

Our son's new liver and mended heart: My journey as a parent navigating an overwhelming medical world

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3 P's of Pharmacy: Patient – Prescription - Professional

- Patient – mother of an infant liver transplant recipient
- Prescription – countless transplant medications, as well as other meds through our son's "medical safari"
- Professional – partnership relationship with transplant pharmacy team, as well as extensive medical team

Objectives

- Understand the variety of positive ways a pharmacy team impacted our son's medical journey
- Identify the importance of the patient/pharmacist/pharmacist technician relationship from a patient/family perspective
- Seek to approach patient and patient families as collaborators in the patient's recovery and medical journey
- Seek to approach each patient interaction openly to ensure patients are treated with respect and care, regardless of their race, gender, religion, ethnicity, sexual orientation, or socioeconomic status

Carson's road less travelled - 2001

- Fargo
 - Birth (breest?) – late April
- Minneapolis
 - Heart defect diagnosis – double outlet right ventricle – June 5
 - Liver disease diagnosis – biliary atresia – Kasai surgery – June 19
 - Open heart surgery – October 23
 - Listed on transplant list – November 7
 - Live donor review – November 9 - 15
 - Kidney function decline/dialysis – December 10
 - Hearing loss – mid-December
 - Liver transplant – December 30

Ongoing "frequent flyer" status

- Ear tubes x 2 – 2002 and 2004
- Bilateral hearing aids – 2002 – 2016
- Second open heart surgery (repair subaortic stenosis) – February 1, 2005
- Tonsils and adenoids out – May 2009
- Cholangitis – February 2013
- Annual liver biopsies since 2002
- Cochlear implants – July and October 2016

Adventures post transplant

- Transplant medication classes
- Connected with University of Minnesota/Fairview Transplant Pharmacy



Post transplant initial meds

- Prednisone
- Nystatin
- Celcept
- Bactrim
- Actigall
- Prograf
- Aspirin
- Prilosec
- Ganciclovir
- Vancomycin
- Cefotaxime
- Fentanyl
 - Methadone
- Fluconazole

Curves in the road: Collaborations with pharmacy team

- Shingles
 - Pharmacist reached out to Carson's GI/transplant team
- Prograf
 - Trough level and many, many adjustments
- EBV
- Communication
 - Prograf vs. generic tacrolimus pros/cons
- Countless pharmacists and pharmacy technicians have played a significant role in Carson's recovery and journey.
 - Evidence of our collaborative relationship – we exchange Christmas cards!

Welcome to Holland

- by Emily Perl Kingsley
- <http://www.our-kids.org/Archives/Holland.html>

Questions?
