

7/3/2020

# Day 189 HOME\*



1/13/2020

Extubated, orogastric tube breastmilk and human mild fortifier: gastric reaction to HMF; TPN 1.5 wks; second blood transfusion, PDA & ASD - 2 holes detected in her heart

Meds list\*  
Weekly labs  
Bi-weekly paediatric dietician by phone  
1<sup>st</sup> Peds appt  
Neonatal f/u zoom appt  
PDA closure procedure-stollery



12/23/2020

## 1 YEAR OLD!!



### NG tube removed premanently,

Neonatal zoom mtg F/U (next clinic booked Dec/21); ACH Oxygen/Cardiac Clinic; Started purees-gagging 9 0% of time; Physio/ SLP/OT Clinics;

3/14/2021  
restart Reflux meds;  
ACH cardiac/  
Physio/  
SLP/OT clinics



4/28/2021  
ACH Cardiac Clinic;  
Successfully eating solids;  
Physio (zoom);  
SLP/OT clinics

2/15/2021  
**ACH Oxygen clinic-FILE CLOSED!;**  
ACH Cardiac clinic;  
Trying soft textured foods-  
vomiting every 4-5 bites/wanting to cont...  
SLP/OT/ Physio clinics

6/16/2021  
SLP/OT clinic



1/1/2020 2/1/2020 3/1/2020 4/1/2020 5/1/2020 6/1/2020 7/1/2020 8/1/2020 9/1/2020 10/1/2020 11/1/2020 12/1/2020 1/1/2021 2/1/2021 3/1/2021 4/1/2021 5/1/2021 6/1/2021  
12/28/2019 12/28/2019 4/17/2020 8/2/2020 10/27/2020 1/19/2021 5/24/2021 6/16/2021

12/28/2019  
Brooke was born  
24 wks 5 days gest

4/17/2020  
High flow O2; Swallow study OT;  
SSB not acquired; Dx BPD;  
Cardiac distress-ACH for care;  
Dx pulmonary hypertension;  
Feeds 3-4 hrs; Intubated for MRI & CT scan;  
Extubated for breathing support



8/2/2020  
Daily regurges;  
pump feeds;  
attempted bottles;

10/27/2020  
Losec for reflux;  
Assigned SLP/OT-Leth;  
ACH Oxygen/ Cardiac/  
Endocrine Clinic (file closed);  
Referral to outpt dietician;  
SLP/OT/  
Physio clinics

### Off O2; THE FIRST TIME WE HAVE SEEN HER FACE TUBE FREE;

1/19/2021  
ACH Oxygen/  
Cardiac clinic;  
SLP/OT/  
Physio clinics;  
can't with trying purees

5/24/2021  
ACH Cardiac clinic;  
Swallow study (no concerns);  
Referral sent to ACH GI clinic;  
denied and sent to SHC-awaiting contact;  
Physio/SLP/OT clinics

Our frustration and struggles come being unaware of what we needed to do next as many ppl are connecting with us regarding what they think should be a priority



Mixed signals and pressure to reach goals have increased stress- we have no medical experience and are coping with the trauma of NICU and pressures of being new parents



"Dietician had no experience with preemies"



In Nov/20 our family got COVID and NG tube had to be reinserted while ill



"our journey has felt like a game of hopscotch, except the next space only appears in mid-jump and we hope we land on the right space"