

# FAMILY VOICES of California

**OUR CHILDREN EAT DIFFERENTLY: A  
PARENT'S PERSPECTIVE ON RAISING  
A CHILD WITH A FEEDING TUBE**



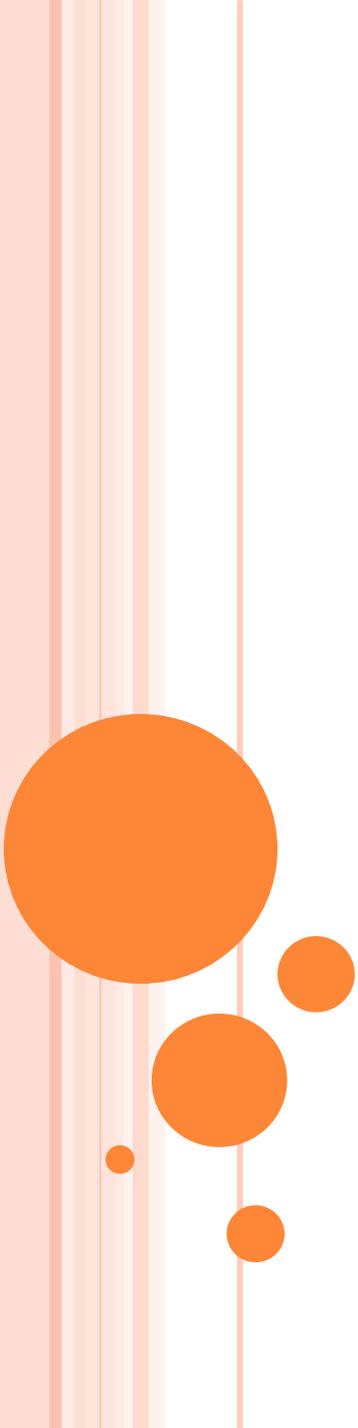
## BEFORE AND AFTER

- On May 22, 2010, I considered myself immune to having a child with health or developmental complications
- I gave birth to a healthy daughter in 2007, and she was a precocious 2.5 year old
- My son Liam was born full-term, 9 lbs 1 oz. after an uneventful labor and birth
- Everything changed on the morning of May 23, 2010, when Liam vomited after every feeding
- At 2 weeks of age, Liam was diagnosed with failure to thrive; G-tube dependent until age 4



# MEET LIAM





**NINE THINGS I WISH I'D KNOWN  
4 YEARS AGO**

# 1. IT WASN'T MY FAULT

- Feeding your child is a parent's most primal, fundamental role
- Being unable to feed my son in the typical ways felt like the ultimate failure
- It took years to understand the medical reasons
- Having a feeding tube was Liam's only option for survival
- His intense oral aversion was a natural response to his experience, and it wasn't our failure



## 2. A FEEDING TUBE CAN FEEL LIKE A BURDEN AND A RELIEF

- No parent would ever choose to use a feeding tube (no, it's not more convenient!)
- Our family experienced fear, grief, sadness, despair, intense loneliness
- It never felt natural to use a feeding tube, but it did feel like a relief
- In the cases where a feeding tube is necessary, it can allow parents the space to evaluate next steps



### 3. NOT ALL FEEDING TUBES ARE THE SAME

Last night with the NG



First day with the G-tube



## 4. IT'S STILL OKAY TO MAKE MISTAKES

What happened	What we learned
NG came out daily for 7 months	We became experts at inserting NG and taping it to Liam's cheek
Set Joey pump at the wrong rate; Liam vomited extra milk	We triple-checked the feeding rate
I took the kids to the park 7 days after G-tube surgery, tube came out, ambulance trip to the ER	I never again forgot that a tube is in my son's stomach
We waited longer than 3 months to change the mic-key button, leading to pain when we did change it-- if you leave the mic-key in longer than 3 months, the balloon can harden	We change the tube every three months without fail



## 5. HOW TO CREATE A SYSTEM THAT WORKS FOR YOUR FAMILY

- Write everything down
- Consider making a schedule
- Do you want to mimic a typical approach to eating (i.e. not look at the clock)?
- Are you giving the same formula each feeding?
- Does the volume of food each feeding?
- Are you giving a water bolus 30 minutes before each feeding?



# LIAM'S TUBE FEEDING SCHEDULE: AGE 2, HOMEMADE BLENDED DIET, 1,500 CAL/DAY

Time	Feeding Volume
7:30 am	2 oz water
8:00 a.m.	4 oz blended formula
9:00 a.m.	2 oz blended formula
10:30 a.m.	2 oz water
11:00 a.m. (before nap)	4 oz blended formula
1:30 p.m.	2 oz water
2:00 p.m. (during or after nap)	4 oz blended formula
3:30 p.m.	2 oz water
4:00 p.m.	2 oz blended formula
5:30 p.m.	2 oz water
6:00 p.m.	4 oz blended formula
8:00 p.m. (while asleep)	2 oz water
8:30 p.m. (while asleep)	2 oz food
10:30 p.m. (while asleep)	2 oz blended formula



## 6. YOU CAN ASSEMBLE A STRONG WELLNESS TEAM FOR YOUR FAMILY

Team may include:

- Gastroenterology team
- Pediatrician/Developmental pediatrician
- Feeding therapist/occupational therapist
- Nutritionist (blended diet or formula)
- Health insurance (public or private)
- Medical supply company
- Social worker
- Child care
- Who will provide the medical home for your child?



## 7. FIND THE RIGHT APPROACH TO FEEDING THERAPY TO WEAN YOUR CHILD FROM THE TUBE

- Different approaches to feeding therapy and tube weaning
- Every family needs to find the approach that is the best fit for them; if it doesn't feel like right to you, keep looking
- Some children benefit from intensive (i.e. daily) feeding therapy
- We had great success with the STAR Center in Denver; comprehensive, sensory-based approach that involved alternating daily OT/feeding therapy for 2 months



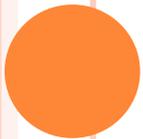
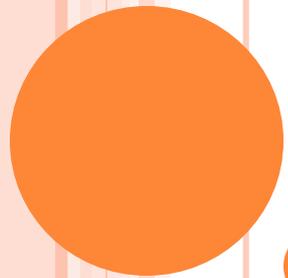
## 8. CELEBRATE YOUR VICTORIES



## 9. YOU DON'T NEED TO DO THIS ALONE

- \*\*\*Feeding Tube Awareness Foundation:  
[www.feedingtubeawareness.org](http://www.feedingtubeawareness.org)
- Family Voices: [www.familyvoicesofca.org](http://www.familyvoicesofca.org)
- Parent support groups/parent mentor groups: ask the GI team if one exists and/or contact your local family resource center
- Listservs and Facebook groups: blenderized diet, feeding tube awareness, pediatric feeding disorders
- Book: Far From the Tree: Parents, Children and the Search for Identity by Andrew Solomon





**QUESTIONS?**