# IZIYAH'S BONE MARROW TRANSPLANT DIARY

***- As told by his Mum Danielle***

**6 June-**

Theatre for Double lumen Hickman line today.

Iziyah is to have ambisome infusions into Hickman line over an hour every Monday, Wednesday, and Friday as a prophylactic anti-fungal for the CGD to help protect him against fungal infections. Started on Augmentin for his cough, chest X-ray clear.

**8 June-10 June**

Cough worse and having high fevers. Admitted to starship medical ward on IV Augmentin and his ventolin spacer as cough was quite wheezy. Snot sample taken to check for viruses. Discharged home on the 10th, antibiotics stopped IV and to continue ventolin 4 hourly.

**11 June**

Iziyah had MRI today

**13 June-**

Snot sample positive for RSV virus a respiratory virus. Will resolve itself soon.

Date confirmed of 30 June to get admitted to BMT ward and start conditioning for transplant.

**14 June**

**Meeting with haematology doctor. She was confident that the RSV would have resolved by admission date.**

**They have to tell us the risks etc. and keep making it clear everything that could happen so really starting to hit hard. And we are getting quite anxious.**

**25 June-1 July**

**Admitted to starship with fevers, off food and drink, irritable. Chest X-ray clear started IV Cephtazadime, abdominal ultrasound showed nothing, CT showed nothing. NG tube put down under anaesthetic and started NG feed.**

**They put it down to drug related fevers so have stopped one of the prophylactic antibiotics Co-Trimoxazole (that Iziyah has been on for months) Changed prophylactic to Augmentin. Fevers stopped within 48 hours. Because of fevers transplant deferred until 1 August.**

**11 July**

**Saw haematology doctor, she said donor- from Germany has a different blood group to Iziyah so before he gets the cells will have to go to NZ blood to get red cells depleted (spun out) to minimise complications. New admission date of 22 July and transplant date 1 August.**

**22 July**

Day -9

Admitted to bone marrow transplant ward in afternoon after seeing haematology doctor. First dose of chemo called Busulphan 2 hour infusion through Hickman line in evening. Started anti-nausea medication to help in case Iziyah felt sick.

Bloods taken 4 times overnight to check Busulphan level in blood from Hickman line. Diarrhoea started and nappy rash also.

**Day -8**

Second day of conditioning today having Busulphan again 2 hour infusion and Fludarabine 30 minute infusion. Quite irritable today.

### Day -7

Examination under anaesthetic for eyes today. Iziyah has had visual loss since he was 6 months old, they don't know if related to CGD or a different cause the problem is with the Retina at the back of his eye so glasses can't correct it. But today found out that right eye has no vision left and the left eye is getting much worse. So not the best day today. Started going off food. Busulphan and Fludarabine today.

### Day -6

Feeling sick today and few vomits. Not eating anything so NG feed turned up. Busulphan and Fludarabine today. Developed a cough.

### Day -5

Iziyah feeling sick all the time, not eating anything. Few vomits. Pentamadine 1 hour infusion preventative antibiotic given through IV 4 weekly. Just Fludarabine today.

### Day -4

Bottom very sore and starting to break down from the diarrhoea, given cream to use. Few vomits. Feeling sick. Fludarabinetoday.

### Day -3

6 hour infusion of ATG today, given antihistamines and steroid to decrease reaction to the ATG. ATG to prepare. Prepares immune system for transplant to kill off last cells.

He reacted to the ATG just by having a fever and needing oxygen as his saturation dropped to 90%

## Day -2

ATG over 6 hours again today. Given antihistamines before and during. Cough worse today. Iziyah sore today and started on regular tramadol and Pamol. Fever with the ATG again. Pain team charted morphine as needed through IV.

## Day -1

ATG over 6 hours again. Cough worse and miserable today. Getting morphine pump so can have a continuous rate constantly through IV and a bolus as needed. Potassium low today so given medication for that. Cyclosporin started today, an immunosuppressant to prevent graft rejection given IV twice a day.

## 1 August - Day 0

## Transplant day!

Needed blood transfusion today as haemoglobin was 79 (need transfusion when less than 80). Few more vomits today, NG tube came out so needed new one in. Never nice, but needs to go back in unfortunately.

Donor bone marrow arrived from Germany in the morning then sent to NZ Blood bank to spin off the red blood cells as the donor was a different blood group to Iziyah so needed to remove red blood cells to avoid complications. Arrived to starship from NZ blood at 5pm, and the 120mls of donated bone marrow infused though Hickman line at 50 ml/hr.

Infusion went fine, no reactions. Still needing morphine sore in throat, mucositis starting. Cyclosporine twice daily.

## Day +1

**(2 August)**

**Lost appetite completely. Sore when coughing and still coughing a lot. Every Friday Iziyah will get immunoglobulin through Hickman line, so they started today. Also methotrexate a low dose chemo to kill T Cells in the body given though Hickman line on day +1 +3 +6 +11. Mouth starting to break down. High blood pressure so medicine for that. Few vomits.**

**Day +2**

**A lot of Diarrhoea today, still coughing. Bottom still broken down and sore, no appetite at all anymore and mouth so sore gums swollen so not drinking either. Vomit twice. Morphine rate put up as in pain with the mucositis which is expected to get worse.**

**Day +3**

**Methotrexate again through Hickman line. Sore throat and mouth broken down. Morphine increased again. Couple of vomits, vomited NG tube out so had to get new one down. Diarrhoea on-going. Cough worse.**

**Day +4**

**Ambisome restarted as anti-fungal prophylactic cover. NG tube vomited out at 9pm last night so new one down this morning. Just lying in bed today and sore. Turned NG feed rate to 10ml/hr to see if helps with vomiting. Fevers started today so Given antibiotics just in case infection somewhere.**

### Day +5

NG feed at 20 ml/hr. morphine increased again and added ketamine another pain drug through line. Cough worse. Slept most of day waking up coughing in between. On regular Pamol, tramadol, morphine, ketamine. Not talking as mouth and throat too sore. Just nods or shakes head for yes and no. normally Iziyah talks a lot and is very bright so it's hard to see him like this. Started vancomycin antibiotic as still having fevers.

### Day +6

Methotrexate through Hickman. Needed platelet infusion today as they were only 15. Still in pain, fevers on-going as well as cough and sore mouth and throat. Morphine increased again. Slept most of day again.

### Day +7

Regular meds. Terrible overnight woke many times in pain, morphine increased again. Fevers on-going. Coughing a lot. Not wanting dummy in mouth anymore just holding in hand- Iziyah loves his dummy so to see this I know he's not right. Chest X-ray done because of cough, was clear. Slept most of day again.

### Day +8

Immunoglobulin every Friday and regular meds. GCSF started to stimulate new neutrophils. White blood cells at 0.22 so doctors not sure why, could be real but will wait and see. Still having fevers, NG feed up to 28 ml/hr. 1 vomit which had blood spots in it. will keep an eye on it.

**Day +9**

Urine sample sent as there was blood in urine. Need platelet transfusion today. Started getting a raised rash, itching, high heart rate reaction to one of drugs. Given antihistamine and hydrocortisone. Stopped itching within an hour.

**Day +10**

(11 August)

Rough night, unsettled, rash again 1am all over body, high heart rate (185 bpm) Top lip swollen so doctor review and gave him adrenaline injection into thigh and antihistamine and hydrocortisone into line. Anaphylactic reaction to the vancomycin started 5 days ago. So vancomycin stopped. Had two more rashes in day. Still got blood in urine.

**Day +11**

Methotrexate last dose today. Oxygen dropped overnight to 88% given ventolin inhaler, and picked up to 95%. Think it could be mucous from mucositis affecting airway. Still peeing blood. Waiting for virus test to come back. White blood cell count still slowly coming up. Slightly better in himself today. Not wanting to eat/ drink, but sitting up and listening to stories etc. Platelets today. NG feed at 30ml/hr. No rash today.

**Day +12**

We have neutrophils today (1.09) which means he isn't neutropenic anymore! This is very unusual especially as Iziyah had an unrelated donor. Doctors are surprised. Red blood cells stayed up as well as platelets which is also strange but docs are happy. We were even able to go for little play in play room today! Bladder ultrasound today to check if any cause for bleeding, bladder wall was thicker than normal, could be virus. NG feed at 35ml/hr. complaining of pain when peeing and straining.

**Day +13**

Woke in night in pain. Still straining and sore when peeing. Blood in urine as well as small blood clots today. NG feed at 39ml/hr. play room again today. Changed morphine to fentanyl, faster acting drug so will help quicker when passing the clots. Iziyah's low vision teacher started coming once a week now, so nice to see her. Diarrhoea still going.

**Day +14**

Woke many times in pain overnight. Put a background rate of the fentanyl through line instead of just the button push. Play room for an hour today, sore when peeing and bottom breaking down again. Vomit couple of times. Platelets today. NG feed 40ml/hr.

**Day +15**

IVIG today (every Friday). Diarrhoea and vomiting several times today. Play room 1 hour. NG feed at 43 ml/hr. still peeing blood clots. One virus test came back negative, waiting for other one. Neutrophils at 2.6 and white blood cells at 4.0

**Day +16**

**Sore bottom from diarrhoea. BK Virus came back positive, which is causing the clots and blood in urine. Started ciprofloxacin antiviral for 14 days, to treat that. Couple of mucousy vomits. Blood counts still going up.**

### Day +17

**Vomited 4 times overnight as well as waking up other times in pain. Diarrhoea still going in day as well as vomits. Peeing and straining often still with clots. NG feed 46 ml/hr. Renal function (kidneys) high today will keep an eye on it.**

### Day +18

**Renal function still high today, may be due to cyclosporin levels (anti-rejection drug) so waiting for that level to come back then they will assess the dose if it needs to be lowered. Given extra fluids through line to try and flush out the clots- didn't make a difference. Stopped the GCSF today.**

### Day +19

**Couple of vomits and diarrhoea, sore bottom and getting broken in patches. Renal function better today. Cyclosporin levels okay. Still peeing blood clots. Play room for an hour.**

**Day +20**

(21 August)

3 vomits in the night. Had to do fingerprick at 5am to check cyclosporin levels, as the nurse took from wrong hickman line and number was wrong :( No vomits during the day. Play room for a bit. Are thinking of changing some of medication to oral in next couple of days. NG feed at 50ml/hr.

**Day +21**

Few vomits, will keep meds IV for now. Still peeing clots and in pain. Getting nauseous at times, could be medication for bk virus. NG feed down to 35 ml/hr because of vomiting. Started anti spasm medication to see if it helps with peeing.

**Day + 22**

Vomited twice over night. Vomited NG tube out in morning new one down. Diarrhoea and clots still the same. Play room an hour. Changed few meds to oral today, NG tube came out again at midday, so had to get new one again :(

**Trying coconut oil on bottom- as recommended by another mum with same problem, apparently works wonders.**

**15 October Day +75**

CT of chest under general anaesthetic today

**+77**

CT results showed Bibasal Bronchiectasis which means an irreversible dilation of the bronchi. Gunk gathers in the dilated areas which means he will always be prone to chest infections. They don't know how it happened but may be as a result of the CGD.

**+78**

Bronchoscopy and ear nose and throat review under GA today. Respiratory Dr sucked out secretions and took photos of bronchi. Said there is a lot of thick green/ grey gunk all through lungs. sent a sample to test for virus/ bacteria. discharged home after 3 hours observation.

**+79**

chest pain overnight, expected from bronchoscopy. chest wheezy today. eating a little bit.

**+80**

had a little outing, was a wonderful day.

**21 October +81**

see Dr at starship today. Lung sample positive for rhino virus, no treatment as its a virus. Met physio and learnt how to do the chest pats to help iziyahs lungs to loosen up the gunk and not just sit in the bronchi. Saw dietician too, weight is good 15.2kg so wants to see if he can maintain it by himself. Can be off feed for 10 hours a day.

**+82-+86**

Average few days, pamol and tramadol as needed. Still having back pain at random times. Unknown cause.

**+87**

Not eating today, NG feed on all day.

**+88-+90**

Keep on feed when not eating. Cough.

3 MONTHS POST TRANSPLANT

**+91-+97**

No tramadol needed. Snacking again :)

**+98 +99**

Couple of random vomits. Feeling nauseous. Not eating. Sore back.

**+100-+102**

Average couple of days.

**+103**

Greenlane to see Dr Carroll, iziyahs eye Dr. Says eyes look the same as last time. No vision in Right eye, small tunnel of vision in left. plan to do examination under anaesthetic (EUA) January

**+104-+107**

## Good days :)

**+108-+116**
Not feeling well. Sore throat, grumpy, regular pamol, not eating- 24 hour NG feed.

**Seen Dr +109**
NPA (snot sample) taken and sent away to test for viruses.

**+116**
NPA results positive for adenovirus, have to ride it out, no treatment.

**+117-+122**
Not eating much, called clinic- advised to put water boluses down NG tube to avoid dehydration.

## 4 MONTHS POST TRANSPLANT

1 December +122
Fire truck day at Leukaemia and Blood Foundation. Fantastic Day.

+124
See Dr. Weight good bloods stable.

+125- +131
Cough ongoing. Couple of random vomits. Not feeling 100%. Fever 38.3

+132
Chest Xray- start amoxycillin 8ml three times a day for 10 days to cover iziyah just in case an infection is starting.

+133
Plan was to have Double Lumen Hickman line out today, but was postponed due to iziyahs chest being unstable for Anaesthetic, they cant take any risks with the bronchiectasis.

+134-+135

**Not right, chesty, not feeling well. Random vomits, not eating.**

**+144**

**See Dr at starship. Could be graft vs host disease (GVHD) of gut. Weight down to 12.8kg today. Start steroids in case it is GVHD. No way of telling except a biopsy but not going to do that unless steroids don't resolve the problem. Chest better with antibiotics. Had monthly Pentamadine (antibiotic) 1 hour IV infusion today as well.**

**25-28 December +145-+148**

**Lovely quiet few days over Christmas with close family and friends. Visited our wonderful friend Lisa and family up on ward 27B on Christmas Day :)**

**+149-+153**
**IDFNZ holiday home at Red Beach for 4 nights. A wonderful get-a-away.**

## 5 MONTHS POST TRANSPLANT

**1 January 2014**
**Sore back today.**

**6 Jan**
**See Dr at starship. Advised to stay away from children who are not immunised as since BMT iziyahs immunisations he had have all been wiped. New NG tube down, Kaylee pulled out.**

**7-12 Jan**
**Okay few days. Random back pain ongoing.**

**13 Jan**
**See Dr today. Bloods good. Steriod decreased to 1ml a day.**

**14-19 Jan**
**Okay.**

**20 Jan**
**See Dr. Bloods in same range as last week. Hickman removal planned for 4 Feb.**

**21-27 Jan**
**Good week.**

**28 Jan**
**See Dr, bloods in same range, Monthly IV pentamadine.**

**29 Jan- 1 Feb**
**Okay.**

## 6 MONTHS POST TRANSPLANT

**4 Feb**
**Double Lumen Hickman Line removal today under General Anaesthetic with Eye Dr coming from greenlane to do examination of iziyahs eyes at the same time under GA.**

**6-10 Feb**
**IDFNZ Mangawhai Holiday Home. What a perfect spot. None of us had been to mangawhai before so was fantastic all the sightseeing and visiting local attractions like the chocolate factory and local weekend markets.**

**10 Feb**

**Home today, Iziyah had his first swim in the pool since last year as he has had hickman line. Got cold and shaky after couple of minutes because hes so skinny, but he enjoyed in so much. Just the little things like being able to get all wet in the bath now, not having to be careful not to get dressing wet has been amazing for him :)**

**11-13 Feb**

**Good couple of days. Iziyah is now officially legally blind as he only has a tiny amount of vision left in his left eye, so we have been referred to the Royal New Zealand Foundation of the Blind. The ladies that are handling iziyah are absolutely wonderful.**

**14 Feb**

**See Dr at starship today. Cyclosporin (anti-rejection medication) reduced so is now 0.3ml twice a day. Steriod also decreased and stopped in a weeks time.**

**15 Feb-28 Feb**

**Pretty good days. Starting to visit family more often now (as long as they are well) and doing more "normal" things like shopping and going to the mall etc. Still not having much contact with children though due to the measles risk. Kaylee (iziyahs sister) had her measles immunisation a month early in order not to be a risk to iziyah.**

## 7 MONTHS POST TRANSPLANT

**2 march**

**Porshe day out at BLENNZ Homai Campus. A fantastic day run by the Blind and Low Vision Network out at Homai. 30-40 Porshe Club members drove their cars over to allow all the children to have a ride in the cars. An amazing experience for Iziyah.**

**3 March**

**Iziyahs 3rd Birthday!**

**Blind Foundation organised a trip to the Auckland City Fire Station on Pitt Street. Iziyah had so much fun feeling the tyres, sat in and pretended to drive all 3 fire engines, and we even got to go for a ride around the block. Awesome!**

**4 March**

**Dr at starship today. weight 13.4kg, bloods in same range which is great.**

**5-16 March**

**Okay :)**

**17-18 march**

**Not feeling right today, slept majority of day.**

**19-23 March**

**Okay**

**24 March**

**Vomited NG tube out**

**25 March**

**Dr at starship. Bloods in same range. Seen dietician too, changed NG Feed to normal Nutrini rather than the High energy one. New feeding plan. Weight down by 400g.**

**26 March**

**Back to starship today for monthly pentamadine, because he doesn't have hickman line anymore, had to get IV line in hand. Went ok as we put numbing cream on so it didn't bother him too much.**

**27-28 March**

**Still just not quite himself, but seems to be snacking a bit more.**