatic. We agonized all day about whether or not to go ahead with the G-tube. Was this a fluke performance or could she bottle-feed and gain weight on her own?

We decided to cancel or at least postpone the surgery. It was a Sunday night, the surgery was scheduled for 7 a.m. the next morning, and the only doctor on call was someone we didn't know. Talking to him on the phone, we somehow tried to explain the day's experiment, and how it made us want to change our minds about the surgery. The G-tube sounded so invasive and scary. I guess in the end we felt embarrassed, and decided we were just suffering from cold feet. He talked to us patiently, and finally convinced us to go

ahead with the surgery. May was 7 ½ months old, and weighed just under 9 pounds.

May gained weight extremely fast with the G-tube. In the first month, she gained 2 pounds. After a few months, she hit the growth chart for the first time. Now using a pump at night, we all got a good night's sleep every night, except when she awoke to spit up. We didn't have to wake up every four hours to feed her. The down sides were hard. Vomiting increased, she required a grueling daytime feeding schedule because she could only tolerate small boluses, and her oral intake decreased to nothing at all by mouth. But the medical implications of weight gain and full nutrition were obvious as she started along the long road to physical recovery and the race to developmentally catch up with her peers. □

*I bought so many different nipples and even ordered a case of the same brand of nipples she used in the hospital, always hoping for a simple solution*

## Bill's Story

Bill was born premature at 26.5 weeks, weighing 1 lb 12 oz, and was on a ventilator for 52 days. We almost lost him twice in the hospital, but he found a way to survive. After he got off of the ventilator, he was doing remarkably well, but gradually he was starting to eat less and less as his breathing became more and more difficult.

We tried everything to get him to eat while he was still in the NICU, different nipples and techniques, but nothing seemed to help. He was spending so much energy breathing, that he had no energy left for eating. At this point, it was pretty obvious that if we wanted him to come home from the hospital, he would need to be fed by a tube, and the best option was for him to get a G-tube. He was then 5 months old and still in the hospital. I knew that he would do better at home but we had to be sure that he would get his nutrition before they would let him go. I was ready for him to get his tube so that he could come home. Of course, I thought that he would only have it for a year, but I guess a little naïveté at the time is good.

Immediately after Bill got home he was doing great with the tube. Then the vomiting began, and continued to get worse (and worse, and worse.) By the time he was a year old, he was vomiting 1/4 to 1/3 of everything that we fed him by the tube. I had home nursing at the time and we tried everything to keep the food down, to no avail.

The doctors then began to talk to us about a GJ-tube. In

some ways, this was an easy decision for us as well. Bill had begun to lose weight, was vomiting 20-30 times a day, and the only other option was a fundoplication. So, a GJ-tube was placed.

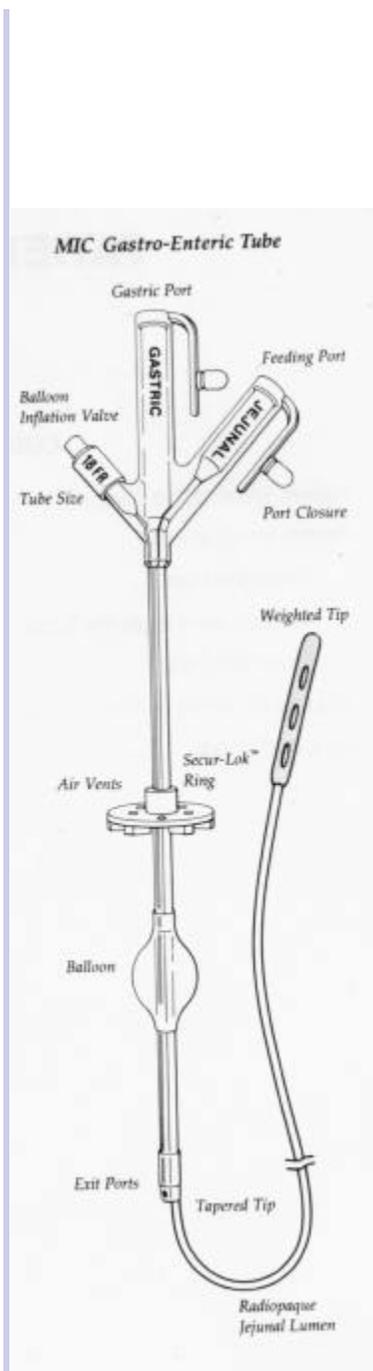
Bill did great with the GJ-tube. He gained weight and started to catch up developmentally. The down side, is that his interest decreased in eating until he stopped taking any bottles at all.

At age 2 1/2, he still does not eat by mouth and gets 100% of his nutrition via his J-port of his tube. Since he is doing so well with the feedings, we are beginning to try to use the G-tube port more to get his stomach

working again. He is vomiting much less than when the GJ-tube was placed. We are very hopeful that with the right combinations of medications, formula, and feeding schedules, we will be able to get him to take all of his nutrition via the G-tube.

As I look back at this, I understand that we traded his ability to eat with his ability to survive and develop at a more normal rate. Every time I see him do something new, I know that we made the right decision for Bill. □

*He was spending so much energy breathing, that he had no energy left for eating.*



The MIC GJ-tube. Taken from the Patient Information Guide from Medical Innovations Corporation.



## Stephanie's Story

I have heard that one of the common reasons that infants have G-tubes placed is because of low birth weight and the issues related to that (weak suck, etc.). My daughter Stephanie weighed 9 lbs 10 oz when she was born. Her heart was not working as it should, and she would later have heart surgery at the age of two which would repair a significant leak in the mitral valve and also to repair an arterial septal defect (hole in the heart). Her higher birth weight was probably due to her heart issues and excess fluid. She also had excess skin on the epiglottis, (floppy folds which move when you swallow, breath), swallowing discoordination, chronic tachycardia and tachypnea (fast breathing and fast heart rate), temperature instability, reflux (before the G-tube was even

placed), irregular EEGs, and the list went on.

In the early weeks, when we tried to give Stephanie a bottle her heart rate would soar. She would sweat and had swallowing discoordination. You could already see her beginning an aversion to the nipple: wanting to suck but not being able to coordinate all that suck/swallow/breath stuff.

We discussed at length with her team of doctors all her issues. She needed an epiglottopexy (trimming of the folds by laser surgery with a few stitches added to help out), medications for the seizure activity on the EEG, medication to make her heart work more efficiently and medications for reflux and a G-tube placed to provide enough nutrition while we pursued the swallowing disorder

and other issues.

While we were trying to make our decision, lots of things happened. Stephanie did not go home until she was 3 months old. During that time we had battles with viruses, colds, lots of ups and downs. One day I was told that her surgery for the epiglottis and a G-tube placement was the next day. I flipped. But we decided that her doctors had seen many children with the same issues. They had experience and they had to know what was right. And so it was done when she was 3 months old.

Today Stephanie is 5 years old and many of her medical issues are not as severe. She has made slow progress, but significant progress which is amazing to us. We remember her as weak and not doing anything. Now it is fantastic to see her with her walker, playing, and just laughing. She is a very strong child who has been through a lot. I can say that there are days when she will eat and days she will not. On the days and weeks when she will

not eat it is very frustrating.

But I have to remember that with the help of her G-tube (and repair of her heart) she had gained weight. She is actually plump, where she used to be dangerously underweight. Her G-tube helped nourish her when she had heart failure (more than once) and helped nourish her during the post surgical recovery. It had also helped during other illness to keep her hydrated. With her heart repairs and good caloric intake through her G-tube, she is physically less fragile. Any illnesses she gets occasionally (colds, etc.) do not last as long.

Though we are constantly working on eating orally, and I know she can do it (her swallowing looks pretty good on that video study now), if she does not want to eat, the one thing I don't have to worry about her is her nutrition. I guess it's a love/hate relationship we have with the G-tube, but it was the right decision. Stephanie had a great team of doctors (and still does) and they helped us make the right decision for us. □



*One day I was told that her surgery for the epiglottis and a G-tube placement was the next day.*

*I flipped.*

## Jessica's Story

Jessica was born in April 1995, 4 lb 12 oz and 17 inches full term. Her weight and height were an immediate concern to the doctors. But we really were not that worried. She was just born small. She was so beautiful (still is) and precious. However feeding was difficult from the onset.

Jessica did not want to eat. Again we were not concerned at first. We had nothing to compare her eating to. After a couple of months Jessica's pediatrician's concern began to alarm us. Then at 6 months she was labeled "failure to thrive." The smallest cold would stop Jessica from eating altogether and she'd end up in the hospital, dehydrated.

Just before her first birthday, Jessica got a stomach bug. She was at a community hospital for 4 days, dehydrated and losing 4 oz a day. For a 12 lb one-year old that was too much. We demanded to have her transferred to Boston Children's Hospital. We wanted answers to the underlying growth problem. Jessica was diagnosed with Russell Silver Syndrome. One of the characteristics of Russell Silver is lack of appetite. We knew the problem but now what?

The G-tube was mentioned shortly after Jessica's diagnosis. However, we and the doctors agreed at first that we would try to treat Jessica with a high calorie diet, which eventually included Pediasure via bottle.

Periactin, an appetite stimulant, was also introduced when Jessica was about 2 years old. Jessica was actually doing pretty well. At 3 years, Jessica was still on the bottle. She was taking 5 or 6 bottles a day, totaling twenty-five to thirty ounces of Pediasure. Sometimes it would take Jessica thirty to forty-five minutes to finish a five- or six-ounce bottle.

However the real dilemma was Jessica, at three, was becoming more social: playgroups, school, dance lessons. At this time Jessica's little brother was born and we were afraid Jessica would associate bottles with babies. It was becoming evident that keeping Jessica on the bottle would become logistically impossible with all her activities and a hindrance to her social development. We were definitely at a crossroads.

June of '98 it was decided to wean Jessica off the bottle and onto solids. It did not work. Jessica lost weight steadily. Even when she seemed to be eating all right, the slightest cold would cause a major set-back. The decision seemed so obvious but we were still reluctant. I believe it was in October that we decided to go with a G-tube. We were not happy about it. We tried everything to avoid this step. I won't speak for my wife at this point, but a part of me felt like a failure. It is not like I said when Jessica was born "I can't wait until she walks, runs, talks, plays and *has a G-tube*". Although we were

not happy about this decision we knew it was the right thing to do. Jessica had to have the calories in order to grow. She would not do this orally unless it was via bottle and that was no longer an option. And we could no longer watch her get dehydrated with each illness. We didn't want our child to be different. We didn't want our child to experience any pain, physical or emotional. We wanted our child to lead an active life.

This was actually one of our biggest concerns. Jessica is a ball of energy and loves to climb, swim, dance, run and wrestle with her dad. So after talking with the GI team at Children's Hospital, and being assured that Jessica would still be able to lead an active life, we decided to have the tube placed. On December 18<sup>th</sup>, 1998 Jessica received the tube.

After over a year, I can honestly say that the G-tube was the best thing we could have done for Jessica. She has gained weight steadily. She leads a very active and social life: she loves to swim, she attends preschool twice a week, she has dance once a week, she climbs, runs and plays. Luckily in the last year we have had no major problems regarding the G-tube. After a year I can also say how difficult it was to make the decision. There were times I was mad. There were times I wept at night for my daughter. There were times I felt guilty because all and all we are blessed with a rela-

tively healthy and happy child. Why should I be mad or sad? Every choice seemed wrong. However, the G-tube for Jessica was not only the right choice, but really, the only choice. □

*It is not like I said when Jessica was born "I can't wait until she walks, runs, talks, plays, and has a G-tube". ..*



## Annie's Story

I remember the day that Lisa, the Nurse Practitioner on the Cardiac Recovery floor, suggested to us that it might be time to consider placing a G-tube in Annie's stomach. Annie was almost 6 months old then, four of which she'd spent in the hospital, and it was the first time that I lost my composure with any member of the hospital staff. I was devastated and angry. We had always been counseled to be patient, to be optimistic and, above-all, to take things one day at a time (sometimes one hour at a time). I felt as if she'd changed the rules and was now issuing a decree upon our little Annie: "She can't do it."

Annie had already endured so much. She was born with hypoplastic left heart syndrome and had her first open heart surgery at 4 days old. She was 4 lb 12 oz, yet the surgery went well. However, her recovery was difficult and she didn't come home until she was 2 months old and only a very fragile 5 ½ pounds. For the next two months she was orally fed, every two hours around the clock. We were lucky if we could get an ounce into her at each feeding and we charted it all: what went in, what came out. But she did grow, steadily if slowly.

At 4 months Annie needed her second open heart surgery, much sooner

than we'd expected. It seemed like everything went wrong: difficulty in surgery, many transfusions, two periods on bypass in deep hypothermia, internal bleeding, then pneumonias, tachycardia, infection and drug addiction during her lengthy recovery. As she approached her first half-birthday we hoped she was nearing discharge from the hospital, but we knew that she wasn't eating well. At each feeding at least half of the total was going down her NG-tube after she abandoned sucking the bottle. Still, we were hopeful that her stamina would improve and that she would return to full oral feeds.

Looking back, the decision to place a G-tube in Annie doesn't seem so difficult. She was too wiped out to suck a bottle for more than a minute or two, she needed supplementation through a

NG-tube at every feeding, she was only 7 lb or so, the NG-tube was not recommended for long term use, and we knew she was uncomfortable with the NG-tube by the number of times that she managed to pull it out. But at the time the suggestion that Annie succumb to being fed by a G-tube felt like just one more aspect of her life that couldn't be "normal." And the loss of yet another aspect of "normalcy" triggered in me all the grief that accompanies coming to terms with having a child with so many challenges and differences. The loss of yet another dream.

Annie's G-tube was placed when she was almost 9 months old. She is now 6 ½ and it is still used to provide her with almost all of her nutritional intake. It was a good and correct decision. She was struggling to

merely survive and it gave her the break she needed to rest and to grow. Looking back I realize that it was hard for *me* to deal with the emotions that the decision aroused, but then, as now, I knew that it was the right decision for Annie. □

*And the loss of yet another aspect of "normalcy" triggered in me all the grief that accompanies coming to terms with having a child with so many challenges and differences. The loss of yet another dream.*

## Amy's Story

Amy was born prematurely and diagnosed with cerebral palsy at about 6 months of age. Since that time, her issues surrounding eating and eliminating (and ultimately nutrition and weight gain) have been two-fold: difficulty with oral coordination for feeding and fluctuating constipation. Yet Amy has always loved to eat orally, despite the times that her severe constipation has resulted in vomiting for the lack of any other way to get the food back out.

Amy's body is like a moving target. She is constantly growing and her muscle tone is forever changing, sometimes from moment to moment. This makes it challenging to maintain any consistent pattern of eating and eliminating, and even harder to understand the emotions and behaviors she has acquired around these issues.

Amy has had several tests to determine why she has such difficulty eliminating her bowels. The main issue is the inability to relax her anal sphincter. We tried a variety of medicines and therapies to help regulate the consistency of her bowel movements so she could push them out. Most were helpful for a period of time, but once she grew some more and her tone changed they became ineffective. It was a vicious cycle of prescription and over-the-counter drugs and oral supplements of which she hated the taste.

Before Amy was 4 years old, to us "PEG" was a girl I worked with and "MICKey" was that cute mouse at Disney World... We first learned about the "other" MIC-Key from a physician who we truly respect. We consulted with key members of Amy's team – Gastroenterologist, Speech Pathologist, OT, PT, Nutritionist, Pe-

diatrician, etc. At that time everyone agreed that things were stable. We weren't losing ground. It was something to think about in the future.

As Amy's 6<sup>th</sup> birthday approached we were in the midst of the tough question again – should Amy have a G-tube? By this time things had changed significantly. Amy was growing by leaps and bounds but not gaining weight even remotely proportional to her height. She was expending more energy from her worsening tone. Her schedule was becoming more full, leaving less time for adjunctive therapies, less time for eating and less time with familiar feeders. Most importantly, Amy was *wanting* to spend less time eating, ready to leave the table with friends who had eaten three times as much as she had in the same amount of time. More of Amy's team was strongly suggesting a PEG. Ultimately the decision was ours.

We sought a second opinion. We were actually more concerned with Amy's difficulty eliminating her bowels than with her ability to take food in. We were assured by highly respected health professionals without disabled kids that using a G-tube for feedings would be easy - piece of cake! In addition, the added hydration, they assured us, would make it easier for her to eliminate her bowels.

A huge concern was the emotional side of this decision for Amy, a child who wants to be approached and talked to like any other child. How would she feel about having a new orifice in her body – one that she didn't even know could exist? And there were a litany of practical questions, too. Would it take away her functional eating? Would her

braces fit over the G-tube? Would she still be able to use the E-stim (electrical stimulation) unit that I spent a year getting for her to stimulate and strengthen her trunk muscles? What would her friends think if they saw it? How would sleepovers go? When would she need these feedings? We viewed it as something else to add to our already bustling routine. Could we manage this, too?

The turning point for us was watching our daughter struggle after long, full days at school. She had little energy upon arriving home, having eaten only a few bites and a few sips of juice all day. It was her first experience being away from familiar feeders for so long, coupled with increasing expenditure of energy. She had a growing body and a more intense school and therapy schedule. She was zapped! She was starving! It was time... it was hard... it was time.

The preparation phase went okay – visit to the new hospital, long talks with Mom, Dad, Amy, Michael, health professionals, close friends, extended family... Initially Amy was against it. We visited with a doctor she loves; we visited with another child also with CP and a G-tube. Amy agreed. Michael understood (so well, I'm told, that on the day of Amy's surgery he gave a fifteen minute dissertation on the PEG procedure to his third grade class!).

Surgery went off as planned. The delivery of home supplies was daunting – five feet of supplies...a vivid Wednesday, trust me. And with Amy's continually-fluctuating tone, her elimination issues were not simply and easily solved after the insertion of the G-tube. Mortify-

ing experiences – from complete body soakings in diarrhea to constipation so packed that it caused leakage around the stoma itself...

It's a piece of cake to look back now, a year-and-a-half later, fifteen pounds later (thanks *in part* to PEG and MIC-Key, but also to changes in medications and tonal control). It's easier, but it's still not easy. Amy has adjusted to the tube, sharing it with certain close friends, her brother, a cousin; keeping it private from others. Sleepovers are challenging, but still possible by changing clothes in private and starting her pump in her sleeping bag after lights out... Her functional eating *has* continued, but now without all the pressure of being her sole source of nutritional intake. We are all happy with our decision. We rest assured that the next year will be different. Can we manage it? We *have* to manage it.

I've got to pack the bags... more driving tomorrow. Off to the hospital. Amy might get a bigger MIC-Key – not the plush kind this trip, but she definitely deserves one next trip to Disney World! ☐



## Commonly Used Terms

### TUBE FEEDING

Giving supplemental nutrition through a special tube that enters directly into the stomach or small intestine.

### TYPES OF FEEDING TUBES

**G-tube, Gastrostomy Tube:** a feeding device through which formula, fluids and/or medication can be given. A G-tube is placed directly into the stomach through an opening in the abdominal wall. The tube can be placed surgically, endoscopically or with x-ray guidance.

**J-tube, Jejunostomy Tube:** a feeding device through which formula, fluids and/or medication can be given. A J-tube is placed directly into the small intestine and passes through an opening in the abdominal wall. J-tubes are generally placed surgically.

**GJ-tube, Gastro-Jejunostomy:** a feeding device through which formula, fluids and/or medication can be given directly into the stomach or the small intestine, depending on which feeding port is selected. Like the G-tube, the GJ-tube enters the stomach through an opening in the abdominal wall.

**NG-tube, Nasogastric tube:** a feeding device through which formula, fluids, and/or medication can be given directly into the stomach. The NG-tube is inserted through the nose, passes down the esophagus and enters into the stomach.

**NJ-tube, Nasojejunal tube:** a feeding device through which formula, fluids and/or medication can be given directly into the small intestine. The NJ-tube is inserted through the nose, passes down the esophagus, through the stomach and into the small intestine. This tube is usually placed using x-ray guidance.

**“Feeding Tube”:** in general, the G-tube, J-tube, GJ-tube, NG-tube and/or extension tube through which formula, fluids and/or medication are given.

### METHODS OF TUBE PLACEMENT

**PEG, Percutaneous endoscopic gastrostomy tube:** a G-tube which is placed percutaneously, or “through the skin,” using endoscopic guidance. In common use, reference to “a PEG” suggests a continuous plastic tube used for feeding which is placed endoscopically.

**Surgical G-tube:** A G-tube which is placed by making an abdominal incision, creating a tract from the skin to the stomach and securing the tube into the stomach.

**X-ray Guidance:** The use of x-ray contrast (fluoroscopy) to help guide the tube into the correct position.

### COMMON TYPES OF G-TUBES

**PEG, Percutaneous endoscopic gastrostomy tube:** While “PEG” technically refers to a method of tube placement, in common use “PEG” may also refer to the type of G-tube which consists of a continuous length of tubing and is placed endoscopically.

**MIC-Key Button:** a G-tube made by Medical Innovations Corporation (MIC). An external “button” sits flush against the skin. An extension tube is connected to the button for feedings. The MIC-Key is held in place by an inflatable/deflatable balloon inside the stomach and can be changed, without sedation, by a medical professional or a *trained* parent or caregiver.

**BARD Button:** a G-tube made by Bard. An external “button” sits flush against the skin. An extension tube is connected to the button for feedings. Unlike the MIC-Key, it needs to be changed by a medical professional.

### TYPES OF TUBE FEEDINGS

**Bolus feeding:** a feeding that is relatively large given over a period of time which is relatively short (based on the child’s tolerance of feeding rate and volume).\*

**Continuous feeding:** a feeding that is given at a slow rate (based on the child’s tolerance of feeding rate), con-

tinuously for many hours.\*

*\*Bolus and Continuous feedings may be given a variety of ways:*

**Gravity feeding:** a feeding that enters the stomach by force of gravity, by holding fluid in an open syringe or feeding set above the height of the stomach and letting it flow through the feeding tube into the stomach.

**Overnight feeding:** a feeding that is given during the nighttime, typically while the child is sleeping. Often given by pump, overnight feedings may also be given by syringe or by gravity.

**Pump feeding:** a feeding that is given using a feeding pump to deliver the contents of the feeding set into the stomach or small intestine.

**Syringe feeding:** a feeding that is given by attaching a syringe to the feeding tube and pushing the contents in by hand.

### SUPPLIES USED FOR TUBE FEEDING

**Extension Tube:** plastic tubing which can be attached to a button-type G-tube device. Typically includes:

**Clamp:** a small plastic device which, when pressed closed, prevents leakage from the tubing when a port is opened.

**Port:** a capped opening at the end of a feeding tube, sized to fit a certain type of syringe. A feeding tube or extension tube may have 1, 2 or 3 ports.

**Med Port:** a small port used for putting medication or formula into the feeding tube. LUER-LOK and Slip-tip syringes can attach here.

**Feeding Port:** a large port used for putting formula or fluids into the feeding tube. Catheter Tip syringes or the tip of the Feeding Set can attach here.

**Feeding Pump:** a small machine, calibrated for accuracy, designed to deliver formula and/or other liquid at a set rate. (Kangaroo, Zevex, Ross, Corpak are some brand names.)

**Feeding Set:** a “feeding bag.” A special plastic bag and its attached tubing that

holds formula and/or fluid. Feeding Sets are typically manufactured to work with a specific pump. The tubing is threaded through the feeding pump according to the manufacturer's instructions.

**Formula:** specially formulated liquid nutrition that can be used for tube or oral feeding.

**Syringe:** a medical device used to inject or remove fluid, consisting of a hard, cylindrical plastic tube and a plunger.

**LUER-LOK:** a syringe with a threaded tip that can be twisted onto certain ports, such as the med port of the feeding tube.

**Catheter Tip:** a syringe with a large, tapered tip that can be inserted into the feeding port of the feeding tube.

**Slip-tip:** A small syringe with a straight tip that comes with the MIC-Key button and is used to inflate or deflate the button's internal balloon.

#### ANATOMICAL TERMS

**Esophagus:** often referred to as the "swallowing tube." The muscular pathway through which food and drink are moved from the mouth to the stomach.

**Gastric:** pertaining to the stomach.

**Gastroesophageal junction/sphincter:** the point at which the esophagus and the stomach meet.

**Jejunum:** the middle portion of the small intestine.

**Oral:** pertaining to the mouth.

**Trachea:** the "wind-pipe" or "airway" that carries air between the mouth and the lungs. In the lungs the trachea branches into two smaller pipes called bronchi.

#### OTHER TERMS

**Aspiration:** the accidental inhalation of something other than air (liquid, food, foreign objects) into the trachea or lungs.

**Barium swallow study:** an x-ray study used to evaluate the anatomy and function of the esophagus, stomach and small intestine. A small amount of liquid barium is given to swallow. Using x-ray, the barium is followed as it goes from the mouth to the small intestine. Usually performed

by a radiologist.

**Endoscope:** a fiber-optic device through which the inside of the GI tract (i.e. stomach, esophagus, colon) can be seen.

**Enteral feeds:** feedings that pass into the stomach or intestines.

**Esophagitis:** irritation of the esophagus, which can be caused by the entry of stomach contents into the esophagus (gastroesophageal reflux).

**Flush:** water given to clear the feeding tube, extension tube and/or button of formula or medicine.

**Fundoplication:** a surgery in which the upper part of the stomach (the "fundus") is wrapped around the esophagus, near where the esophagus enters the stomach, in order to reduce or eliminate regurgitation or vomiting of stomach contents into the esophagus ("gastroesophageal reflux").

**Gastroesophageal Reflux (GER):** involuntary regurgitation of stomach contents into the esophagus. Also called "acid reflux," actual vomiting may or may not occur.

**Gastrostomy:** an opening through the abdominal wall (a "stoma") into the stomach ("gastric") cavity.

**Granulation tissue:** red, raised and irritated tissue, caused by excessive wound healing, often found around the stoma. This tissue may bleed, drain mucous and be uncomfortable.

**Jejunostomy:** an opening through the abdominal wall (a "stoma") into the small intestine (the "jejunum").

**Modified barium swallow study:** an x-ray study used to evaluate the ability to swallow and to protect the airway. A small amount of liquid barium is given to swallow. The x-ray focuses on the swallow only. A speech pathologist and a radiologist usually perform this test together.

**Oral-Motor:** pertaining to the muscles of the mouth.

**Oral-Sensory:** pertaining to the sensations of the mouth.

**Parenteral feeds:** liquid nutrition given

intravenously, usually through a central venous line.

**Sensory Integration:** the neurological process that organizes sensation from one's own body and from the environment and makes it possible to use the body effectively within the environment.

**Stoma:** a surgical opening in the abdomen.

**Venting:** releasing air or fluid from the stomach or intestines by opening a port on the feeding tube.

#### MEDICAL SPECIALISTS

**Gastroenterologist:** a physician specializing in the diseases of the stomach, intestine, liver and pancreas.

**NICU:** Neonatal Intensive Care Unit (ICU). A medical ICU for newborns.

**Surgeon:** a physician who specializes in performing operations.

**Speech-Language Pathologist (SLP):** a specialist in the evaluation and treatment of oral-motor and oral-sensory skill development. A Pediatric SLP pays special attention to the implications for feeding, speech, and language development. Often works together with an Occupational Therapist.

**Occupational Therapist (OT):** a specialist in oral-sensory and oral-motor concerns, sensory integration (SI), general motor control, and how they impact each other. A Pediatric OT focuses on both gross motor and fine motor skills.

**Physical Therapist (PT):** a specialist in motor control. A Pediatric PT uses physical and mechanical means to facilitate gross motor skill development. For tube-fed children, the PT focuses on overall gross-motor functioning and its impact on oral-motor functioning.



## Thank You

Kids with Tubes News has been produced with a financial award from The Hauslein Early Intervention Parent Leadership Awards. Kids with Tubes is grateful to the Early Intervention Parent Leadership Project for their generous support.

## Our Next Newsletter

### *Daily life with a tube-fed child*

The next issue of *Kids with Tubes News* will address the challenge of integrating tube care and feedings into "normal" daily life. We would love to hear and publish your stories on this topic. If you would like to contribute a story to the newsletter, please send your article to [info@kidswithtubes.org](mailto:info@kidswithtubes.org). The deadline for submissions is September 8, 2000. Write your story now so that you don't forget!

*To be added or removed from our mailing list, please contact us at:  
[Info@kidswithtubes.org](mailto:Info@kidswithtubes.org)*

## Recent Quarterly Seminar Summaries

### Tube Tips

On December 4, 1999, Lori Parker-Hartigan, R.N., Children's Hospital, Boston, MA, moderated a discussion on tube tips. Participants shared wisdom gained in the day to day living with tubes. Approximately 20 parents and caregivers participated. Topics included:

- caring for the stoma site
- managing granulation tissue
- PEG vs. surgically placed tubes
- use of blenderized foods in the tube
- frequency of button replacement
- tube feeding active toddlers
- potty training while maintaining overnight tube-feedings

### Nutrition

Heidi Quinn, M.S., RD, Director of Nutrition/Developmental Medicine Center at Children's Hospital, Boston, MA, spoke on February 5, 2000. She spoke on the topic of Nutrition and the Tube-fed Child. Her talk covered the following topics:

- Formula selection based on type, caloric density and medical condition of child
- Fluid requirements and the considerations that determine them
- Various types of dietary supplements
- Readiness criteria and plan considerations when transitioning to oral feeding

Handouts were provided, including one that listed various blended tube feeding formulas. 18 people attended.

### Previous Quarterly Seminars

A complete list of Kids with Tubes Quarterly Seminar topics includes:

- Managing Reflux
- Transitioning to Oral Feeds
- Talking with Children About Their Feeding Tubes: A Developmental Perspective
- Public Benefit Programs for Children with Special Health Care Needs
- Oral Stimulation: The Developmental Significance of the Mouth
- Meeting the Special Needs of Tube-fed Children in the School Setting
- Tube Tips
- Nutrition and the Tube-fed Child

## Regional Support Groups

There is an ongoing need for parents to connect with each other at a more personal level than we are able to accommodate at our Quarterly Seminars. In response to that need, we have formed Regional Support Groups. These parent groups meet periodically, and quite informally. For example, one group meets at the same time every month at a restaurant. Another rotates Moms and Dads. Another group meets on weeknights in members' homes, just a few times a year. Currently, we have regional support group meetings throughout Massachusetts and in Vermont. If you would like to inquire about attending a meeting, please contact us at:

[Info@kidswithtubes.org](mailto:Info@kidswithtubes.org)

## Can You Help?

Kids with Tubes is operated exclusively by parents. We welcome you to share your talents with us to carry out our mission of supporting families and caregivers of tube-fed children. As much or as little time that you have to offer is gratefully appreciated.

While we welcome help of all kinds, the following are Kids with Tubes' current areas of specific need:

\* Establishing Kids with Tubes as a non-profit corporation in Massachusetts: do you have legal, corporate, or governmental experience that could help?

\* Clerical and/or editorial responsibility for this newsletter: are you interested in collecting members' stories, working with a desktop publishing program and honing your editorial skills?

\* Publicity: can you help us get the word out about Kids with Tubes, contacting hospital GI departments, private GI clinicians, Early Intervention and other social agencies with our brochure and materials?

If you can help, please send email to [info@kidswithtubes.org](mailto:info@kidswithtubes.org)

## Upcoming Quarterly Seminars

May 6, 2000  
Sensory Integration

July 15, 2000  
Family Picnic

October 21, 2000  
Reflux

Pre-registration is necessary by calling Irene Walborsky (781) 275-0469. A minimum of 8 people must be registered 5 days before program to avoid cancellation.

Dates are subject to change. Refer to the Quarterly Seminar announcements for exact time and place.

### ***Kids with Tubes***

*support for parents and caregivers of tube-fed children*

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