

# WHAT I WISH I'D KNOWN

TRANSPLANT FAMILIES SHARE WHAT THEY WISH THEY HAD KNOWN  
BEFORE THEIR CHILD UNDERWENT TRANSPLANT SURGERY



- I wish that I would have known that upon a successful transplant, patients would recover and still live productive lives.
- Transplant is a lifelong journey that includes many highs and lows. Trusting the medical team, utilizing available resources, and creating a support system are all essential parts of the roller coaster ride of transplantation.
- I have learned to not be afraid to ask questions. I naturally don't like to bother people. However, we are our children's greatest advocate and it is our responsibility to understand as best we can what is going on. The doctors can't see what we see at home, so I've learned if I'm concerned, reach out. Our transplant team is so good at educating and supporting us throughout our journey. I can't say we were blindsided by anything.
- We were told to do fundraising immediately and we did. That's what kept us going during transplant.
- Take care of the caretaker (that's you!). If you don't take good care of yourself, you cannot take good care of anyone else. Selfcare is not selfish.
- That it was going to take an emotional toll on me, emotionally and physically. I wish I would have known that there was a possibility that I would have to go home with the JP drain and change dressings, it was very traumatic. I wish I would have known that there was a possibility that he would have to go back in for surgery because one of the bile ducts were not draining through properly. I wish I would have known more about what it meant to be intubated, the difference between life support and intubation, that was traumatic because I didn't really understand until after the fact.
- Mental health issues related to surgery and overall health: body image issues related to steroids and scars, risk-taking behaviors, and facing mortality.
- An episode of rejection does not mean the transplant is not going to work. Rejection can be treated easily and then your child will resume their regular monitoring.
- There are lots of follow up visits and blood work during the 1st year. LOTS!
- What resources were available to parents and siblings to help them understand what was happening.
- One of the best tips we got was to continue to require him to do all school and do chores and not allow him to assume the "sick role" (obviously within reason). I believe it has greatly helped his compliance and post-transplant health.

This information should not replace medical advice from your doctors or medical team. We encourage our readers to follow their transplant team's medical advice and reach out to their doctors and medical team for further recommendations.

*This information sheet was created with support from the American Legion Child Welfare Foundation*