

TAKING HOME T-REX

A journey home from the NICU/PICU

TRIAL BY FIRE:
OUR FIRST WEEKEND
AT HOME





BIRTH OF A T-REX

- **Born at 25w5d, 1lb 13oz
Sept 2022**
- **Diagnosed with BPD**
- **PDA closure at Seattle
Children's (7 week stay)**
- **Trach + G-tube Feb 2023**
- **Transferred to PICU June 2023**
- **Home after 332 days! Aug 2023**

GOING HOME! HERE'S YOUR CRASH COURSE IN CRITICAL CARE

- There is literally no amount of information you can give a parent to prepare them to take their Trach/Vent baby home.
- Like having a newborn for the first time again but with impending doom.
- Peer support is crucial... And should be a program everywhere.

FIRST DAYS AT
HOME SWEET
HOME...
AND ALSO A MEDICAL
SUPPLY WAREHOUSE





RUNNING ON CAFFEINE AND DETERMINATION

- So many appointments in the first month home.
- Alarm Fatigue and possibly PTSD
- Leaving the house for the first time
- Trying to reconcile it all

NURSES FINALLY!

There's a Stranger Holding
My Baby...
And I Think I Love Her
(or Him)



GO DIRECTLY TO THE ER

DO NOT PASS GO

THEY WILL ASK TO COLLECT \$200

- Does the ER offer frequent flyer miles?
- ER: Where they look at you like *you're* the doctor.
- Can you manage this at home or do you need to go to the PICU?





LOST: ONE PEDIATRIC SUBSPECIALIST (LAST SEEN 200 MILES AWAY)

- **Monthly Trips to Boise (you can't go it alone)**
- **Waitlists (especially for therapies)**
- **We only have one appointment a year for that test and its at the worst possible day and time**
- **Telehealth is nice... Unless you need to physically examine your patient**

OUTINGS WITH A MEDICALLY COMPLEX KID:
LIKE MOVING, BUT JUST FOR THE AFTERNOON
Also, Eww People!



SOCIALIZING? IN THIS ECONOMY?

- **Medical Parent Loneliness**
- **The impact on the rest of the family**
- **So this is germaphobia...**
- **Medical Staff, your new best friend**
- **The joys of explaining things to the normies**
- **Adjusting to your new normal**

INSURANCE PAID FOR IT—BUT SO DID WE

*Receipts Include: Lost Wages,
Time, Gas Money, Meals, Sanity and
Retrofitting our house.*

IS THIS LADY GOING TO MAKE HER POINT TODAY? (STAY TUNED...)

- Preaching to the Choir
- Streamline and follow-up, don't overwhelm
- Avoid the ER
- People relate best to their peers
- PDN is everything
- We need more...
 - Options
 - Specialists
 - Support
 - Resources
 - Awareness
 - Gift cards for Starbuck and DutchBros

HOME IS WHERE THE HARD CONTINUES
—BUT SO DO THE MIRACLES.

*All the chaos fades when you see your
child do something no one was sure
they'd ever do.*



THANK YOU FOR LISTENING TO ME RAMBLE ~ BOBBI K.