Our Journey as Parents

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Lessons That We Have Learned Along the Way

- Things do not always happen as anyone expects.

- Feel comfortable with the decisions being made.

- Trust your instincts. You know your child in a way that no one else does.
Parenthood

- Life changes
- What will my child be like? Hopes and dreams...
A Child with Special Needs

Will she be smart? Funny? Good at sports? Have lots of friends? Love playing with her brother?

How big will her scar be? Will she need a stoma?

Will she eat? Will she grow?

Is she going to live? Does she know how much we love her?
How It All Began

- Born at 34 weeks with IUGR, BW 1.39 kg/ 3 lbs
- DOL 1—diagnosed with distal ileal atresia
- DOL 4—resection and re-anastomosis
- 2 months in NICU
Recovery?

- 1 week later, readmitted for a cholangiogram to evaluate her jaundice
- In and out of hospital for failure to thrive and malabsorption
Can We Get Our Lives Back?

- At 3 ½ months old – OR for broviac, G-tube, ileostomy
- 1 day later, takeback for ischemic ileostomy and a seizure - majority of bowel necrotic requiring resection and jejunostomy
We’re in Trouble

- Severe liver disease
- Hyperbilirubinemia / Jaundice
- Failure to thrive—2.8 kg/6 lbs
- Short bowel syndrome
  - TPN dependent
Get a Second Opinion

- Medical team’s option: consider transplant
- Take our daughter home knowing she would probably not make it to her first birthday
- Try to get her on Omegaven
  - In LA
  - At Boston Children’s Hospital
  - Looking for miracles
Have No Regrets

- Transferred to Boston Children’s Hospital
- Started on Omegaven
- Spent next ½ year in Boston
Highlights

- Intestine was re-connected
- Over next few months, finally able to cycle TPN to run over 12 hours, not 24 hours
- Walking
- Hope
Bumps Along the Way - 2011

- GJ tube, another prokinetic medication
- Inability to advance enteral feeds
- Decreasing albumin - protein losing enteropathy
- Lack of progress in getting off TPN
Life is the Journey

- Acceptance

- Still on full TPN and Omegaven 7 days a week

- Continuing to advance enteral feeds

- Overall, she’s doing well. She’s happy with never ending energy and nonstop talking.
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Happy 4\textsuperscript{th} Birthday
Special Thank You

- Our extended family— the grandparents

- Omegaven Team at Boston (Dr. Mark Puder and Kathy Gura)

- Dr. Rob Venick and Laurie Reyen at UCLA

- Home health care company, ThriveRx