Hannah's story and BMT Transplant Journey – *Told by Mum Lisa*

Hannah was a normal baby, toddler, and child until May 1st 2010 at 9 1/2 years old, when she started a cough that doctors thought was viral.

She then became sicker, lost weight became extremely tired and was still coughing. After a CT scan doctors took us to a room and told us she had lymphoma/leukaemia. We were on the next flight from Invercargill to Christchurch, This put our lives in turmoil, having to pack up last minute and leave our other 2 children aged 8, 13 with grandparents, sort out the house, pets, bills etc.

On admission to Christchurch hospital which ended up 38 days of tests , her diagnoses went from cancer, to more tests to tell us it wasn't cancer, then to be told it was some rare immune disease called CVID!

We were told all about it which was like so much information and complicated but basically that she will require 3 weekly IVIG transfusion done in hospital for the rest of her life, so flying back home to Invercargill we thought we could cope with that diagnoses.

Well the rest of Hannah's journey I would need to write a book, it was a mixed bag and extremely complicated. Only 2 months after being home she ended up getting sicker and we got transferred to the paediatric immunology team in Auckland Starship. From there the next 2 1/2 years we made at least another dozen trips. With issues with lungs, liver, spleen, platelets, haemoglobin, pain in limbs, eyes, sinuses, gut, bowels, oesophagus etc. Hannah's had 12 surgical procedures from lung biopsy's, bronchoscopy, and colonoscopy. She was re tested for many other diseases; there was even a meeting which included overseas doctors who consulted about Hannah.

Hannah has spent most of her time at home or in hospital, having 3 weekly immunoglobulin's (she did try sub cut (SCIG) at home but didn't work out). Plus many other medications and treatments even blood transfusions, and platelets. Ng feeding tube has been in for nearly 2 years. Life in simple terms was rough.

Finally September 2012 after another lot of haemolysis the immunology team discussed bone marrow transplant. It was a big option but last resort due to the complications and severity of Hannah's extremely rare immune condition (they say there no one else in NZ or Australasia is like Hannah, she's one of a kind).

In a very lengthy process, we found out Emma her sister was a perfect sibling match. Dates were set for transplant for May 2013 but Hannah's lungs after CT scan showed they were too sick to start chemo, so more treatment was started. June 26 we packed up over 100kg of luggage ready for the transplant journey, - as you will read below it's been a roller coaster ride!

Our hope is than in a years' time she will be cured. (June 2013)

Hannah's Transplant Journey 2013

Hannah opening a much loved
Cheer gift from her Aunty

DAY 1 arrive in Starship 26th June

Didn't sleep much last night, up 5am, can't believe we are packed ,6 large suitcases, (10 kg of that craft stuff), heading to another city no family no friends, leaving our daughter in the hands of many doctors, it all feels like a dream I can't believe this is happening to us. It's been a long wait but the journey is about to begin.
5 hour trip, then settled in Ronald mc Donald house.

Meeting with doctor to be given the day by day plan for the month of July, Wow!
Surgery tomorrow to have double Hickman line put in.

DAY 2:

Hickman line put in Hannah was in theatre an hour, she woke up very sore. Recovery day stay ward for 4 hours, then back to Ronald McDonald house. Hickman line a lot more involved than we thought she was extremely bruised, wee cut in the neck being the most painful she said.

DAY 3:

Up to hospital for dressing change, sinuses suctioned to test for infection, blood tests done. Cut in the neck she is finding very sore.

Made some meals at Ronald McDonald house to put in freezer.

DAY's 4/5/6

At Ronald McDonald house.
Cruisy days, made more meals, popped to Newmarket and got some kitchen utensils, and a clothes horse so we can hang washing in room at Ronald McDonald house.
Finding it hard when we are talking to other families and we say our daughters having BMT, they ask "what cancer has she got", and we say "it's not cancer but a very rare combined immune deficiency". People look at us like... what's that?

DAY 7:

Packed up suitcases to be at ward 3.30pm, admitted to bone marrow unit. For some reason I was very nervous. Hannah put on IV fluids, then pre-meds before starting Campath drug tomorrow

DAY 8:

Campath started, reacted with high temperature, headache, heart rate 172 Bpm.
Took more bloods checking for infection, potassium low so had tablets.

DAY 9:

Dose 2 Campath reacted with big raised itchy spots. Hannah not happy.
Did crafts today, had health school in. Seen dietician.

DAY 10:

Dose 3 Campath, today reaction with cup size welts, added ranitidine to the already antihistamines she's been having since day 1 of Campath. Also she needs furosemide to help with fluid retention. Potassium low again.

Decorated Hannah's room.

DAY 11:

Last dose Campath, slight less reaction with just spots on legs, feet, neck; potassium low again. I'm Feeling tired already.

DAY 12-19,

Because Hannah's immune system more vulnerable due to having Campath she's to stay in BMT unit, chemo not to start until day 17th July. So basically just filling in the days.
Monday/Wednesday/Fridays having drug called Ambisome. Hannah gained a cough but x-rayed showed nothing to worry about. Steroids being weaned off and replaced with Cyclosporine.
Did a lot of craft stuff so the 10 kg of craft stuff was an essential asset we brought up....
Hannah's Hickman line decided not to work, so nurse put special medicine in it and left overnight. But still a no go, so going to X-ray. We found out its curled inside her so theatre on Monday to have another one put in We were devastated her having to go through that again.

DAY 20:

Theatre, surgeon not sure how he's going to fix as this has never happened to any other child before, that's our Hannah one of a kind.
Had meeting with her haematology doctor, and signed forms etc. and the mention of the chance of death rare but had to be mentioned, so it really hit home what was about to happen.

There were a few tears. Really missing home already was a week ago! To think we have weeks to go.

DAY 21:16th July

The most sleep I've had since we've been in unit even though I was still awake 4-5 times.
Doctors told us Hannah has CMV virus in her blood so on twice daily Ganciclivor.

DAY 22: first day chemo

Feeling very anxious about what to Expect with chemo, Hannah looked very scared, and at the same time chemo was started the hat ladies came with selections of hats etc. that Hannah can choose for when she loses her hair, but she wasn't keen on any she's going to wait until hair comes out. Chemo Fludarabine all done in an hour. Feltscary real that our daughters just had chemo, but all went fine no problems.

DAY 23:

Dyed Hannah's hair pink today that was fun. Chemo went fine.
On anti-nausea meds.

Day 24:

Really missing home even the cat, so quite teary today.
Hannah's lungs crackly so organised chest X-ray which showed no additional problems.
Tea time Hannah went quiet and ate nothing.
Had 21gms IVIG today and this happens now every Friday.

DAY 25:

Hannah's appetite nearly nothing now and she's quiet and fell asleep.
Alastair went grocery shopping at Newmarket.
Emma (our other daughter who is donating the Bone marrow) is very excited as she fly's up on Monday to visit with my Mum for transplant day on Wednesday.

DAY 26:

Chemo again, Hannah not really eating. Put on 158 mls per hour IV fluids from 8pm protocol before a different chemo she is to have tomorrow.

DAY 27:

Chemo hits.
Diarrhoea started today, she ate and drank nothing at all Day.
Chemo called Melphalan one dose given today.
Mum and Emma arrived tea time, lots tears. And lots presents for Hannah.

DAY 28:

Rest day today no chemo.
Low day today, vomited feeding tube out 1am, still has diarrhoea.
Having more medications and added anti- nausea. Emma had a doctors check before transplant, we found out they are taking more marrow from her as she weighs heavier so now taking 840mls, wow it seems a lot. I signed more consent forms.

DAY 29:

Transplant day.

The big day, awake super early, how am I going to split myself between the 2 girls today?

Hannah very sick, diarrhoea and vomiting, up all night. Eating and drinking nothing and fast losing weight.

Alastair had Emma up at day stay. When she was called to theatre 8.30 am mum sat with Hannah while I went down to theatre. Hannah slept a lot this morning. We went up and waited with Hannah while Emma was in theatre.

Then we were called to recovery, at the same time marrow was still warm was taken up to Hannah, I missed Hannah holding Emma's marrow but mum got pictures and quick video, I was up there in time to see it being started.
Alastair stayed with Emma the whole time I ran back and forward doing short video clips and taking pictures.

It was such a long day. Emma was put on IV fluids due to the amount of marrow taken. Then she got quite dizzy when being checked before being discharged this scared me.

Was a very long awaited emotional day to be over and done just like that. I was totally exhausted.

Hannah holding the precious Bone marrow from Sister Emma.

DAY 30: + 1 transplant

Very, very rough night. Hannah had diarrhoea every hour (suspect mucositis) in between that it was alarms on the monitors, nurse coming in etc.
Medications today was wow a big list. I'm trying to keep a separate list of them in notebook and what each drug is for. Hannah on 40mls per hour of ng feeds.

Hannah not speaking at all today, sad and slept a lot. Vomited everywhere tea time and ng tube came out, so new one had to go back in.
Emma pale, tired but ok.

DAY 31

Rough night again. Hannah's mouth white yucky, vomited again but ng tube stayed in. Up all day with diarrhoea.

She's not talking and very unhappy. This is hard to watch as a parent.

I am so pleased to have Alastair (husband) here for the whole journey I couldn't do this by myself and he wouldn't be anywhere else but with his daughter.

DAY 32

Today I'm soooo tired!!! Rough night, up half hourly.
Found out tests show she has CMV virus plus adenovirus which is causing diarrhoea and that there is nothing they can do until it has to run its course, while we await signs of engraftment, but added more strong antibiotics. Vomited again despite changing anti - nausea meds.

DAY 33

Pain in tummy worse today, put her on Tramadol. Vomited 3 times today.

Mum and Emma left to fly home, Emma very upset!! This made the rest of day very emotional for us all.

Hannah high temp, and heart rate this evening, doctor treated her for dehydration, plus started 2 broad spectrum antibiotics urgently. Night nurse stopped her ng feeds because she just keeps pooing. I'm feeling something's not right.

DAY 34

Didn't think things could get worse but doctor called in at 5am due to worse tummy pain and very low blood pressure. Gave her potassium IV, Albumex transfusions x2. Pain team came and set up Oxycodene pain pump in the morning.Not a happy day it's emotional and hard watching your daughter go through this.

DAY 35

Weight going up they think fluid retention. I'm not well glands up and I so can't get sick so took hi dose Echinacea and vitamin c.
Very excited IDFNZ paid for one of the kids to come up in 3 weeks, missing them a lot haven't seen our son since we left home. Hannah in a lot pain and still got constant diarrhoea....

DAY 36

Still long nights up hourly with diarrhoea still, 2am high temp and heart rate.
Big day for drugs here goes: Amikacin, Timentin, Ganciclivor, Cyclosporine, Platelets. Bus Copan, Oxycodene and ketamine, Magnesium, IV fluid, Albumex and Cidofovir. She's on 5 pumps on her pole now.

Has the worst tummy pain which concerns me as she has a high pain tolerance. Doctor confirmed Adenovirus in blood and that's not good.

Things tonight not good doctor came to review Hannah then said he would consult another doctor, next minute picu doctor came down just as a precaution if she needed moved to picu it would be a planned moved not an emergency.
I was scared now and hoped she didn't get worse during the night.

DAY 37

Hannah's hair starting to fall out.

The worst day and night Hannah not sleeping more than half hour, she's not right she's like hallucinating but sort of going into deep sleep within seconds then hearing people she knows and thinks we speaking to her. Her eyes very red and small. She's very puffy 3 kg extra weight.

Doctor came and explained the current issues with Hannah, and organised urgent ultra sound in tummy. And they think hallucinating is due to delayed reaction to a drug. A full day of doctors, even eye doctor, and pain team.They removed ketamine this in case it was that causing weird dreams.
Burning feet and hands (sign of engraftment)

DAY 38: WORST DAY

CHAOS DAY, lots happened!!!

Pain severe 10/10 on the pain scale, long night got no sleep just a couple nana naps.
High heart rate, temp. Ultra sound and X-ray done in morning, then urgent CT scan on brain, chest, and tummy they wanted to check meds weren't affecting her brain. I was really scared today Hannah was so ill!!

Scan of brain was fine, but tummy/bowel showed NEC disease and it was serious. So ng tube that had to be pulled out for scan had to go back in and put on free drainage. And no feeds at all, only sip of water for the next week!!

New antibiotics started, Fentanyl pain pump added. Gave Platelets urgently due to blood in poo.

11.20 pm doctor called up due to low blood pressure, oxygen stats. Put on oxygen, gave Furesamide due to possible overload of fluids maybe in lungs, gave extra IV fluids, and Albumex.

There were concerns blood tests showed an infection in Hickman so if new antibiotics don't work in morning there's a possibility of new line having to go in.

Today was so scary what else could go wrong? Hannah beyond miserable it's the most horrid thing to watch your child like this.

DAY 39: + 10

Platelets again this morning, Hannah looking terrible eyes glassy/yellow and squinty.
Hair coming out in bigger clumps she just wanted me to keep brushing it out, she's not happy. Doctor said this is the sickest Hannah can be besides intensive care and to hope cells start showing soon.
Worst part of today was after tea Hannah's hair was coming out really bad she just wanted me to take it all off, a nurse gave me clippers and scissors it was indescribable but I stayed strong as she cried as I cut what was left of her hair off with scissors then doing a number 8 with the clippers. Hannah cried for over an hour hubby and I had many tears too.

DAY 40:

I found a hairdresser in Auckland who came out free of charge and did a number 1 on Hannah's hair couldn't do blade cut due to risk of cutting and bleeding as she's got basically got no Platelets.

Hannah very sad and quiet all day. Still up hourly day and night too loo this is exhausting, by the time you plug all the power cords to all pumps, help Hannah out of bed to go to loo, get her back to bed plug everything back in then put pan in sluice room.

The reality of Hannah losing her hair was worse than she thought.
Transplant journey part 3

DAY 41: + 12

Once again rough night, needed potassium at midnight levels the lowest yet, getting no sleep at all, nothing prepares you for the sleep deprivation! Hannah looks really terrible and very sleepy.

Showered Hannah that was hard work she was freezing and shaking hard out the due to having fever.
Hannah gets make a wish tomorrow so very excited she needs something nice to happen.

DAY 42:

Wow had 34 days in the bone marrow unit, extremely rough night up half hourly, some 1 hourly, pooing blood this morning from 2am scary, gave 2 units platelets this morning. Hannah's temp in the 39's heart rate 150 Bpm something's not right, I've learnt through this experience us mums know when something's not right so I always stick to that gut instinct. Every pan we took out was black the nurse said its blood this is scary and we were told not a good sign. Surgeons came to see Hannah this in case of an emergency. We were sat down and told why Hannah was pooing blood that she's been pooing out her bowel lining a lot recently and now it's raw and bleeding!!!! And that she's a sick little girl.
MAKE A WISH CAME, this was so exciting Hannah was so surprised with her gifts it put tears in our eyes seeing her smile for a bit.
Hannah had IV line put in that didn't go well took 2 tries.

Night was long!! This is an example of our night of toilet trips not including doctors, nurses and pumps going off:
8.40pm, 10.30pm, 11.30pm, 12.15am, 1.30am, 2.10am, 3.15am, 4.25am, 6am, and 7.15am.
High temps and heart rate 170bpm during night

Hannah attached to her many pumps

DAY 43: + 14

Highest temp yet 40.5! Another busy day, totally lost track of the amount of drugs , she now has 7 pumps on her pole nurses said that's the most they've had and usually in intensive care or on a little kid who stays in bed and they can split pumps on 2 poles. Hannah very sleepy this afternoon.

DAY 44:

Hannah a little bit brighter today and up only 7 times in night.
Had platelets and red cells today. Plus all the other drugs, in my note book we are up to 35 different drugs/transfusions but not all in one day that's since day we've been here.
All the little bits of her number 1 haircut have now fallen out.

DAY 45: + 16

No signs of engraftment at all. Still got fever on and off. 2 unit's platelets.
Got the go ahead from tummy doctor she can eat selective range of foods. So she tried de crusted piece of toast ate only 1/3.
Missing home today even my pussy cat.

DAY 46:

Today I was so stressed, and exhausted I've done 37 nights in unit it was time to do a night swap tonight with hubby.
Hannah not good today, high fevers on and off she slept all avo except waking to go to loo. Hannah didn't eat anything and vomited at 6pm.
I went back to Ronald McDonald house at 7pm I felt guilty leaving Hannah but knew I needed time out and a night to sleep.

DAY 47:

I wish I could have slept all night but did get 4 hours straight which is more than I've had for weeks.
Hannah tried a bit of apple and a few squares of pears, on 5mls per hour of ng feeds.
Hannah slept on and off.

DAY 48: + 18

Bad night up 10 times!! WBC is showing signs 0.55; increasing ng feeds 1ml every 12 hours. IV line in arm removed.
Hannah's slept on and off, had nose bleed.
Platelets again today. Hannah had mouthful lemonade then vomited half an hour later.

DAY 49: ENGRAFTMENT TODAY!!!!!

Hannah has neutrophils 0.69 and WBC 0.85, they were getting worried a few days ago and said if no signs by +24 then we in trouble.
Same night but Hannah's tummy sorer, 5 am nose bleed.
Hannah vomited mid-morning in a lot pain despite being on pain pumps fentanyl and ketamine.

4 more small nose bleeds, gave platelets.Vomited again tea time.I went out for walk today it was nice to get fresh air.

Hannah with her make a wish life size teddy bear

DAY 50:

Vomited on and off all day, high temps. CMV bloods results show still high.
Hannah sleeping on and off this is not like her.

On an exciting note our 2 kids arrived up this afternoon thanks to IDFNZ for contributing to the flights. Hannah got presents and it was nice to see her happy for a bit even though she vomited minutes after they walked in.
Hannah's tummy very sore

DAY 51: + 22

Same sort of night maybe up couple times less. Hannah just sleeping and waking for loo, to vomit, or to push pain button. It's quite hard with kids being here to see her like this.
Ng feeds up to 6mls per hour.
Doctors say CMV virus levels still up so consulting with infectious disease team and still awaiting adenovirus results. But starting new drug and stopping others.
Alastair took kids up sky tower
Neutrophils and WBC levels up a bit more yeah

DAY 52:

Hannah still vomiting and sleeping on and off I'm getting concerned. High temps still a big day for drugs today so didn't fit her Friday IVIG so doing that tomorrow.
Had platelets and red cells.
I took kids to Newmarket for lunch and a bit of shopping was lovely to spend time with them.

DAY 53: + 24

Much the same vomiting, sleeping, loo, pushing pain button. She's not even playing on her devices so I'm getting really worried; it's been a week of this.
Kids left mid-morning its hard saying goodbye.
I'm tired but surprised at my inner strength that keeps me going

DAY 54:

Yes another day of vomiting, sleeping. Gave potassium again levels low, and furosemide due to holding onto fluid. Today she seems very sad she doesn't even want to brush her teeth my concerns are growing. Doctor's main concern is the CMV and ADENOVIRUS. With all the vomiting they may change her ng tube to Nj.
Few issues with low potassium again later in evening doctor came in at 11pm so gave more potassium.

DAY 55: + 26

Long long day again, vomiting more, very pale and not happy!! Did X-ray to see if the ng tube had been pushed in enough to change it from the ng to a Nj tube they are hoping this will eliminate vomiting.
Pain doctors changed fentanyl pain pump to oxycodene as she's going through a lot of fentanyl also not working and pain worse.
Doctor called due to blood in poo again so they gave her more platelets.
I've got that something not right feeling with Hannah.

DAY 56:

Things changed today 2 early morning vomits were bright yellow, (not good) so night nurse changed her ng feed rate down. Ng tube down further but not in Nj position so just leaving it. Put her tube on free drainage and no feeds. But still getting TPN (IV feeds).Vomit the same at 8am (yellow) so new concerns there may be a blockage. X-ray done. Then we seem to wait all day for surgeon to see her.

Doctor kept coming in and checking her though.
I'm concerned!!

DAY 57:

Big day lots of information to take in. Night ok up less but still getting up. Vomiting still but nothing left to vomit.
Ct scan done at 1pm, IV line had to be put in and left in due to all the meds she needed an extra line. Then we had a meeting with results, scan shows tummy/bowels still very sick they said due to the adenovirus and CMV she's had for a few weeks, despite drugs given nothing is changing. They want to now biopsy bowel to check it's not GVHD that's causing problems too as new treatment would be different depending what they find. Because her new cells take time to make the T cells that she urgently needs to attack these viruses they have sourced from Australia some cytotoxic T cells engineered specifically in lab to target the adenovirus and CMV virus. So Hannah will be the FIRST IN NZ to receive these so quite exciting, but scary at the same time. And wouldn't arrive till next week. They need to act now before viruses travel to vital organs.
Also told we will be here for a lot longer!!!!
Theatre tomorrow. It's so not fair Hannah's seems to never get a break from something going wrong.

Transplant part 4

DAY 58: + 29

Rough night pain seems worse. How much pain can one wee person take?.

Poor Hannah did not want to go back to theatre she hates it. She cried and was very upset as they put her to sleep I held back the many tears filling my eyes.
She needed unit of platelets before and then during theatre as platelets still under 10.
Found out blood tests for adenovirus were worse they have to just wait for the cells which we found out will be here at 1am in the morning and they will be giving to her tomorrow. So that was so quick.
Hannah itchy all over today.
One sad thing I forgot to write is the past few days Hannah's got in one hand a sick bowl and her pain pump button in the other that's so sad to see.

DAY 59: CYTOTOXIC T CELLS

Another rough night!! I'm feeling sad, grumpy, so tired and for some reason hungry.
Big day cells arrived; there was a lot of excitement in the ward especially for the people who organised them. 1pm was the time it all happened a whole 3mls of cells,(donor a lady in Australia) inserted via iv line, got some pictures and Hannah got to keep the wee steel box they came in for a keep sake.
We now all have fingers crossed that they work.
Hannah was very very grumpy today, I took time out at 3pm and got a coffee and rung my best friend.

DAY 60:

IV line taken out had a better night up only 4 times. She's Feeling nauseated all the time now. Still receiving platelets daily.
Vomiting still but only twice today, still sore tummy.
She tried staying awake most of day.
Still got diarreah not as much but nurse said she's still pooling lining of bowel I'm like really how much lining can one have, this has been going on for weeks. It's going to take a very long time to heal.

DAY 61: + 32

Crap night, up an extra time to loo, and had night nurse that was so noisy and pump alarms kept going off.
Hannah quiet today I think she was really sore. But she did go for wee walk not far just to see where the kitchen and playroom was, it was cool to see her up and walking.She slept 3-6.30pm.
NG tube taken off free drainage. Still vomited 3 times today.

DAY 62:

Gave continuous oxycodene running over night so we had best sleep yet in over 50 days she only up twice!!
Vomiting more today, each time she keeps saying "I'm sorry mum". Poor Hannah.
She not happy today and slept on and off all morning.
Lady from canteen came and did her nails and chatted with her, me and Alastair had half an hour time out.
Hannah had random high blood pressure for couple of hours doctors not concerned as no other symptoms.
NG feeds started 4 pm at 5 mls per hour.
Tonight Hannah not happy at all night nurse even commented. Heart rate 140's Bpm, temp only up once in night.

DAY 63: + 34

Another good night on the oxycodene running at a continuous rate. Woke twice.
Vomited 5 times today thankfully her NG tube stays in! Platelets again today.
Hannah came for walk and watched me make lunch in the kitchen she looked quite good up and about. Then slept all avo. Increasing NG feeds 5 mls every 12 hours. So we will see what happens.

DAY 64: 9 weeks today we've been here

Missing home and missing my mum who's my best friend, yes we talk every day and Skype twice a week, it's just so hard being a long way from home.

More diarreah since feeds increased vomited only twice today.
Still on no food just small amounts of water and juice.
Had blood transfusion today as haemoglobin only 74.
Very unsure of what the days ahead will bring.
DAY 65: + 36

Doctors said Hannah's liver functions up high due to TPN feeds so keeping close eye on her as she needs the nutrition but can't afford for something to go wrong with liver. TPN feeds will not stop until she's at 75mls per hour of ng feeds. Currently on 22mls per hour which they stopped increasing today due to diarreah and vomiting.
Vomiting small blood clots. Platelets again today.
Still awaiting biopsy from bowel results for GVHD.
Hannah did come for walk to watch me make lunch so it's a positive sign she wants to get out bed even if it's only for 5 minutes.

DAY 66:

I'm not happy today, rough night Hannah's tummy sorer, small nose bleed and large vomit in night.
Pain team came and are trying a new oral drug to see if that helps.
WBC 4.03, NEUTRAPHLS 3.00, still on GCSF but reduced amount

DAY 67:

High temperature in night took cultures again, tummy sorer from mid-morning, Not a good day diarreah more and vomited 8 times so a very unhappy sore girl. I'm very worried.
Finally a decision was made late in day to turn off ng feeds completely. Temperatures in the 39,s.
Pain team upped her oxycodene boluses from 2 mls to 3 mls.
Had platelets.

DAY 68:

Another night in the life of transplant, Hannah put on oxygen due to stats falling to 87, they think could be due to the increase in oxycodene and her being in a lot of pain.
Dr came at 11pm to check her.
Started ng feeds after lunch back at 5 mls per hour, vomited twice today so way better than yesterday.
I took time out today as Hannah slept all afternoon (I kept ringing to check). Went to Newmarket, it was nice to get fresh air and stretch the legs.

DAY 69 + 40

Hannah on oxygen all night, vomited 4 am.
Sleepy most of morning, vomited again before lunch blood in it again. Temps still in the 38's.
Slept 1pm - 8.45pm, just woke for loo and to check we were there every now and then and to push her pain button.
Started antibiotic ceftazadine.
Oxygen sitting at 94/95 today,
I'm worried something not right AGAIN , due to vomiting kept feeds at 5 mls per hour.

AY 70:

Hannah's tummy still in pain, because of the nature of her tummy pain the pain team said it's very hard the hardest thing to treat. So now trying octreotide but this involves the nurse putting a wee lure in her thigh, and then they can access it without putting a needle into her. So Hannah was very upset and distressed about this!!!
Hannah put on oxygen from mid avo oxygen dropping even while awake.
Hannah made herself comfee in the lazy boy this afternoon and went to sleep.
Vomited 3 times. We have learnt that during this experience you become an expert and dealing and describing vomit and poo.

DAY 71:

Still getting platelets. Pain team made decision to reduce oxycodene boluses and add methadone IV 3 times day.
They are getting really stuck of what else to do.
Got results Hannah's adenovirus levels are higher than last week. Could be another 2 weeks before the see changes and there's only 70% chance these cytotoxic T cells work...
Ng feeds stopped again late morning due to vomit not looking good, and tummy not sounding good and quite puffy.
Re started feeds 4 pm.
Hannah not happy, very sore and groaning in pain in her sleep.
How much can this wee girl take, very hard to watch every day and night for such a long time.

DAY 72: + 43

AN EMOTIONAL DAY. Giving GCSF today as WBC dropped to 1.05 and NEUTROPHILS to 0.85!, tummy sore this worries me a lot. Doctor told us that this adenovirus can be life threatening hence the reason for trying the cytotoxic T cells. Some Concerns of high liver functions but they said the liver is tough so just waiting to see, and the reasons due to TPN IV nutrition or possible adenovirus in liver. Reducing cyclosporine to allow T cells to do their job but there is small risk (as we had sibling donor) of getting GVHD in doing this.
Hannah slept all day, except to go loo, then vomited mid-afternoon then I showered her and she slept until 7pm.
This journey is beginning to SUX big time; nothing can prepare you for all of this so far.

DAY 73:

Hannah slept a lot of the day, groaning at times in her sleep in pain. Think the methadone making her sleepy.
Pain team added ketamine again and upping the dose of gabapentin, and decreasing the boluses on her oxycodene to 10 minutes instead of 5.
On oxygen late this avo due to stats dropping to 83%.

DAY 74:

Bad day for vomiting!!! She says I don't like being sick mummy.
Bleeding nose 8.30pm that didn't stop, then she vomited just blood (just from nose bleed running back into her tummy) she was very scared. Gave her platelets straight away which within 5-10 minutes bleed stopped.
On 7ml per hour of NG feeds.

DAY 75: + 46

Hannah's still got this very productive wet cough she's had for weeks, doctor thinks could be from adenovirus or from her pre-existing lung issues she came in with.
Now concerns as liver functions higher GGT was 1330 is supposed to, be between 0-50, plus her other liver functions up. Will be discussing with team tomorrow.
11am vomited the biggest blood clot I've seen since we've been here so gave platelets straight away weren't going to give until 5pm.
Hannah slept again all avo. At least when she's in a deep sleep I know she's comfortable.
Hannah's very quiet and not saying much.

DAY 76: + 47

Some mornings I wake up and wish this was all a dream.
Hannah's pain a 5/10 pain team said with the sort of tummy pain she's got is very hard to treat so that's the best they can do. It suxs seeing her in pain all the time.
Liver functions GGT in the 900's .Tummy dr been in (actually the register) she had gone through Hannah's notes going back to 2011 when she had liver biopsy's. reasons for high liver functions are adenovirus, TPN, GVHD, drugs or something else. So,going to do an ultra sound tomorrow morning.
Sorting out occupational therapy and physio and try to get Hannah out of her room at least once a day I don't think Hannah was happy about this, she's very sad, sleepy and not talking much.

DAY 77

Ultra sound 8 am, Hannah vomited twice after that.
10.30 am Hannah was taken off all her lines and we took,her to Ronald McDonald house for 1-2 hours. I was a bit nervous but excited as Hannah was wanting to go.
Took,her in wheel chair, she made some juice then went to sleep on couch.
Off ketamine today, reducing oxycodene as she said its not really helping and that the pushing of the button is habit.
platelets 22, HB 84, GGT 910

DAY 78 :

Blood transfusion today.
I had to wake Hannah this morning for pain team she was not happy and actually rolled over and cried. They decided to increase methadone doses and making the 5am slightly more to hope that it covers the pain in the morning????
Child physicologist seen Hannah today and will do so regular I think it's about time this happened.
Hannah not happy

DAY 79 : + 49

SUPER NEWS adenovirus levels down from 6.17 to 4.58 so the cells from Australia are doing there thing.
NG feeds at 11 mls per hour. Hannah's weight is now dropping she looks so thin and I can see her bones.
Tummy drs decided to put her on drug to help/protect her liver.
Hannah walked down to nurses station today (with strong influences from nurse to do it).
Completely off oxycodene today.
Still vomiting/diareah

DAY 80 :

Busy day, physio now involved to try get her up out bed and to gain back some muscle.
15mls per hour ng feeds, slept from 3pm until tea time

DAY 81 :

Tummy in a lot of pain so gave her oral oxycodene .
Was allowed to take Hannah down to,house this avo in a wheelchair. She was knackered as I showered her before we left. She made some juice and then slept on the couch.
Was nice to have her out.

DAY 82: + 53

Not a good day vomiting a lot 6 times today, she feels sick all the time and tummy sore, this is not fair anymore so tomorrow I'm going to ask more questions!!
Hannah really not happy i don't blame her so she didn't even want to go out room today.
I went for my Sunday walk and shopping I got some new jeans and top.
Hannah's feeds reduced from 21 mls per hour due to the vomiting to 15 mls. It seems we are going around in circles, feeds increase then vomiting worse then they decrease again. Or is it my original thought the brand of feed?? Or something else wrong other than the adenovirus.

DAY 83 :
This is my worst day I ended up so mad and upset it been brewing for a while now I think, it's very complicated long story, Nurse being a bit pushy today in getting Hannah up and out room even though she's still in pain and sick/vomiting. And because miss Hannahs not one to speak up (and she never has since she got sick)she sort of just did what they said. I do understand she needs to get up etc but not when she's like this.
Then I ended up having discussion with doctor wanting answers for pain? Vomiting , diareah etc. long story but in the end I asked dr to leave the room as i wasnt getting answers, then I took off for some air I was so upset and angry.

If I could pack Hannah up and go home I would.

DAY 84 : + 55

I was still mad from yesterday so didn't sleep that well. We had the best nurse on today who came in at 8am and saw Hannah was in horrific pain I felt an instant panic come over me this is not good!! I filled the nurse in on yestersay. She called pain drs urgently and basically pre warned them before they came into her room that they better have something they can give her!!!! Anyway we found out her 5am of methadone the biggest dose of the day was missed!!! So at least that proves methadone takes pain from 10/10 to 8/10. Plan to increase all 3 doses to the same as 5am dose and allow boluses during the day if hannah needs.
I said a few words and expressed my concerns to pain team and all the doctors who all came in at the same time, poor Hannah with 7 doctors around her bed.
Hannah had all doses she could have today of methadone not really changing pain.
4pm nurse took Hannah off all her lines and we wheelchaired downstairs and she brought her older brother birthday present/card we will be missing his 18th birthday on Sunday.
Excitement after that we went down the road and had tea with another family in ward. Hannah still had her vomit bowl and was still sore but gave her different scenery and fresh air.
Possibly doing gastroscopy this week.
Still vomiting on 5 mls per hour

DAY 85 + 56 adenovirus nearly 0!!!! Detectable in blood

Hannah slept better last night.
Drs etc all came around again, poor Hannah's just saying nothing so im getting frustrated with her not speaking up. There were some things said by drs and I could feel another slight argument coming on I'm getting very frustrated she's still vomiting and in pain it's been 8 weeks!!! .
Hannah went to teen room today and did craft with canteen lady which was great for Hannah.
Hannah's main dr came and chatted to us and explained things so we understood.
All about adenovirus and how her levels were so high that she could of died and that they were extremely concerned. Proof that T cells have worked with the nearly nil detectable in blood of adenovirus. But it will still be in her intestines and could take a very long time to heal which means she will continue like this which SUX!!!!
Also explained that she needs to have platelet/haemoglobin engraftment and tolerating feeds and have no infections before we can leave transplant.
I expressed my concerns that is there something else wrong with her tummy???
Decision made late in day to take to theatre and scope.
Vomiting continues and diareah 5-8 times day for both.

DAY 86 :

Red cells today and platlets. On list for theatre, had to Be prepped for sigmoidoscopy partial colonoscopy but she had to have enema, poor Hannah, and no ng feeds from 2am.
Then at 3.30pm surgery was cancelled due to an emergency case.

DAY 87 :

Hannah's pain still a 6 or 7/10. Waiting for theatre. A lot of meds going thru today so stayed connected to all lines.
After lunch we persuaded her to go for walk and in the end she met up with canteen lady and she found another girl similar age in ward and they went to teen lounge and played game, I was very excited to see Hannah do this.
Theatre called and she went in 3.30pm upset as usual (this is about number 14 surgery since late 2010).
Back in room by 5pm, theatre had put a baby NG tube in as that's all they had as her other one came out during gastroscopy. Grr grr All we know is her duodenum is inflamed they took biopsy of there oesophagus and tummy.
Biopsy taken at other end too.
Vomits urso (for liver) medication when they put it down NG tube

DAY 88 :

WBC, NEUTRAPHILS dropping :-(may give GCSF tomorrow. Decision made to turn off NG feeds at 10am due to amount of vomiting since 1.15am review Monday.
Hannah feeling sick all the time.
Took her back to Ronald McDonald house for couple of hours which was nice even though she was not happy.

DAY 89 : + 81

Ok night she seems more comfee now sleeping well up only twice, the doses of methadone is working.
Vomited baby NG tube out (we knew that would happen) not happy about new one going in.
Hannah not talking at all just sits/lies with her friend "mr white vomit bowl"

DAY 90 :

Decision made today to put NG tube further into her passed the stomach passed the duadenum into the jejunum making it an NJ tube. This was done via X-ray , and was a horrible experience she cried big tears, vomited, gagged.
Returned to ward with even a sadder wee girl.
Feeds started again at 5 mls per hour

DAY 91 :

NJ tube really hurts and moves when she vomits , she's vomiting grass green bile.
Hannah went down to gym today and played the wii, she's so unsteady and wobbly standing I am shocked at her weak condition. But was cool to see her have a bit of fun.
Feeds to be increased 2mls every 12 hours

DAY 92 :

she had a bleed from a tiny sore that lasted 2 hours once platelets given it stopped.
Slept all morning. Gym in avo had a go on the bike she did amazing I was very proud.

DAY 93 :

Not a good day, vomiting hurts so much she squeezes my arm, (still vomits at least 6 times a day) she said she hates vomiting, also diareah more frequent again every 1-2 hours and containing bits blood. I am concerned this is not good something's wrong.

DAY 94

Not good night was up 9 times too loo, diareah with quite a lot blood, plus vomiting. Decision made to give fluids due to weight loss obviously due to amount of loo stops. Gave platelets 4am and started tranexamic acid for bleeding/clots.
Something's wrong but drs said its just all due to her gut being very sick.
(I know it's something else!!!). So I am not happy.
By mid avo after X-ray to see position of NJ tube was still ok dr came back and said X-ray revealed she has NEC disease back!!! Omg I was devastated and knew something was wrong. I mean 20 pans of diareah most containing blood in 24 hrs.!!!! Very freaky stuff.
The cause is some infection/ bacteria so tests done and put on complete gut rest no ng feeds. Started on 3 broad spectrum antibiotics.
So yet again another set back. Life can be so cruel , and Hannah's so depressed more so on some days.

DAY 95 : + 66

Platelets today due to nose bleed, and red cells due to low HB, (77) Diareah frequency stopped, and no blood.There is a chance the adenovirus is worse, but they hoping its just an infection easily treated with antibiotics.

Hannah not happy, vomiting large volumes of bile they may have to put NJ tube back to a NG positiio and put it on free drainage to drain the bile.

DAY 96/97

Most tests for viruses negatives. Apart from that just another 2 days of a sad Hannah. Note counts are dropping I'm concerned is someone wrong.
Lymphocytes 0.23 were up to 0.5, neutraphils 1.23,

DAY 98 : NOT GOOD NEWS DAY

Where do I start!!!
Called into a meeting room, i knew something was wrong, to be told that Hannah's counts are dropping and that she has mixed chimerism and that her T cells were only 3.8% (were hoping for over 50 % normal is 100 %) which is seriously bad and that basically her graft is failing. I started to cry. OMG why Hannah. They said there's 3 choices 1- leave her which is NOT an option, 2 - re transplant NOT an option as she wouldn't handle chemo, 3 - is to do a mini transplant of Emma's T cells, this will hopefully boost the graft.. They said she's been through enough and they weren't expecting all these problems. Also we were told they'd never seen adenovirus levels of 6.17 (from weeks ago) and that they were surprised she was alive. Alastair and I were in total shock, our heads spinning with information. Mum and Emma flying up as we had meeting. They want to do T cells on Monday.
Hannah had GCSF today.
Mum and Emma arrived 3pm, we filled them in and made decision to keep Emma up with us, mum flys home Saturday as planned.

DAY 99 : + 70

10 weeks today since transplant. Hannah's counts back up thanks to GCSF. Vomiting a lot today. Emma seen dr, had blood tests etc done.
Good news Hannahs adenovirus levels just the same as the last 3 weeks just barely detectable, and CMV negative.
They think NEC disease just caused from the existing adenovirus in her gut.

DAY 100 :

I'm not happy today I'm just so worried at how sick our girl is, thoughts spinning in my head what happened if T cells don't work. Trying to think positive though.
Feeds have been re started yesterday at the usual 5 mls per hour and increased to 7 mls today.
Physio today played the wii with mum and Emma

DAY 101 :

Low counts neutraphils 0.91, WBC 1.20. HB 89, platelets 21 GCSF today again Mum flew home

DAY 102 :

Another day in bmt, Needed platelets

DAY 103 :

Hannah went to sleep last night at 7.15pm up 3 times to loo and vomited then I had to wake her at 11.15am today I was getting worried but she must of just been exhausted.
Headaches all avo.
Had hannah down at house for couple of hours

Emma donating T cells and saving her sisters life for the 2nd time

DAY 104 : + 75

Alastair now on his 4 th month of work, he's here all day and at night he goes back to Ronald McDonald house does washing, meals etc. this has been his/our routine now since being in the BMT unit.
Hectic day I was totally knackered. Al and Emma at ward early 7.30am, Emma had cream put on all possible veins. Dr put first line in and blood bank did the next one in opposite arm. Poor Emma they were huge needles. She was all set up what an amazing machine. But then bad luck one line blocked so she had to have new line put in each arm.

Finally all ran smoothly and took until 4pm, Hannah will not get cells now until tomorrow as they have to be split into 4 lots. Hannah gets smaller lot first as there is a risk of GVHD, we then wait 4 weeks to see if they are working.
Day was busy me running from Hannah to Emma.
Hannah did sit in room with Emma some parts.
Hannah got headache all avo again, drs have stopped some antibiotics and tranexmic acid. GCSF today.

DAY 105 : + 76

Cells put into Hannah 8.30am, Emma got to warm her cells up first and check all the numbers etc off on them to make sure they were her cells and going to Hannah, which was so cool for Emma. She's done such a big thing for her sister again.
Only took 12 minutes to infuse via IV.
It's really weird to sit back and think where we are and all that hannahs been and going still through, and what the next year could bring, it's still all an unknown journey for us and even the doctors.

DAY 106 : + 77

11 weeks today since Hannah had BMT , counts so low today neutraphils 0.39, WBC 1.03, platelets less than 10 so she had them before 9am. GCSF given again.
Hannah was quite chirpy today. Got her down to gym for some strengthening exercises with walking, she's slightly weaker on the left side. We never imagined how weak Hannah was going to get its so hard to see, but she's so tough so I'm sure will bounce back.
Severe reflux today, found out omeprazole dose had been halved so put her back on full dose.
Headaches still all avo with a difference of later at night it hurt when she looked up.
Pain team have decreased mid avo dose of methadone from 7.5 to 2.5.

DAY 107

Well today's not gone that well, Hannah woke in the pain she was in a few weeks ago before the new doses of methadone were increased. Something's not right with her and she had a diareah with specks blood at 7 am.
The day continued with bad pain, more frequent trips too loo and pans started containing blood? The decision was made to leave her until tomorrow and see what happens. I was not happy about this she's in a lot pain and its the same thing that happened 2 weeks ago when they re diagnosed NEC disease.
Pans from late avo increased, doctor was called 8pm, decision made to x ray tummy tonight. Doctor came up just before midnight and said X-ray positive for NEC again, not as bad (that's good). So stopping Nj feeds completely. Started 3 broad spectrum antibiotics.
Hannah's feeling really sick all the time, a lot of pain, new added pain in front of tummy it's always been down either side , feeling really full, and still refluxing.

DAY 108 : day 100 in unit, + 79

Counts low, neutraphils 0.57, WBC 1.19, HB 73. Red blood cells today and GCSF Hannah pretty low today. Headaches still bad, ct scan ordered and came back all good.
No vomits today yeah.
Methadone mid day dose decreased from 7.5ml to 2.5.

DAY 109 :

Not much change is her counts, GCSF ,needed platelets, Quite cheery today best weve seen her for weeks. Managed to get her off her lines down to Ronald McDonald house for 2 hours.

DAY 110 :

Another day, Hannah played cards, and I have to move some stuff from our room into room in ward while BMT room gets done up.
Counts lower

DAY 111 :

Alastair and Emma left today i was so shattered and Emma was so upset this is one part of this journey that's the hardest saying goodbye to family specially when we don't see them much.
Moved rooms to room 1
Doctor came in this morning and said they were very concerned about Hannah's counts still falling WBC 0.70, N 0.22, platelets 17, HB 89. They said there a few possibilities why.
1 - that graft fails and Hannah's marrow returns back
2 - taking time for T cells to work and they may have to give more
3 - graft is failing and another BMT will have to be done, having meeting on Thursday about her. If counts still falling by Thursday they may do a globe marrow search for donor, if nothing shows then it would be back to Emma.
IM shattered, devastated and so damn scared.
Mum arrived 3.30pm it's so good to have my mum here.
Hannah vomited 3 times today

DAY 112 : + 83

Hannah's counts lower again despite GCSF, she's now only got 0.16 neutraphils. Needed Blood today.
Hannah's main dr came as and chatted to us this morning, she was very honest and said she is very concerned and said she has no idea what's happening and has consulted other drs around the globe.
basically there is no statistic for a case like Hannah. So the will just wait for more pieces of the puzzle to appear and just keep her safe in the mean time.
Will re do the chimerism test early and do that Monday and get results urgently.
Upping her dose of GCSF to the highest they can give.
I'm so scared. Im tired, teary, my chest feels tight but I'm so,pleased my mum is here.

DAY 113 :

Slight rise in counts so very excited, needed platelets.
Hannah quite cheery and chatty and we played cards.
New NJ feed started called vivonex

DAY 114 :

Not a happy girl today, pain and vomits. She asked for boluses of methadone so im ver pleased she's speaking up.
Moved back to transplant room a bigger one so busy day.

DAY 115 :

Hannah not the happy vomiting and sore. She did do a craft activity with mum so that was nice. Physio brought the wii up and Hannah was amazing and so determined to complete a level.
Very tired after.

DAY 116 : + 87

Feeds increasing 2mls every 12 hours.
Mum had to,leave this morning I was shattered, i wish we could just go home!!!! then Hannah vomited and was crying and so upset.
Slight drop in counts

Needed platelets .
Alastair flew back today with his mum and sister, so was great to see more family from home.

DAY 117 - DAY 119

Busy days with family here, Hannah quite cheery some parts of the day.
Still vomited a few times.
Counts increasing slightly each day. Needed platlets. And on day 119 gave her 2 units of blood just to see if it brings her levels up to 100 and keep them up.

DAY 120 : +91

Bit of a dramatic wake up call at 3am, she went to loo, at the same time was vomiting plus added a bleeding nose to that. Not a happy girl. Quite bad diareah.
In laws left today sad to see them go it's so nice to have family around, but back to reality just the 3 of us.

DAY 121 :

Another day of hospital life

DAY 122 :

Counts up, WBC 3.40, Neutraphils 1.48, HB 105 yeah, platlets 10 so a unit of them today.
After tea Hannahs nose started feeling blocked, then she vomited, she asked for some oxycodene as her tummy was in so much pain. As the nurse slow pushed it, hannah felt really sick, her lips, hands and feet went tingly, heart rate 170 Bpm, then she vomited again, I was scared for a minute. Then she came right so maybe was just a one off reaction to the oxycodene. Hannah was then so tired she went to sleep.
Results of the chimerism tests were the same as a few weeks ago 70 % Emma, 30 % Hannah, T cells they couldn't pull any out so no answer to that last time there was only 3.8%. Dr pleased results had not got worse and still unsure if graft is stable. Will give more T cells in ten days.
Feeds at 29 mls per hour, increase of 2 ml per day.

DAY 123 :

Life seems so unreal some days, we've been here 4 months today!!
We have Hannah off her lines except her Nj feeds so we went down to Ronald McDonald house for a couple of hours.
She's grumpy today.

DAY 124 - 128

The next four days are much the same, Hannah's at times the best she's been since transplant, she's bright, doing crafts, talking, being silly, it's just amazing to see and so long over due. She's still has quiet parts more so in mornings she's so tired.

Get her off her lines and down to the house for 2 hours in the afternoon.
She's walking better. Feeds going ok she's just feeling really full and yucky, and no vomits!! Still feeling very nauseated but at times the white bowl is not in her hand. Diareah has settled and there's none.
She's allowed to start to eat tiny bits of bland food but she's not interested at the moment.
Her counts are still good they have reduced the GCSF down a little. Still needing platelets.
And they have started one of her meds orally (down her nj tube) instead of IV.

31 st
October
dress up day for
Halloween
she had a fun
day.

Da 129 : + 100

Wow one hundred days since transplant!!! Hannah now has CMV back so that was a big low was told that 3 days ago so she's on foscarnet every 8 hours this was started yesterday.
This is the first Friday she's not havering ivig her IGG levels are good but IGA and IGM very low.
3 vomits today so she's not happy.

DAY 130 :

Hannah slept until 11.45am she's so tired at the moment, but was up of course to the loo.
She's got no diareah so that's great, just one vomit today. Needed platelets AGAIN

DAY 131 :

Hannah not happy today didn't want to have shower , tummy sore, she's still on 3 doses methadone daily and they allowing boluses of oxycodene when she needs.
Doctor said she was allowed to go out out yes we were allowed to take her to a mall first time she's been out mixed with people. I was very nervous about germs etc. but we were only gone 2 hours, even though she was in wheelchair she said she was so tired when we got back to hospital- recovery is going to be a long road.

DAY 132 : T CELLS DAY

T cells today so 2nd lot of Emma's magic cells. Her haemoglobin is low -80 so skin and lips are pale but they won't give blood until tomorrow with her having T cells today.
Hannah was allowed to thaw T cells and check them etc. so that was really cool for Hannah.
Hannah's tummy feeling very full and yucky 41 mls per hour she's up to.

DAY 133 :

2 units of blood today and GCSF as counts down.
Very exciting day well evening Hannah got to meet some shortland street cast; they were cooking down at the Ronald McDonald house for tea.
Hannah was so so excited she was smiling so much, so got lots of photos. Even Rachel hunter was there.
This was a boost Hannah needed well even her mum and dad as we were so happy to see her happy.


Ronald McDonald House
AUCKLAND

DAY 134 :

No platelets needed today wow day 4!!! It's is the longest since transplant she has not needed them. Dr had chat with us and basically they are waiting for the chimerism test and results to see if graft is safe. They are hoping the results are more % of Emma last time it was 70% Emma 30% Hannah and we want no Hannah.
Today I feel totally exhausted; I think this hospital life is catching up on me.
Hannah ate 1 grape today and it stayed down.
If she drinks a couple of mouthfuls of water she vomits it straight back.
2 vomits today

DAY 135 :

A few of her IV meds have been changed to putting down her tube, bad day she vomited 4 times very time meds went down tube she's not happy vomiting hurts her tummy so much.. She feels sick and full and yucky.
Hannah happy in room didn't want to go out.Janet from IDFNZ weekly visit today.
Foscarnet causing kidneys to play up a bit so taking one daily dose out.
Have added erso back in which they only took away 2 days ago as liver functions levels creeping up again.
Added lactose syrup in as they think she's not pooing enough now!! So gone from one extreme to the next.
CMV and ADENOVIRUS negative.
Whispers in the ward we might be getting out discharged down to ronald mcdonald house, but no one has come told us officially. I think it's a bit soon still a lot going on with Hannah. I'm very nervous when we get out but I suppose that's to be expected we've had nurses and dr by our side for 128 days today.

DAY 137 :

Good day not feeling sick and didn't vomit.
We even got out down to house for 4 hours.

DAY 138 :

So much for good day yesterday Hannah spiked temperature and wasn't as chirpy today. Will she ever get a break, I know she's way better, but a temperature is not what she needs. Will wait and see what's causing it. But it's better to happen now than if we had just got discharge she would be back into hospital and once we get out of here I don't want to come back. But we have been told she will have things happen which will require hospital admission. I know our journey has a long way still to go its going to be months before we know if she's cured. She still doesn't eat by mouth so don't know what's going to happen with that. She has no interest in eating at all!!

DAY 139 :

High temp continued through the night so they took blood to culture and yes results in the avo show something is growing so put on 2 antibiotics vancomycin and ceftazadine. CRP which is infection level is up too.
I asked about the whispers of her getting discharged and they said now the infection has set her back. And there's still Iv meds that need to be tolerated orally and the big wait for results of the chimerism. But the end is near yeah.
No midday dose of methadone it's been slowly weaned over the past 10 days.
Still needed no platelets amazing she's making her own!!!!!
OFF TPN !!!!! After 14 weeks on it

DAY 140 : + 111

Hannah's counts low neutrophils down to 0.7. WBC 1.46, platelets that had been up in the 20's now 17. So GCSF today.
Low potassium, vancomycin antibiotic levels in her blood high so have stopped that until levels lower if its high its toxic to the body, CMV virus low detectable this week damn, creatinine levels high possibly due to the foscarnet.

Meds now taking by mouth and they seem to be giving her so many pills so she's just vomited them back up today very time. Not a happy Hannah yet again. But she did manage to hold down a small pill some part of the day.
Hannah not been feeling that great since Sunday (day 138)

DAY 141 :

Positive results back today for staphylococcus epidrmidis is her Hickman line, hopefully antibiotics doing the trick as we've had no more temps. Have done more blood to culture today to double check.
Low potassium and phosphate, may add different laxative as the syrup she had few days ago she just vomited when she had it.
Hannah still no interest in going out, sleeping till really late in the morning.
But did do some craft activities today.
It's been a month since we've seen family so missing them a lot.

Part 9

DAY 142 : + 113

Hannah slept in, she's spending a lot of time in bed, physio came late avo and she walked down and played the Wii. When she cam back to room she vomited, then 10 mins later vomited again.
Adding stool softener to list of meds as tummy feels very full and yucky she does not like the feeling at all.
Low potassium and phosphate so had a infusion IV over 6 hours.
Still not eating or wanting to drink except small mouthfuls with her meds.

DAY 143 :

GCSF today as neutraphils down. Vomited after oral meds.
Drs said its just iv meds holding her back from being discharged she need to take them orally or by her tube.
Made the decision to rent a car was great to have transport, Hannah was allowed out all afternoon so we went to a shopping mall- fun but busy. She was in wheelchair she's too weak to walk too far.

DAY 143 - 147

Pretty much the same these few days, Hannah gets of her lines all avo some found some more shopping malls. She's trying meds orally still vomits sometimes when she takes them. GCSF every 2 nd day.
Weather stunning.
Needing phosphate and potassium infusions over 6 hours at night.
Platelets creeping up all by themselves up to the 50's now.

DAY 148

I'm not sleeping much.
Find out tomorrow Hannah will be discharged down to Ronald McDonald house, omg lots of thoughts and feeling running through my head, the day has finally come.
Hannah's liver functions still high due to TPN, kidneys due to drugs and she needs to drink at least 10mls water per hour. But miss Hannah's stubborn personality she doesn't like taking pills or drinking, she feels sick full and yucky (poor Hannah).
Another infusion of potassium and phosphate.

DAY 149 : 141 days in hospital, + 120
DISCHARGE DAY !

The day has come, omg we have so much gear the car was full and there was no room for me, Hannah and wheelchair so we walked back to house.
Results of chimerism back 67%emmas, 33% Hannah's of Peripheral blood, but the Tcells which are all emmas were up from 3.7% (when they said graft was failing) to 44% so very happy with the result. Hannah will still get mote T cells beginning December.
Back to hospital every day as Hannah has the vancomycin antibiotic just done as a lock in just her hickmen line now and needs to be changed daily, plus blood tests daily.

DAY 150 :

Very strange being out of hospital words can't describe what I'm thinking and feeling. Hannah still vomits. But she's perky and has a wee attitude back sometimes which is great to see.
Bloods all good. On weening programme for methadone.

DAY 151 - 155

These days consist of 1-2 vomits after meds either orally or down tube. She's feeling yucky and full still. Doesnt want to take her pills. She tried for the first time in 4 months 3 little tiny potatoe roasters but vomited straight back up she said she's never going to try eat again. Needed GCSF on day 154. Platelets going up yeah but heamoglobin low but not requiring blood yet.
Our exciting news we received in these few days is hospital gave Hannah taylor swift concert tickets, then friends kindly paid and are accompany Emma up as they too are going to concert. I'm so excited Haven't seen Emma for 7 weeks.
Also Ronald McDonald house along with snow planet have given both girls a helicopter ride to snow planet where me and Alastair will meet them there followed by fun in the snow as VIP guests. Amazing and so exciting.

DAY 156 : + 127

Finger prick for Hannah she hates these reason behind is to avoid accessing her hickmen to often so it avoids infections. Then we returned to clinic as she needed a 3 hour potassium infusion.

DAY 157 :

Another finger prick. Then to Clinic to see Hannah's specialist we were with her for at least an hour discussing Hannah, her liver functions were creeping up she suspects due to not all doses of urso been given as Hannah having great difficulty with any meds and its proofing a big issue.
Vomited oral methadone up this morning , we waited half an hour repeated and she vomited again. She's full and feels yucky and just not as good as she was when discharged.Plan made to take all meds down NJ as if she vomits at least the medications don't vomit up. Only anti nausea oral.Reduced feeds to 40 mls per hour, needed potassium again and GCSF.Will not be home next weekend like I'd hoped. Dr Will review Hannah Tuesday.

DAY 158 : +129

Day off having bloods. And Hannah's not well, and we had the snow planet thing today.
Got Picked up 9.45am, arrived at air field were our 2 very excited girls went on helicopter with no doors and flew to snow planet 10 mins away Alastair and I met them there.
As VIP guests at snow planet we all,got kitted up,with snow gear, got photos taken and headed to the indoor man made snow part. Amazing. Poor Hannah was exhausted just getting gear on. 3 goes down on the tabogins Hannah had enough she didn't want to do anymore this is the most she's done since transplant and its just too much and harder when she not as well.
In the snow dig girls won prizes Emma picking up the PSP I was so excited for her.
Returned to Ronald McDonald house by 1.30pm. Hannah looking slightly jaundice in her eyes.

DAY 159:

Not at all well didn't want to get out of bed, didn't walk anywhere, quite jaundice. Vomited twice. Headaches and sore tummy again. Slight cough.
Bloods : she needed GCSF. She's pale and something's not right.
Taylor swift concert night Hannah got changed at last minute. We took wheelchair.
But the night was too much she was extremely cold, fidgety, and just really not well I know something's wrong and am very worried. We left concert early took her back to house and she went straight to sleep.

DAY 160:

Monday clinic to access hickmen for big lots of blood tests and normal viral tests. Hannah had 2 vomits this morning not related to meds going in. I asked to see a dr. A registerer saw her and her main dr she straight away could see someone was wrong, she was very dehydrated. So put in treatment room, heaps and heaps of tests done, put on IV fluids, and were told she could be admitted.
Some bloods came back and yes it's her liver. Plus something is wrong with her tummy as she's vomiting more, tummy sore , Counts low.
Did tummy ultra sound.
Admitted to ward just before 5pm. Only been out for 11 days.
I'm so scared what's wrong now, life is so unfair.
Weight dropped quite a bit
Very quiet sad Hannah

DAY 161 :

NOT A GOOD DAY!!!!! Vomits total over 10, rough night, extremely agitated and fidgety, there was talk of possible methadone withdrawl but team want to wait to see what's wrong with her liver and tummy first .
Diareah started 1pm omg this is like going back a few months, talk about a flash back, now I'm really worried .she needed phosphate , GCSF as counts low neutraphils only 0.9. Plus monitoring glucose and had to take it out of her iv fluids. Did snot sample. Coughing quite a lot.
Decision made to do liver biopsy tomorrow poor Hannah it's her birthday so all our birthday plans we had to cancel :-(.
A very unhappy Hannah, how quick a child can become ill. I'm devistated.

DAY 162: +132

I forgot how tired you can get being up all night Hannah was in such pain she was groaning a lot, and cried, and vomited, and had regular loo trips, cough waking Her as well.
So no sleep happened last night. Was given oxycodene but its was via Nj tube so she not happy it makes her feel so sick or vomit.
Busy morning, theatre 8.30am, she cried " it's not fair I didn't want to do this on my birthday", that made me cry.
Out of theatre back Up in ward by 9.30am.
Day consists of pain so all meds now IV she was given 2 hourly oxycodene .
Coughing much more. Blood pressure low. Needed phosphate 6 hour infusion which was iv plus connected to ECG monitor. Added pump 2 tonight so she could have all her meds on time.
Still dehydrated, still got sme diareah. CMV levels low detectable so her dr decided due to past issues to give ganciclivor.
It was her 13 th birthday she got spoilt and deserved every gift.
She's so sad and sore. Life deals some blows I really thought things were looking up even though I know there was a long road still to go. But now it feels like we are back a few month. Will we ever get home.
So now we do what we do best wait for biopsy results.
Emma still with us which is nice, just long days in a small hospital room.
Missing rest of family down home.

the journey continues

DAY 163 : +134

Not a good day, Hannah up regularly to loo which means across the hallway from room to get there. At 5.45 am on yet another trip I was standing at the toilet door when I felt hot, sick, dizzy, the next minute I was flat on the floor, I was so scared nurses around me I had collapsed/fainted I was out for a couple seconds, woke to realise what had happened and that Hannah was in loo. Poor Hannah she was so sick but yet sat in floor beside me she was so worried. Nurses wanted me to go down to a&e I said I would when Alastair got up here in couple hours.
Day continued with Hannah liver functions really high, all her potassium, magnesium,phosphate etc low.
She's vomiting, loo trips 2 hourly or less. She slept on and off all avo.
I spent 4 hours in a&e I was dehydrated so put line in did bloods gave me a litre fluid.
Dr did ECG then called cardiologist cos it was slightly abnormal they re did it still the same, but cardiologist happy to discharge me and to go back if I faint again.
Big day I'm stuffed and feel like I've been run over by a bus.

DAY 164:

Life is not fair, Hannah is so ill!! Like back 4 months ago after transplant. She's slept all day inbetween 1 hourly loo visits, she now has commode in room she can't make it out of bed. She's vomiting, in pain, coughing. Life is so cruel I'm so exhausted I really don't know how I can keep going.
Meds changed again as CMV positive in her blood.

DAY 165 :

Night very rough!!, Hannah is more yellow billirubin levels up more. Hannah on 2 hourly iv oxycodene and have not reduced her methadone like they were going to do.
I'm very worried.

DAY 166 :

Things are really not good. She's now got blocked nose and more of a cough. Too weak to even shower and its an effort to get her to even brush her teeth.
I went back to Ronald McDonald house for sleep.

DAY 167 :

Omg yes things can get worse 18 trips to loo in 24 hours!! Vomiting still, billrubin up to 146. Starting TPN feeds tonight, I'm shattered its like we back to the beginning the last 5 months just disappeared. Results of biopsy's show she has grade 3/4 GVHD of liver and grade 2 in tummy. WE WILL NOT BE HOME FOR XMAS. So no more emmas T cells for Hannah so unknown what graft is going to be like when this part is over. Started high dose steriods tonight only issue is that it fixes GVHD (they hope) but is an immunosuppressive and that is bad for the CMV virus so one drug doesn't help another.

DAY 168 :

Another day of horribleness !!!!!!

DAY 169 :

Today I'm beyond shattered and emotional, I've had many days through this journey I've gone away and cried, or cried myself to sleep, cried to my friends over phone and mum, BUT today I cried when anyone even spoke to me. Concerns vomits has flecks blood, back to diareah, CMV still in blood despite medications. New concerns too part of her kidneys playing up so called renal team in. She's. loosing a lot of bicarbonate from kidneys so they have to keep replacing it IV.
I am very very concerned today and really miss my mum.

DAY 170 :

Much the same day and night no sleep only 15-30 min naps , lots of meds included albumin infusion.

DAY 171 : + 142

Happy birthday to me!! Well Friday the 13 th day of terror.
Really bad night toilet trips now containing blood , clots etc and blood in vomit, dr called 3 am due to temperature. Put her on another antibiotic ceftazadine. Needed platelets today.
6 am nurse concerned due to blood in poo and severe tummy pain. Doctor called again and her main dr called who was on call. Ordered urgent X-ray which ended up being the most horrific things to get Hannah to do she was in so much pain she couldn't move at all but we had to get her onto X-ray table that took 5 of us Hannah screaming in pain.
Started her on amoxicillin, fluconazole, metronidazole, bicarbonate infusions.
Now on pain pump of oxycodene so she's got 4 pumps on her pole.Cough worse needed oxygen, X-ray has added to the list pneumonia in left lung.Also a chance they may do broncholoscopy next week if no improvement.THIS IS THE ILLEST I've seen Hannah since August 2nd on a really bad day.Life is not fair why is this happening to our precious daughter.

DAY 172 :

Same day same night these are the roughest nights we've had since our journey begun up every 30 mins - hourly , concerns as she's pooing blood, lining of her intestines/bowel and clots. Dr said all part of CMV and GVHD in her gut. Hannah has blurry vision we think its due to ganciclivor drug. Issue is they can't stop that drug as its the only one for CMV and the foscarnet she was on is causing added kidney problems.She's itchy so added phenerghan to list of drugs, and swollen puffy feet.

DAY 173 :

Hannah needed blood today, albumin, and platlets.
And bad news poo sample positive for damn ADENOVIRUS I really hate this virus!!!!
Rough night loo trips some 40 mins apart, and loosing undescribable bits and blood, it makes me sick each pan I take to sluice room.
Doctor called after tea blood cultures from the other day positive for a bug so replacing some antibiotics with the big boy meropenium.

DAY 174 :

No improvement so drs are doing broncholoscopy and colonoscopy tomorrow to see what's going on.
Needed albumin and blood .
Happy part of day my brother glen arrived and surprised Hannah, in return a priceless giggle and smile from Hannah.

DAY 175 :

Theatre 8.30 am Hannah very upset as usual she hates going to theatre.Decision made to start another med cidofovir for adenovirus.Needed platelets again today.

DAY 176:

Still concerned about how much is coming out the bottom end, but the drs said until GVHD and adenovirus are fixed it will just keep happening, and just replace by giving her blood and platelets.

DAY 177 : + 148

Well totally 158 days sent in hospital now!!!!!

Example of Hannah's night weve been doing for a week or so now, these are the times she was up to loo 8.40pm, 9.50pm, 10.30, 12am, 1.20am, 1.30, 2.45, 3.30,4.30, 6, 7, 7.45am Not a happy day found out this morning a boy in transplant passed away, I found myself hugging and crying with his mum in corridor. Reality of transplant anything can happen. Biopsy preliminary show adenovirus and GVHD no CMV it's only present in blood. Halving steriods tonight. Possibly trying for more cytotoxic T cells from Australia.Today I feel beyond exhausted theres no words to describe how I feel.Hannah's feeds started 5 mls per hour and she was allowed a cup,of tea.
She has not vomited now door a few days amazing one positive thing.

DAY 178 :

Another day in what we now call our home ward 27b, room all decorated Xmas thanks to Emma it's kept her busy.
Full day of meds one after the other.
I went back to house for wee sleep took me agers to get to sleep.
Improvements in liver functions and billirubin.
Hannah allowed to try something to eat amazing it's been 5 months, but because of high dose steriods she's starving. So she had a Tablespoon of steak casserole.

DAY 179 : + 150!!!!

160 days spent in hospital today, Hannah's very pale haemoglobin low but it's priority to give other meds first so blood will be tomorrow unless she needed urgent then they will put a line in.
Nights the same up 9-10 times.
Drinking a lot of water and juice, and having iceblock.
Had tablespoon beef stir fry and its staying down, not sure if its helping the bottom end though but drs happy.

DAY 180 :

Heamoglobin only 54 this morning no wonder she was feeling terrible and dizzy, so priority blood today and platlets.
Pretty much the same, still loosing blood etc from bottom end, meds full on 24/7.
Still no vomits feeds up to 15mls per hour.
Still can't get her to shower, I wash her hair in bed she has quite a bit of hair now.
Her muscles in her legs and arms have gone she's so weak and so thin.

DAY 181 : + 152

All drs plans have changed , back on no feeds of any kind just TPN, no juice or ice locks just water, to see if it help reduce the blood, clots etc from her bottom end.
Apart from that on Xmas eve eve just another day in 27b.
162 days in hospital since 26th June.
Cameron arrives tomorrow so we will all be together for Xmas just won't be with the rest of family :-(.
Hannah's very tired and not happy today but I don't blame her just wish as a parent we could take all she's going through away.

DAY 182 : +153

Ultra sound today. Bicarbonate infusions x 4 this is due to her suffering renal tubular acidosis. Cameron flew in tonight.

DAY 183 Xmas day

Really hard to believe we are in a small room in another city and in hospital for Xmas. Though Great to have us all together for Xmas, but missing other family at home so much.

Lots and lots of prezzies for Hannah and Emma from lots different people and charities and the ward.

Me and Alastair got spoilt too.

DAY 184

Weird day got moved back into transplant room 15 where Hannah's journey began nearly 6 months ago.
Hannah's weight has dropped. Needed platelets today and more bicarbonate infusions.
Nights much the same.
Really can't believe how many steps back we are, she's so unwell.

DAY 185

IVIG infusion today, plus 3 bicarbonate, plus all her other meds. Neutrophils and WBC dropping so may need gcsf tomorrow. Hannah's feeling of nausea has come back today she's actually been off all anti nausea meds for a wee bit, so re started them straight away.

DAY 186-187

An example of a nights toilet trips this is not counting the times pumps beep, nurses come in etc
8pm,8.40pm,9.15pm,10.30,11.40 ,1.15am, 2.45am,4,5.10am, 7.15am Needed platelets and bicarbonate and she vomited.

DAY 188-189

I'm worried Hannah's counts have dropped neutraphils 0.69 so gave high dose gcsf today. Hannah vomited and has blocked ear. Dr came and said GVHD has improved great in her liver so the issues with her gut are still adenovirus and CMV and may re biopsy on Friday. Kids flew back to invercargill this was a hard day of many tears.

January 1st 2014

DAY 190 : day 171 in hospital ,+ 161

Happy new year NOT, I went back to house last night Alastair stayed with Hannah I'm so so exhausted but I couldn't sleep at all, so I'm not feeling any better today. Will try again tonight. Hannah's counts low despite high gcsf they think due to the drug ganciclivor she's on for viruses is knocking her counts.
Really really homesick .
bicarbonate infusions x 3, platelets (still needed due to blood loss out her bottom end) Plus gcsf.

DAY 191

I got some sleep last night yeah.Drs have not given ganciclivor today due to neutraphils only 0.34!

Vomit today again. Needed gcsf, bicarbonate , and albumin - 2 infusions of that, plus all her other meds.
Up 9 times to toilet in night (exhausting) Decision to go to theatre tomorrow to biopsy do a colonoscopy.

DAY 192

Rough night I'm back on nights at hospital. She vomited, had temperature so dr called 5.30am. Theatre cancelled due to temp, and low counts. Added more antibiotics due to fever.
Feeds changed to peptisorb not a brand used much.
Things so stressful on us all, I'm fed up with this life, I'm not feeling well today and wish we could go home .
Blood transfusion today, platelets and bicarbonate but just one today of that, plus lists of other meds.

DAY 193- 194

Much the same , still needing all the usual infusions shes been having with the addition of potassium today as her levels low. No vomiting now. Counts low so have stopped ganciclivor all together.
Very puffy face due to the steroids. But muscle tone in legs and arms go e she's so thin, makes me sad to see.

DAY 195

Theatre today went really late afternoon. Losing fresh blood still in poo.
They went in 90cm for the colonoscopy and took 4 biopsy s. poor Hannah was very upset in recovery because the nurse wouldn't let her go to the loo. So when we got up there with her ward nurse we took her straight to toilet she was so upset.
Hannah in a lot more pain, so on 1 hourly blouses of oxycodene instead of 2 hourly that she was on.
Had 2 units platelets today, plus gcsf, and bicarbonate Not a happy girl

DAY 196

Results show there is signs of healing in the top 60 cm they went in but bottom 30 cm show GVHD , still awaiting viruses to come back. In a hard place as what treats GVHD doesn't help the viruses and what treats viruses doesn't help GVHD but they need treated for both, as both are life threatening.
Chimerism results back wow amazing 100% donor even the T cells. Great news Started feeds 10mls per hour, allowed juice and clear chicken soup wow

Day 197

Much the same, mum arrived today so excited.
Hannah put on PCA pain pump of oxycodene so then she can give her own doses instead calling nurse.
Diazepam tried but didn't help/work.
Hannah very low and down not saying much at all, or sleeping

DAY 198

Hannah not good at all today slept most of morning, then back to sleep at 1pm.
I'm going back to house with mum for next 3 nights, I really hate leaving Hannah specially when she's worse, i dont do it often this will be 6 nights out of the 179. She also had pain in right side when she breathes tonight, so I'm very worried.
Blood, platelets, bicarbonate x 2, gcsf, plus all her antibiotics and meds etc.

DAY 199-200

Days the same, she's sleeping most morning but wakes for loo. Pain has increased , so pain team increased her oxycodene. Then decision was made to add a ketamine pump, so Hannah is now has 5 pumps on her pole and her feed pump.
Lots meds going through they sometimes run out of space.
Things very stressful for all I didn't realise how much of a toll this can have.
Feed at 18mls per hour
Positive biopsy s for damn adenovirus and CMV

DAY 201- + 171

Slept the best sleep ever last night my eyes actually feel open.
Hannah's toilet frequency has improved slightly, and nowhere the amount of clots and blood loss and clumps.
Basically we been told Hannah's been in intestinal failure but those words were scary when we heard them today, in the hope they can heal and fix it of course.
Hannah very down, doesn't get out bed, has such thin and loss all muscle tone in arms and legs. And yes physio come sometimes and do bed exercises and if she's not too sore stands and does some.
Platelets again, gcsf and bicarbonate.
Mum went home its so hard her having to go. I realised how much I miss my mum.

DAY 202-213

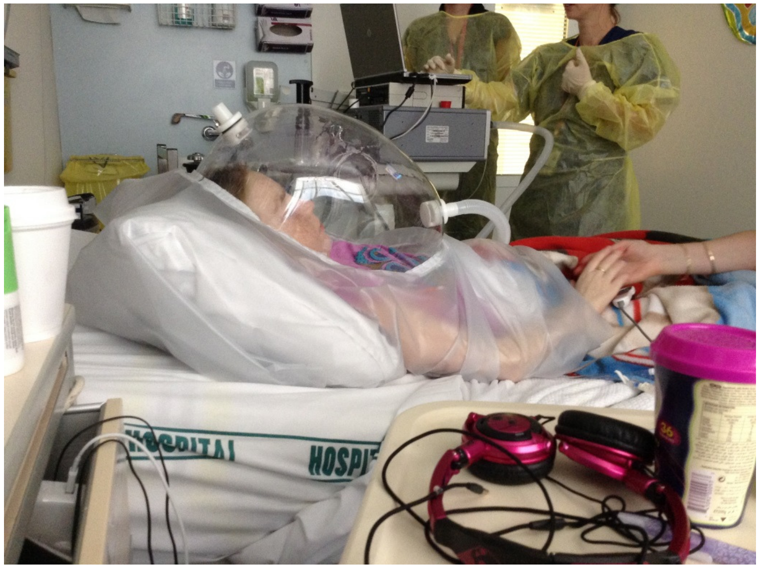
Thought I would try to shorten things. So here's a whole week. All much the same, same medication, and infusions.
She's having cidofivir for the viruses every alternate week as its what's effecting her kidneys. Ganciclivor stopped completely due to low counts. Hannah's pretty much very quiet, on her iPad, or watches the odd DVD.
Toilet trips have improved so up 3-4 times at night. Still small blood losses and clots but nothing like the horrific loses she's had.
New issues of liver functions eg one of the 4 liver functions the GGT normal is under 50 she clocked 1880! They are not sure so will watch and wait, hoping its not intestinal failure worsening so they decided to put her NJ feed tube back to NG (and a clean tube) which will help the liver as NJ position is not ideal. This was an aweful 15 minutes getting this done.
Ketamine increased this week also to 4 mls per hour On day 211 they are taking the gamble of adding morphine (she was allergic before BMT) pump and taking away oxycodene as she's immune to that now so needs a change of opiate drug. From today gcsf being given every 2nd day.
Slept down at Ronald McDonald house day 212 and had best sleep I've had in 7 months I think my body was just beyond overtired and exhausted and I just slept.
Hannah sleeping late in mornings and some avo sleeps, she's sore and just so withdrawn now it saddens me so much to see this.

DAY 214 - + 185

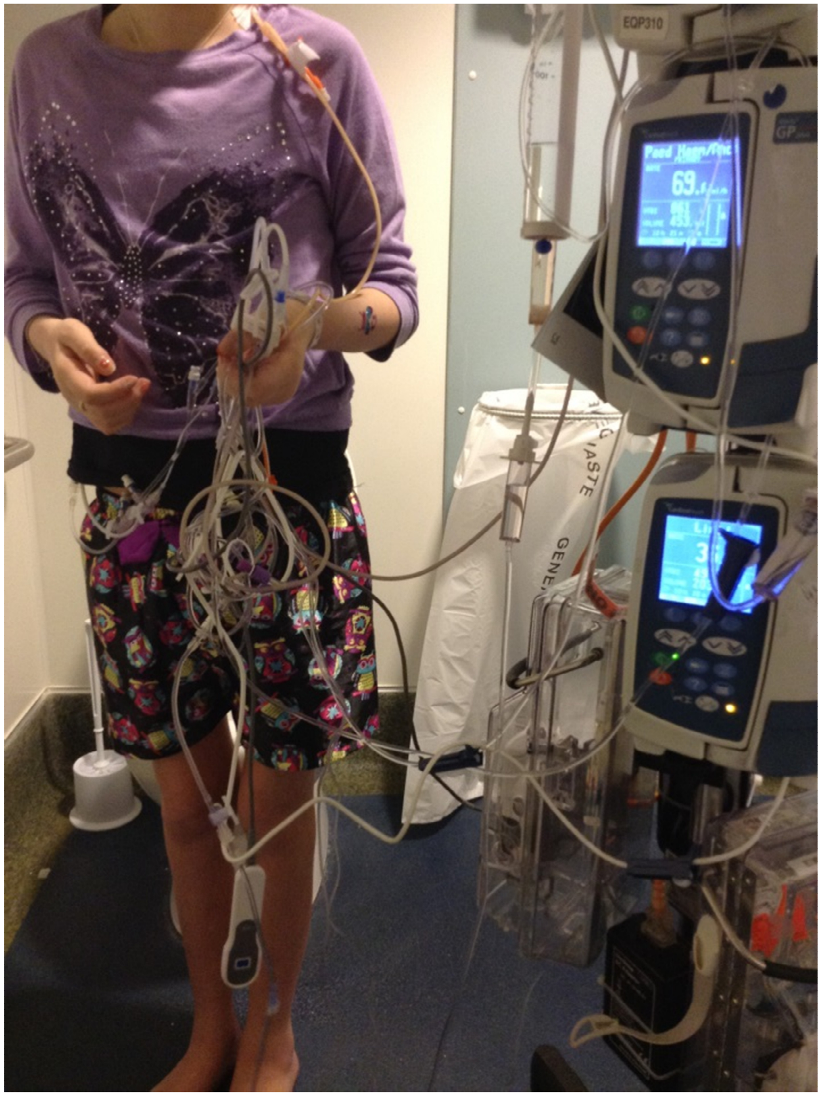
Hannah vomited fresh blood today just when feeds were up to 21 mls per hour, Then a big vomit at night blood and old blood and mucus she was so scared of what it looked like I told her to try close her eyes and not,look at it.
Decision made to give platelets at 9pm.
Bicarbonate just 1 today, and gcsf.

DAY 215/216

No light at the end of the tunnel yet with more vomits, haemoglobin low so needed old transfusion both days plus platelets because of blood in vomit and from the bottom end.
She's very sore there seems to be no relief from all the pain meds she's on. I wish I could take all the pain away from her.
Ng feeds reduced back to 19mls per hour and will not be increasing.
Drs said this could take a very long time for her tummy to heal and they think? some of the ulcers are bleeding and that causing her to vomit.
197 days today she's spent in hospital with no light a end of the dark tunnel.
Neutraphils low again at 0.77.



Hannah having indirect calimentary test



Part 12 the nightmare continues

DAY 217 + 188

Really crap sad day, emotions I can not describe.
Awake to check my Facebook page to find out a wee 9 year old who had been in transplant last year passed, then an hour later a friend from the US her wee girl wasn't going to make the day. My heart is broken and so scared , anything can happen our children's life's are so precious.
Hannah's very withdrawn today, vomiting black still (old blood) and some fresh blood,and still very sore .
Methadone has been increased and reducing the ketamine to try get her off some pain meds.

DAY 218 :

Neutrapenic today neutrophils only 0.28!!!
Still vomiting Noticed tonight a wee sore on corner of thumb is hurting her.

DAY 219 :

Crap day, there's no way to describe this journey anymore!!, Hannah woke 4am, vomiting, tummy very sore, and thumb she was saying was sore.
By 7am she woke thumb was red and swollen and extremely sore.
Hannah's blood positive AGAIN for damn CMV virus Thumb a concern so got the orthopaedic team to come look, they decided under local anesthetic to slit the side of thumb take sample. This ordeal was horrible poor Hannah, she actually screamed and cried.
Heaps doctors came around this morning and said they were having a meeting about Hannah (again) and what were our concerns.
Changing drugs around, reducing steroids, adding cyclosporin. Adding heaps of meds to cover what ever could be wrong with thumb. Counts low having gcsf daily, and needed platelets today.
I'm shattered and so upset and feel helpless as a mother.

DAY 220

Theatre today for one serious thumb infection that's got worse and spread all up her arm through her lymphatic system. A wee voice saying inside my head a serious infection could kill our girl. (I knew how bad it was after a comment from her dr) Feeds stopped due to vomiting and as she had to go to theatre.
Hannah's holding onto a lot of fluid and is in so much pain tummy and thumb and all up her arm.
Today is horrible I have invisible tears in my eyes all day and night, I want to keep them hidden and stay as strong as I can for Hannah and hubby.
2 units platelets today and gcsf

DAY 221 : + 192

Suck start to the day after me not sleeping much at all, surgeons came in at 7 am to check thumb. Hannah not happy, then they said the nail they had stitched back on had to come off they can't risk infection growing under the nail they would do this later today.
9.30 am Hannah endured yet again pain I can not describe as they removed the stitch and thumb nail (NO local anesthetic).
Both Alastair and I had tears by the end of this ordeal as we glanced at each other.
I left to make a cup of tea and cried on a mums shoulder from the ward I just couldn't hold my sadness in.
Hannah cried herself to sleep after many blouses of morphine.
I really have no words to write how we feel watching her suffer day after day .
Hannah needed furusomide today, platelets, ambisome (anti fungal), plus albumin as her levels were low, gcsf, plus all the other xtra meds she's on for her thumb.

At night nurse noticed the tracking (redness) up her arm was worsening, dr called who then called Hannah's dr and started her on vancomycin.

DAY 222

Still vomits black and poo black.
Counts still low, needed blood transfusion and platelets, 2 lots furusomide and gcsf.
Feeds started at 5 mls per hour at lunch time

DAY 223

Slow boring day, Hannah slept 11-30am - 5.30pm poor wee thing is just so sick and knackered.
Bicarbonate infusions have stopped i week or so ago i think so that's one positive.

DAY 224

Much the same. Surgeons re dressed her finger , and results came back as a staph infection. No guarantees she will ever grow a new nail.

DAY 225

CMV still positive in blood despite medications to kill it. Hannah slept most of morning.
Platelets seem to be a daily need. Plus blood today and 3 lots of furusomide as she's very puffy and holding onto fluid this is not good.

DAY 226 : + 197

Hannah's nights are better only up 2 or 3 times. Still vomiting black and poo is black which they said is old blood well blood that's been sitting for an hour or so in her gut Increasing methadone again (wow).
Hannah's weight still up. Drs watching liver as liver functions up and billirubin and kidneys playing up too maybe drugs, CMV or GVHD.

DAY 227 :

Concerns of weight increase despite being given furosemide. So big day today checking heart (that scared me) to make sure there's no issues with that leading to the increase of fluid. Doing liver and tummy ultra sound, and kidney dr called to keep eye on kidneys. Hannah's never gets a break - wonder what's going on with her now???
Vomiting increased, and pain in tummy.
Heart scan shows its all good yeah
Platelets, gcsf, and furusomide plus IVIG today.

DAY 228 :

Hannah not well at all today , counts low, vomited 5 times, she's sleeping a lot, very quiet when awake.
Drug changes today thinking may be a drug adding to increase liver issues.

DAY 229: + 200!!

Hannah's way worse increased vomiting and pain. Her words early hours of the morning were " something's not right mum, somethings wrong " as she's on loo and vomiting yucky black and clots and mucus.
She slept 4 hours late this avo.
Liver functions increasing (not good sign)

DAY 230

211 days spent in hopsital today. Things same as yesterday but liver worsening. Called liver dr in and decided they will do liver biopsy and gut biopsy under the gastro team while she's asleep and orthopedic team will re dress and clean thumb too.
They unsure what's going on as it could be more than me thing, as we know we've been through this so many times already. So yet again put her to sleep and biopsy.
Hannah's so ill and is saying she feels really terrible, she's so sore despite the pain meds.
I feel we are getting no-where with her health at all. It's just not fair!!!!

DAY 231

Example of vomits today 1am, 5am, 9.15am, 2.30pm, 9.30pm.
Platelets x 2, blood, furosemide, gcsf, plus all other meds that continue daily.
Theatre 3.45pm.
In horrific pain after theatre!! Hurt to move for her to sit up to be sick, and go to loo.
Tummy dr came and told us her tummy was basically full,of ulcers and blood very very sick tummy. Awaiting results.
Steroids reduced to 5mg very 2nd day, and another drug stopped immediately thinking it might be contributing to liver that is worsening daily.

DAY 232

Another day, same old. Needed blood, platelets, gcsf counts still low. Furosemide .
Changed her morphine pump back to oxycodene as she gets immune to one drug.
Hannah's pain is so hard to control and this is very frustrating!! Pain team reviewing again.
To top the day off the laptop got multiple viruses and had to be taken to tech guy to fix $250 (not what we needed right now).
I'm so so tired.
3 vomits today, shes sleeping a lot, she's slightly all over jaundice today.
dressing change on thumb as it had blood soaked through the layers and layers of bandage.

Now this was absolutely horrible, Hannah doesn't cry much but she did, even on so much morphine it didn't take the pain away.3/4 hour to remove the dressing yet again I had in viable tears in my eyes, my heart hurts to see her go through this.
Then she was very upset at how her thumb looked, no nail (and probably will never grow new one) and a wee bits been cut out of the side.

Brave Hannah – so sore!

DAY 233 : + 205

Biopsy Results back no CMV or any other viruses which is great news.
Liver results still not good. Hannah yellow all over and her eyes.
She slept from 10am - 2pm.
Gcsf still daily shes still neutrapenic amd low WBC and 3 doses of furusomide today.

DAY 234/235

Much the same but she is sleeping alot like most of the day.
Still vomiting . She's in alot of pain so pain dr called in. Putting any meds down ng tube causes more pain and many tears. (This is horrible to see) Platelets and gcsf

DAY 236

Hannah again slept most of day, ECG done to check heart with being on methadone.
Meeting with Hannah's dr, she said all results from biopsy show no GVHD and no viruses so finally !!!! she's got none of them issues, the liver is due to TPN feeds and her gut not working because its not had enough or any regular feeds for many months so concentrating on pushing up ng feeds slowly. Sorting out a rehabilitation programme with physio etc to get her up and out bed. No more ganciclivor so hoping that her counts will now recover.
Pain team have changed her from oxycodene to fentanyl. Reducing methadone from 12.5 mg to 10 mg 3 x daily.
One vomit today.

DAY 237

Hannah had really good night.My best friend flew in today, so lots of tears, smiles and chat.
I stayed down at house was great to have no hospital noises etc 2 vomits today, platelets, gcsf . Furosemide x 2 daily still

DAY 238/239

Much the same, Hannah sleeping alot. I didn't sleep which I expected.
My best friend and I went shipping was a great afternoon.
Lots drs, dietician, etc in on day 239, pain team have turned off fentanyl and that's a pump gone off her pole its just not helping the pain so no point putting un necessary drugs into her.
Best friend went home lots of tears, I miss home so much!!!!

DAY 240

Big day with very long talk with Hannah's dr, very hard to explain in writing what she said.
Going fwd with ng feeds 1ml every 12 hours. Can pause when she has bad patch which is more vomiting but will not decrease the rate . Keep an eye on her liver and her clinically. Off alot of meds which is great.
Physio etc will be regular and we are to have Hannah off her lines in the afternoon so we can bring her back to house, this will be good for her mentally etc.
the hope is we are out of hospital by mid march!!!!
And dr said we will no doubt have some speed bumps with her but just hope they not big set backs like we've had.
3 vomits today ng feeds at 16 mls per hour

DAY 241/242 : (days 223/224 in hospital)

Bad weekend!!!! Vomiting increased, not a happy girl, so feeds staying at 17mls per hour. Still low counts. Got her back to house for 2 hours each day, she just lay on couch. Gcsf and platelets

DAY 243-247

Just much the same, liver still the same, she's still yellow, still vomits with some days worse than others so not fair she hates vomiting so much, basically shes been vomiting now for over 7 months!!!! Still has blood and small clots from her bottom end, still needing platelets, gcsf, furosemide to keep fluid off. Unit of blood on day 244.
Sleeps most of mornings. Afternoons off her lines, a little physio, then down to Ronald mac house she stays on couch or has a bath which she enjoys.
She spent over an hour one day at the hospital classroom doing crafts was really nice to see her do this as she has had no interest or felt well enough to do so.
Friday 28th feb was world rare disease day/liver awareness with IDFNZ so we met at the duck pond at the domain, Hannah lasted really well and after 1 1/2 hours asked to leave we took her back to house. This was the best we had seen her for a while.

DAY 248 : + 220

Hannah slept all morning she's exhausted.
IVIG today that took 3 hours. Went down to house. I baked which was fun its been so long. Gcsf reduced slightly. And her wbc and neutraphils are up perfect today yeah finally so very excited., reduced dose of Gcsf today.
Pain is much better now we think the nortriptaline has helped.

DAY 249

Platelets again today she just can't seem to make any, haemoglobin low 85 but not needing blood until they 80 or less. Hannah felt sicker today and slept at house on couch. She's said she feels sicker and not happy at all.
I'm so tired at the moment this journey is taking its toll. Still vomiting.

DAY 250-252

The same, but Hannah's very dizzy even when in the wheelchair, or sitting up she's not feeling well and got headaches. Haemoglobin 86 so I suspect they lower but they not re doing bloods until Thursday (day 254) I'm a bit grumpy about this as if it is low HB then why leave her feeling like this???
She's still vomiting 2 times a day. Feeds now increasing 3 mls per day so in the 30 mls per hour now. No interest in doing anything, feeling not well at all.
Physio every afternoon only for ten mins she really can't do much at all standing for up to a minute throwing a ball resting and doing again 2 or 3 times is her limit. This is so sad to see how weak, sick etc Hannah has become even though we have small improvements medically.

DAY 253 :

Hannah haemoglobin 80 (so i was right its been low all week) so gave a unit of blood today, so we didn't get her out in the afternoon. She's not feeling well at all, she had trouble walking a few metres down the ward. Liver much the same maybe very slight improvements but her bilirubin has gone down alot so her skins less jaundice but eyes still yellow. Feeds in the 40's ml per hour she's feeling full and sick.
No Gcsf today are trying every 2 nd day. Neutral hills and WBC are great.
2 vomits today.
Hannah's just not at the stage were she was last November before she got discharged for the whole 10 days.
Still negative cmv and adenovirus in her blood (fantastic)

DAY 254 : + 226

Hannah's said she feeling not right today more tired, still dizzy, very mucasy you can hear it, some diarrhoea this morning, more vomits, feeling full and sick and heart rate up.
Down at physio they could see she wasn't right, and made the call not to push her to do anything (if she can't even sit up) and were going to talk to her drs.
We took her down to Ronald mac house she lay on couch all avo.

DAY 256/257

Another weekend, Hannah is not right she so low in her self, doesn't say much at all has no energy for anything, doesn't want anything to do with food the doctors keep asking her. We have a long way to go , drs said she's been sick for so long now it's going to take a Long time. :-(OFF TPN finally it's gone we hope never to see it again. Liver is improving!! Yeah Potassium levels now dropping so adding in potassium into her Iv fluids and taking pills to see if that helps . Gave platelets due to levels only 19 (normal 150) and she's loosing fresh blood again out bottom end again.

Meds at 4.45am (ng tube) woke her and then she vomited them all up, so very hard with the change of some oral/Ng Tube as it hurts her tummy and 50% chance she vomits them up. Got a long long road ahead.

DAY 257

Headache, dizzy, pale, bloods show haemoglobin 76! Big drop from the 104 yesterday so re did bloods and it was correct so having a unit of blood today.
She sleeping a lot , not well enough for any physio today. Did do 20 mins school work when she was awake late morning.
New ng feed plan once at 60ml per hour she can get disconnected from feeds for 2 hours a day. Only working on her having 75% of her nutrition (1320 calories) and working on more being on no attached lines and getting out etc.
no Gcsf for 5 days now counts stable, furosemide given yesterday due to 1 kg weight gain in 2 days. May have to give more tomorrow.

DAY 258

240 days spent in hospital now!!! Hannah's pain in side still sore and tummy really sore this morning, she has tears and her face says pain. Got prescribed some morphine. Unit of blood yesterday only brought her levels up to 94 (normal is 115), I still feel another unit of blood would make her feel better.
Physio today was just horrifying to watch, Hannah sat outside on the balcony attached to the gym, she walked a little bit, then sat down, then did this again and then sat down and said " I can't do anymore", she's just so weak and said she feels really terrible.
Meds down her ng tube cause her to cry and squirm in pain, watching this is heartbreaking , even when she's a sleep and they give meds it wakes her.
Down at house all afternoon, Hannah did do some Japanese homework on laptop.
Ng feeds at 60ml per hour, she's allowed 2 hours off her feed today she's very happy about that. 2 vomits today
Hannah's potassium falling

DAY 259 :

One week with no Gcsf and her neutrophils and WBC are perfect.
Haemoglobin has fallen to 87, hannahs dizzy and headaches, platelets 34.
Meds down her tube caused severe pain and crying then she spewed them all up, so dr decided to give this med Iv for next couple days.
Nice part of today Hannah spent over an hour down in the teen lounge with one of the canteen ladies they did beading and Hannah met another girl. Me and Alastair went back to house for lunch it was a nice break for us and great for Hannah.
3 hours off ng feeds today. Vomiting meds up so not going well at all.
Potassium levels falling so gave 3 hour IV infusion

DAY 260

Potassium very low so gave 3 hour Iv infusion.
Hannah in extreme pain this is so unlike her meds just hurt too much she said "no more meds down my tube", poor thing this is not fair for her to endure this every time for meds. Then she vomits it all up anyway.
Doctors made the decision to stop some Iv meds and try just one med by mouth instead via ng tube.
Her tummy is still sore she's dizzy feels bloated and sick.
This afternoon down at house she seemed quite chatty which was really nice, we even sneaked her into farmers (she was in wheelchair of corse) to buy some new onzie pj and she wanted nail polish was nice to see her being normal for half an hour and do what she likes to do shopping.
Got a phone call from ward saying Hannah will not be connected to her Iv lines tonight omg wow, so we stayed at house till 7.30pm.
Some meds Hannah's has refused to take by mouth as she just can't she feels like spewing or does vomit them up.

DAY 261 :

NOT HAPPY day, Hannah basically woke in pain crying etc, so we turned her feed off as part of the 4 hours she's allowed off today, she went back to sleep.
Her nurse had chat to her about how important the meds are, Hannah is complete opposite to yesterday afternoon very very grumpy just not happy girl at all.
Vomiting still, meds not going well!!!!!!
I had tears tonight as I helped Hannah to toilet she's so unsteady on her feet and she just cuddled me for agers she doesn't do this very often I think she's just exhausted and had enough its taking its toll on her now.

DAY 262 :

Potassium still low and because the oral pills didnt absorb at all in her tummy they back to Iv pottasium. Hannah not happy about pills still being put in front of her to take, vomits them up. Then she just refused other ones.
She not happy tummy full yucky sore, nothing seems to be changing.

DAY 245 : + 235

High dose potassium Iv so plugged into ECG for 3 hours.
In a lot of pain still, drs said its a bad patch.
Hannah is UNHAPPY this suxs more than words can write.
Still got her down to house she just lies on couch.
I've been baking still, it's fun, I take it back for the nurses.
4 vomits today

DAY 264

DISASTER DAY, I mean we have lots of these days but today was different we've never seen Hannah like this , beyond upset , crying, kicking, just so sore .
Nurse gave morphine, then dose 2, nurse wanted to give the 3 rd but drs said no that this is just basically a bad day, and feeds are not to be reduced.
Then we were told her methadone lunch dose had been reduced too quickly accidentally, I was like omg if this is what Hannah's going to be like coming off methadone it's just not fair. But still think something's not right motherly instincts.
4 vomits all big amounts.
Got her to sleep down at house for 2 hours she was so distraught and said she wants to go home. And she said something's not right I feel really terrible!!!
Emotionally very hard day for both Alastair and I.

DAY 265 : NEW PLAN

Finally a new plan after how Hannah's been yesterday and since last Thursday,/Friday reducing feeds today and slowly increase during the day back up to 60ml ad slow down and go back to some meds Iv they think it was all done too quick (I said yes) also with the accidental methadone dose stuff up and a med given a few days ago that's like fizzy could of set the pain off in her tummy.
Hannah's now been Turning her feeds off this is not recommended but she is her own person she has the right, this is very unlike Hannah to do this but honestly she's just had it and we don't blame her.
She actually felt better this avo way less pain and still feeling a little full but not as severe.
An example Feed intake today 860mls (only 860 calories) she vomited up 750mls.
She's actually on 75% nutrition which is 1320 calories the dietician and team are happy with this at the moment cos at least she's off TPN.
I stayed at house tonight I'm just sooooo tired. 3 vomits

DAY 266 : CMV is back

Called into room for meeting this is where you know something's up. And yes Hannah's got CMV back in her blood levels 2 point something. The decision is to give cytotoxic T cells from australia engineered for CMV Hannah had the adenovirus ones last year and they froze the CMV ones. They don't want to give drugs as they are the ones that make her very ill and stuff counts up and were now 2 weeks in to perfect counts.
A very "I've had enough" Hannah keeps Turing feeds off. I managed to get her in a bath and the poor wee thing is so weak that when she was sitting on the floor she can't get back up :-(. Weight has dropped 2 kg since last week.
Also liver functions are back up, great that's all we need.
4 vomits, on 50 mls per hour

DAY 267

T cells given today a whole 3.2 mls let's hope they work there magic.
Hannah's worsened in the last 12 hours, very distressed and turnjng feeds off, I see her getting thinner losing another 500gms since yesterday.
6 vomits today!!!, feeds now at 40mls per hour, dr rung while we at ronald mac house to say shes not allowed to turn feeds off as she's not getting enough fluid (pee very little and concentrated) and she's needs to flush the preservative that's in the t cells out as it can affect the kidneys.

DAY 268

Really bad night Hannah constantly turning off feeds, nurse would come back in turn them back on, she was awake basically all night.
Woke 8.15 am in extreme pain again kicking, crying, really agitated, found out 6am dose of methadone wasn't given!!! Finally nurse gave methadone at 8.30 am but Hannah did not Settle , my heart was even crying watching her like this as Alastair and I glance across at each other what can we do.. Dr charted morphine ,3 doses were given and finally at 11am I got her to sleep. 15 mins later it all began again, dr said they not giving anymore morphine but gave lunch time methadone .then physio came and she was told by drs that Hannah was medically ok to do physio, I was quite mad yes I understand about keeping her mind busy etc but she's in pain and feeling basically like shit..
4 vomits today

DAY 269/270: the weekend

The same, vomits , pain, but morphine was charted yesterday for over the weekend.
So she needed blouses of that which does settle the severe pain. Turns her feeds off, eyes yellower, peeing frequently and very small amounts so put on Iv fluids morning and through the night due to dehydration . Got to house mid avo but she's not happy at all, took her back hospital early on Sunday due to pain she wanted morphine.
Feeds at 40ml per hour not enough calories or fluids when she keeps turning off.
Weight down 3 kg. still 4 vomits a day.
Meds going sort of ok as we put them in her ng tube the reverse way so instead of going directly into her tummy (as any boluses hurt) they go up the tube then just go into her at the rate of the ng feeds and the feed just pushes them thru.
Potassium low giving and extra dose at lunch time of liquid potassium. Bilirubin up hence the yellow eyes and skin.
We did make Hannah walk a small way each day as we do know the importance of this.

DAY 271:

Whispers about us going home to invercargill hospital this was mentioned at a meeting last week, (caught us by surprise) but no one has confirmed anything. Usually Hannah would spend 4 weeks down at Ronald mac after discharge from hospital.
Hannah still Turning feeds off and dietician said she only had 33% of her daily calories yesterday so she needs more and she needs the fluids.
Physio pushed her more than they have before (I think this is cruel when she isn't well).
Methadone midday dose stopped today, and nortriptaline doubled Hannah the same and 3 vomits today

DAY 272 : first night on leave

This is a nightmare I wish I could wake up from it I don't want to do this anymore.
I'm not a happy mum today watching Hannah go thru this day after day I just lost it and was so upset, they've increased her feeds, she's in a lot pain, still vomiting, she says she feels really terrible (I feel something's wrong).
So yes Hannah going to be transferred in invercargill hospital they are having a meeting with them this week via conference. Anything medical can now be done down there. Its the best thing for hannah to be in her home town.
I'm so scared about everything no details it's too hard to explain.
We were allowed to have Hannah stay at house tonight as a trial in preparation for discharge. Quite scary.
What a disaster trying to do the meds, one lot we had to give 3 times as she vomited them. Took 5 hours in the end to give all her meds.
Counts have dropped slightly over the week but still ok this is due to CMV they said .Haemoglobin dropped to the 90's and liver functions slightly better but still high.

DAY 273

Horrible horrible day!!!! 9 vomits today!! And poo loose again, Something's wrong, Hannah's still saying I feel really bad, she is not happy and looks really terrible.
The night was not the best her waking to vomit, turn her feed off, go toilet etc. so no sleep for us. Drs just going to watch and wait.. She also is a bit rashy under her arms and back. Drs still want us out during the afternoon and tonight but room in hospital still ours so all our stuff still in it. (I'm not really comfortable doing this when she's like this).
I have a lot of mixed feelings at the moment about everything!!!!! I'm so tired and exhausted.
Hannah in screaming pain when given the liquid potassium she needs twice a day then she vomits it up and the severe pain goes away. She said I am not having that medicine again we said there is no way were giving it to her again we are not watching Hannah endure that.

DAY 274:

Well much the same night, after 3 vomits this morning and she looks not good and said she really not right we took her back to hospital 9.30am.
Her drs said they will watch and wait, have taken swabs off her lips as they all blistered and yuck. Her CMV levels have gone higher they expected this so now giving IV ganciclivor for 48 hours (which they didnt want to give as it causes her counts to drop) then will try oral and if counts drop They will watch and give Gcsf. And invercargill is all go just trying to sort when ,as they are happier if we arrive at the beginning of the week. If Hannah at all they think is not right or something happens that invercargill can't deal with then we will not fly home when planned .Mum and Emma still flying up this Saturday until Tuesday we were going to go home on the Wednesday but might have to be Sunday.
We have no idea how Hannah will handle the flight the drs said we can always change the day if she not well enough. Everyone been put in place down home, drs,Hannah's outreach nurses,dietician, physio, etc. Ganciclivor first dose 4pm.

DAY 275 : massive day for vomiting

Hannah's really not good!! A cruel day. This is so distressing as she vomited 11 times!!! Today, she's exhausted. The night much the same. had to wake her to be at hospital by 9am for ganciclivor and Iv omeprazole. Then back at 8pm.
Drs said that it vomiting maybe due to higher levels of CMV and there's nothing they can do.
And yes sent back to house to cope in our own, I'm so not happy and I'm worried.
Today we actually seen the physiology team, and yes we've somehow slipped through the system as we were suppose to have consults with them before transplant !!!!!
They were very nice but unfortunately 9 months + too late , but will be passing info on to invercargill team so hopefully someone will be put in place down home specially for Hannah.
Yet another day my heart breaks for Hannah.

DAY 276

Another night up and down, or I just couldn't sleep. Hannah's very restless too.
Hannah's day less vomiting 5 today.
Her pain has settled a lot in her tummy (accept when she vomits) so at least that's a it improvement. She just feels full a lot.
Mum and Emma arrived today at lunch time OMG we hadn't seen them for 3 months!, lots of tears and hugs.
This afternoon we decided to do a zoo visit. It was nice to see just a few smiles from Hannah but this was really exhausting for her, even though she was in wheelchair.
We were only there for a couple of hours but was really nice to be out for a bit, and with mum and Emma.
Hospital at 8-9.45pm so tiring for all.
Hannah's more raspy, arm back, under knees.
Weight dropping, dietician said when she drops to 37kg then that's too low, she's 37.3.

Day 278 : 250 days since transplant

Not a good day full of a lot of emotions, I didn't sleep well at all, the we had to be up have Hannah awake,it takes her so long to get up etc, she had already vomited twice 6am. 8.30am so yes had to re give meds as she spewed them up. Last morning for I've gancivclivor as of tonight it's oral.
Big discussions re oral meds omeprazole and gancivclivor they want them given in empty tummy which is totally impossible as she would loose so many hours with no feed and then if she vomits then we have to re give the meds so she be off feeds for longer and they just didn't understand that we put the feeds into her ng but let her feed slowly push the meds through. We just feel like we've Been pushed out with this huge responsibility of meds and having such a sick girl, it's just too much pressure we are not feeling that comfortable at all.
More vomits today after the morning 2.
Actually got to Kelly tarltons Hannah so wanting to go as she missed going for her birthday, we took Emma and mum.

DAY 279 :

All on our own, hospital rung to say they didn't want to, see Hannah now until Thursday today is Tuesday, so really feeling like we've been thrown into the deep end.
Hannah's rash was quite bad and she said she feels really terrible, she's so so thin now and so weak.
The liquid omeprazole is causing her to vomit and she said it burns and really hurts her tummy. Gave morphine today for very sore tummy.
5 vomits
She spend most morning asleep except for when she spews and then all day just lying on the couch.
Only had 976mls of ng feeds over 24 hours its not enough

DAY 280

Tummy a lot sorer I think it's the omeprazole.
Hannah's not talking and just lying and has no interest in anything.
I sorted out a lot of stuff ready to pack to come home.
2 doses of morphine for Hannah, 5 vomits today this is ridiculous 8 months of vomiting!!

DAY 281 : DISCHARGE DAY

Weight now 37.15kg
Cmv levels still over 3, Hannah's rash is worsening.
Well cleaned out Hannah's room, seen a couple of mums we hadn't seen for a while a couple of nurses popped in but apart from that we just walked out so quite sad really after being there for 9 months, it's just so weird.

Blood in poo tonight so I'm very nervous Omeprazole not giving anymore Hannah didn't want it and that's fair enough what's the point giving a drug that causing horrible pain and extra vomits.

DAY 282/283

The same still spewing, just not a happy girl. Doctor says she now has chronic skin Gvhd and her mouth has ulcers and her lips still really bad and yucky , dr added loritadine for itch.
Spent the days packing up, cleaning cupboards etc.

DAY 284 HOME FINALLY

Can't believe we are all packed up and going home . A Really hard day for Hannah who was not well at all this morning with 2 vomits in an hour, we were up early as we fly out 11am. The saddest part for me was watching her getting up the few stairs onto the plane she couldn't do it so me and Alastair had to help her, i held back the tears as I realised how ill and weak our precious girl really is. She slept well tried to on both flights. I can't believe we are going home.
Very emotional homecoming at airport in invercargill lots of tears, heaps of tears.
Fish n chips for tea and a bourbon (long awaited) very enjoyable. Then all Hannah's meds then bed.

7th April - 25th.

Just a summary being home is way way harder than I expected its very hard to explain. But I do love being home.
Hannah's the same spewing 4-5 times a day, just lying on couch all day no interest in anything except her I pad, not talking much, brushing her teeth is a mission she said I don't care if they rot. She's just so sad. nearly full body chronic Skin Gvhd worsening so pics sent to starship, more drugs added and yes steriods again!! Plus 2 Creams which I'm suppose to rub on twice daily 15 mins apart but Hannah's won't have a bar of this but is letting me once a day. Skin biopsies done this was the worst I've ever seen Hannah out of all the procedures she's had done in the past 10 months she just lost it. My heart wishes I could just take this all away, she kept saying sorry to me as she cried so hard.. It's not fair any more I'm broken. She was so sore after this I gave morphine for couple days.
Doing Hannah's medications is a nightmare well just so much pressure to,get it all right and it's so involving and both me and Alastair double check everything and write everything down. Meds have to be given 45 mins apart as if she vomits it means only re giving one med at a time. We're just exhausted mentally and physically. I help Hannah shower still, basically do a lot for her.

Regular visits with invercargill dr and outreach nurses, (the team in invercargill are great and know Hannah very well and the only support we have.). Hannah needed 2 units of blood one day, Ivig another. But no physio has been put in place or someone/counsellor for Hannah to talk to, so feeling very very annoyed just sent home with no help just to cope by ourselves.
I'm not sleeping well, actually Hannah said she's not either cos she feels so sick all the time. I'm totally exhausted.
Cmv still positive until the week of the 23rd it was non detected yippy!!!Liver functions much the same still high but improving compared to a month ago, bilirubin coming down so she's not as yellow.
Feeling isolated as we've left the security of familiar faces and parents going through journeys (even though there own) but at least they understood us and we'd chat and cry together etc.
24th started Hannah on tacrolimus an immunosuppressive to help stop the Gvhd but usually immunosuppressive muck up her counts and they start falling. So we will watch and wait.
Also Alastair Hannah's very clever dad made her a pole for her feed pump etc to go on this is much easier for Hannah to get around the house than trying to carry heavy bag of ng food and pump in a back pack.

26th /27 th April

Hannah's had sore eye this weekend and some of her skin has spots which look infected. And her Hickman line entry site a bit sore.
Much the same but she is vomiting less only 1-2 times a day so big improvement, her tummy pain has worsened a lot since the 24th were she started a drug called tacrolimus, plus she has had diareah back again for at least a week some days blood in it (samples taken).
Home life still very complicated.

28th APRIL

Hospital visit for bloods and to see dr, wow eye way worse this morning 2 lumps on it and red and sore, 7-8 spots on her skin all red and infected and her Hickman line very red and gunky. Swabs taken and admitted to hospital for IV meropenem and teicoplanin antibiotics as no risks can be taken so hit it hard with IV antibiotics.
I was not happy about staying and either was Hannah.
2 vomits today, tummy sore

29th

Luckily all infected sites looking better so by 3pm discharged on oral (NG tube) flucloxacillin 8hourly.

30th April

Not a good day for this mummy Im just not coping with life I'm so broken inside.
Hannah's eating little bits of an ice block and ate a slice of carrot and parsnip and a tsp of meat this is great to see she has a little Interest in food.
One vomit today
Alastair off work still

1st may-4th may

Much the same but Hannah is walking around the house more so this is great and chatting more, and we get the odd joke.
Steriods reduced. Diareah still. Some days better than others, fell asleep one avo she was just exhausted. Tummy sore worse some days.
Neutrophils and WBC and platelets and hb are falling slowly.

5th may

Travelled to auckland today, big day flights are tiring, Hannah still in wheelchair so we took her one from invers with us. Was really weird being back at RMH it was like we'd never left.

6th May

Clinic today bloods taken, line re dressed then appointment made again for later in avo for when all her results are back.
Popped to ward was really nice to see all Hannah's fav nurses we never got to say goodbye to them when she was discharged. It's hard to explain but I felt really warm and happy being in a place we'd spent 3/4 of a year. Also seen 2 close friends with there kids in the ward was great to see them. Hannah was very chatty and was looking quite good actually this is a big change compared to a week ago.
Dr visit went for an hour going through everything in the last month. Watching her platelets (as they have dropped to 42) Gvhd, viruses and infections etc.

7th may

Shopping day, miss Hannah had the last of her make a wish prezzy card she wanted to spend on her bedroom, so she ordered a new slat bed and bedside cabinet and tall boy. She was very happy.
Big day very tired.
No vomits for 5 days but one tonight.

8th may

Quick catch up with friends on the ward, lunch with idfnz was nice to catch up.
Very long exhausting trip home Hannah wasn't that happy and very tired . Home 8pm Hannah's NG feeds are up to 55mls per hour but she's only having 1100-1200 calories a day so weight low but stable low.

9th May

Ivig today and big toe now infected looking like how her thumb started so put on IV antibiotics but this was done via a paragon that district nurse came and changed at home so no hospital stay. Stopped valganciclivor due to neutrophils dropping heaps and she's now neutropenic WBC only 1.3, platelets 33. Gave gcsf but this was given through subcutaneous in her thigh she did NOT like this.

10th may

Toe better but district nurse didn't come to put new antibiotics up she was 4 hours late so toe back red and sore.
Hannah has slightly runny nose.
Hannah doing her room up she's doing a feature wall was nice seeing her spend a minute trying to paste the wall..

11th Sunday Mother's Day

Hannah not happy at all today, pale and just not feeling well.

Blood test again all counts lower again!! I'm worried and hope there feeling it's the valganciclivor is right, but I have a motherly feeling it's not that.

12th Monday

Blood test again neutrophils Lower than yesterday so 0.5 now. Psalters only 33 so hoping we don't have a bleed anywhere or be off to hospital for platelets. Gcsf again Hannah not happy about this as it involves a needle.
Headaches been happening on and off for a week now Hannah said tonight I really don't feel well at all not nausea just not well.Health school has started so this is great for Hannah.

13th MAY

Hospital again, gcsf again, checked her throat as she said something's there and caused 2 vomits this morning dr looked and said small ulcer could be the cause .
Then they decided she needed new ng tube so poor Hannah went through the horrible ordeal of ng tube removal and putting one back in. NOT happy girl today and not as well as she was last week, when her counts are low like this it makes her pale and not well.
Tonight looks like both toes are red and both sore so will see what tomorrow brings when she goes back for gcsf.
She's feeling hot then cold??

Part 16

MAY 14 th

Gcsf today again via subcutaneous (needle in thigh) she does NOT like this. Other big toe red and sore tonight and her Hickman line. She's feeling full and yucky.

MAY 15 th/16th

CMV positive (levels 1.93) drs just going to watch and wait. Platelets only 26.
Toes the same.

MAY 17th

Saturday today Hannah not happy or me about being at hospital 9.30 am for bloods and to see dr to have toes checked etc. got phone call from dr at lunch time to say her neutraphil low 0.9 and WBC down 2.2 she needed to come in for gcsf and would be via subcutaneous, hannah said NO!! I said to the doctor we will try be there in 15 mins. Hannah was NOT going, and because she's 13 and I can't physically put her in car and take her we didn't go. 4 pm ward nurse rung asking why she hadn't been, I explained and said she won't have any more needles, nurse said we can do gcsf via her Hickman (so basically a lack of communication) the outreach nurses had set it up on Friday for IV gcsf. So all good went down and she had her gcsf.Hannah's not well at all tonight.

MAY 18-21

Much the same. Feed rate at between 50-57mls per hour, she turns it on and off or the rate down sometimes during day. She's not having enough calories really only 1100-1200 per day but yet weight somehow stable so that's one good thing.

MAY 22

Pentamidine today, this doesn't go down well as she vomits half an hour into infusion poor wee thing vomited 3 times in less than an hour, despite been given anti nausea.Cmv still positive but levels slightly lower

MAY 23

First, yes first physio appt since being home. She said her legs and arms were surprisingly strong, she did a few wee exercises, even to go up and down just one step was difficult and she only just managed 10, on the excercycle she just managed 90 sec but she gave it an awesome go. Just shows how long it's going to take to get her strength etc back. Had to see dr, toes worse, put back on flucloxacillin and new antibiotic rifadine for 5 days. There was mention of a surgeon being brought in as she may need the nail on the sides cut away.

MAY 24- JUNE 1st

This next week is Much the same, some days/nights worse than the week before Hannah's tummy pain has increased a lot so giving morphine, she's pale,feeling sick, having the odd rough night of only a few hours sleep so giving anti nausea and morphine in middle of night. Her haemoglobin falling slowly every few days now so only 90 at this level she's always symptomatic headache ,dizzy, pale but they don't transfuse until 80. She keeps turning feed off or rate down. I'm worried.Still having 3 weekly Ivig . Diareah increase. Still getting really hot then really cold but temp is fine. Toes better but still get sore. Has started a wet mucosy cough on 31st. Still the odd random vomit every few days.Cmv levels now 2.55 (I'm scared I don't like this virus wish it would stay away).Finding weather very cold compared to auckland.

JUNE 2nd

I was a bit panicked tonight as Hannah suddenly had sore neck, and still feeling sick and coughing and it hurt when she breathes, I said to her we might have go to hospital she said NO, so I just kept eye on her and checked on her through night.

JUNE 3rd

As predicted rough night, cough woke her and neck, tummy is still really sore (it's really not fair watching your child in pain) feels sick, I hate when you have that feeling asking yourself do I take her to hospital or not. Bloods and dr check this morning they can't find reason for neck pain and just to watch for signs of floppy mouth etc, or worsening pain, temp.As for cough her lungs sound ok just reduced air in bottom right lung. So yet again off we go home to deal with it.Tonight pain moved from neck down her spine and lower back, seems unusual and I am very worried, gave morphine.

JUNE 4th

Hannah slept well until 11am, she's very pale today and slight pain just in lower back now , She's very puffed just getting off couch today.
Hannah got a wig today, despite how ill she was feeling today I've never seen her smile like she did with her new wig on, she wasn't liking her short hair at all she just wanted her long hair back.

JUNE 5th

Much the same today, bloods again Hb gone up by itself so 96 today.
I suspect the way she is feeling is due to cmv and have strong suspicion levels will be higher will know tomorrow.
Physio today Hannah did amazing doing some fun activities for 15 mins, she has such determination.

JUNE 6th

Yes my motherly gut feeling was correct cmv 2.74, so back on valganciclivor. Remembering all things with Hannah are instructed by starship, so feeling were the last to know anything at the moment.No wonder she's got more tummy pain (as cmv usually is in her gut) and feels just not well. despite this Hannah spent her first 2hours in the new health school classroom in town with 2 other kids, as I drove away leaving her there I cried all the way home this is the first time I had left her, I felt so empty, I felt like a mum who's just dropped there 5 year old off for there first day of school. When I picked her up she said she was ready to come home she was sore and tired.

JUNE 7th- 9th

Not really anything different to report. Alastairs back at work now after 11 months on an emergency benefit, so weird not having him around.
Life is still hectic juggling family life but only those who know what it's like to have a seriously ill child and/or spent a very long time in hospital will understand this.Despite having amazing friends in invercargill I still enjoy my regular Facebook/phone chats with some amazing mums I have met in starship who understand, and are going through there own medical journeys with there child.

JUNE 10th

Not a good day today but for me, woke up vomiting (I never get sick or vomiting bug) by late morning that vomit caused my heart to go into AF (atrial fibulation) so my heart was very irregular and very fast. So poor wee Hannah was worried, I rung an ambulance. Mum stayed with Hannah while I spent the day in a&e, medications didn't convert my heart so they had to jump start it, very scary, so now I have to see a cardiologist and feel like I've been hit by a bus.

JUNE 11th/12th

I'm not feeling great but have to carry on. Miss Hannah still in a lot tummy pain. Her wrist is sore as she fell at physio on the 9th. Had bloods done and wrist looked at but said not broken if worse take her back and will X-ray.
Update on Hannah's bloods for the past month ,liver slowly improving finally getting better each blood test 2 out of the 4 liver functions are normal other 2 slowly getting there, her platelets are now finally increasing the most they have been since November last year not normal yet but way way better. Hb also up to 94 then 99 today so getting there too. WBC and neutrophils are normal after being low again for a couple of weeks recently but not low enough to need gcsf.

JUNE 13th

Today Hannah did big vomit she hadn't vomited for 10 days, she said her hole body hurts and now she has burning down/up her oesophagus it hurts bad (reflux) so the randitadine she's on isn't working, she's not happy. Wrist still sore.

JUNE 14th

Still bad reflux , and wrist has small bruise now on the side, she's pale and not well.

JUNE 15th-18th - STARSHIP

big days 2 of them to fly there and back. Monday (16th) clinic 10am,Hannah had rough night in a lot tummy pain and vomited at 2am, didn't get taken until 10.45 done bloods and changed her Hickman dressing, to be told then to be back at 2pm to see Hannah's dr as all her results will be back. So we organised storage for our car which is still in Auckland we are leaving it there until our visits become longer apart and Hannah's much more stable. Dr visit well in brief I expressed some of my feelings re Hannah still having all these health issues, she said Hannah was so seriously ill it's going to take a very long time to recover. Her platelets are over 100 which is amazing and her WBC and neut are normal,(well see how long that lasts) her liver has improved heaps so taking her off urso medication.
We are allowed to try panadol again regularly as she hadn't had this for months as it effects the liver. Have swapped randitadine for omeprazole to see if this helps the reflux we are to go back tomorrow to see how things are.
9.30am appt a lot was discussed as Hannah has Gvhd in her mouth today so here goes that see saw AGAIN , she still needs the immunosuppressive drugs for the Gvhd which they are wanting to ween her off as they work against the cmv virus and the drug for the cmv makes her feel even worse. Hannah had wrist x-ray and no break and no answers why it's still sore. Now on weekly visits for bloods etc, hananhs still to have Ivig 3 weekly and monthly pentamidine.
Trying to focus on her strengthening at physio.
Seen 2 friends while in auckland a part of me wishes I was in Auckland to be closer to friends in person instead of via Facebook, and was nice to see familiar faces in clinic too.
Travelling home day, Hannah's NOT happy, she vomited and wouldn't let any meds be put in, kept turining her feed off, I'm not a happy mumma and feeling worried.

JUNE 19th

Hannah slept until 11.15 am!, things much the same, damn tummy pain is just NOT fair anymore why I have to watch her in pain day in day out it's been months, but more recently the pain has become worse. (I suspect cmv, reflux, drugs something else?) . Her hand on her sore wrist all of a sudden swelled up a lot I was worried but just watched and waited , a few hours later swelling came down.

JUNE 20th

NOT A GOOD DAY , this all seems a repetitive roller coaster ride. Wrist extremely worse I could take her to see her dr but I'd already spoke to them and just get " if you worried bring her in" pressure all on me and I get the feeling they all think I'm just a worry wart. Hannah's pain is bad the regular panadol and morphine she said has helped tummy pain but I can't give her these meds every day???
We have hospital Monday all day for Ivig, and pentamidine so will be getting her wrist checked. I think I'm just one tired mum who wishes this was all a dream I mean it's been nearly a year since we flew up for BMT and Hannah's been sick now for over 4 years.

JUNE 21/22nd

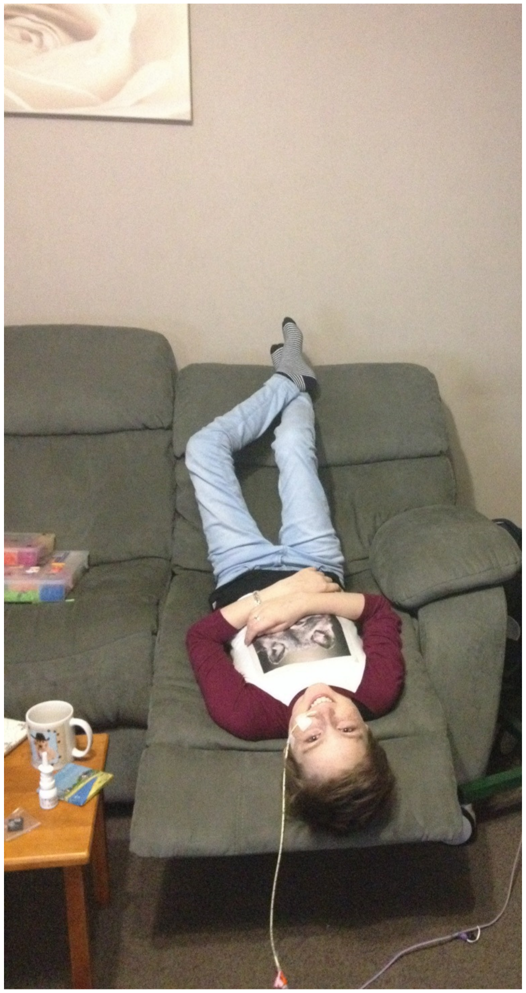
Another weekend in the Capil house. Hannah very unhappy ,very sad, very sore tummy and wrist and her muscles from physio on Friday. In pj and on couch all weekend. So I'm one unhappy sad mum. An example of meds for one day 6am-9.30am methadone, panadol, flucloxacillin , omeprazole ,valganciclivor , cyclizine, tacrolimus. Then started again 2pm for morphine, panadol, omeprazole, a vomit so had to re give omeprazole , valganciclivor, nortriptaline , flucloxacillin , more morphine, cyclizine, methadone , tacrolimus added to all that would of been urso as well 2 x a day but has been taken out to see what her liver does without it.

JUNE 23rd

9-5pm down at hospital for Ivig then pentamidine. Had long chat with hananhs dr down here it was good to talk to him (he knows Hannah best) it had been a few weeks, instead we've been seeing the registrars that are on and we seem to get a diff one each time even though they are nice. I expressed all my concerns as I didn't seem to get to say much in starship for several reasons.
Tummy X-ray done it showed nothing different to be concerned about, wrist X-Ray showed no break but as a precaution as her bones are weak from drugs ,have casted her arm to rest this in case there's a small fracture or damage to the part that's sore. If still in extreme pain once cast off in 1-2 weeks may consider MRI.
Hannah vomited 3 times today, was so tired she actually fell asleep late avo in the hospital during treatment.
Awaiting cmv results from last week. Added urso back in for liver as liver functions jumped up heaps which is a shame. Adding ranitidine if needed along with regular omeprazole for the bad reflux. Also considering 2 other meds for tummy pain.
We've still got a very long road ahead of us.
Very excited to see normal WBC and neutrophils and her platelets the highest they've been since BEFORE transplant.

JUNE 24th

My heart is broken today my eyes filled with hidden tears, Hannah had very rough night, she was up snuggled on couch first thing this morning and after another vomit she feel asleep until 1.15pm this is very unlike Hannah she fights sleep during the day unless she is extremely not well. So I'm worried. She turned her ng feeds off all avo she felt so sick and yuk, by tea time she had no choice but to turn it on for pain and antinausea meds and all her other meds too, but rate was set low.rest of evening Horrible , Hannah full of tears, rocking in pain, and she kept vomiting, so had to re give meds and some in the end I missed cos she kept spewing and I just couldn't get them in. Finally she settled to sleep late evening. Will see what she's like during the night and tomorrow.



Hannah's Topsy Turvy world – still smiling.

July 27th

I've decided because this journey is going to be a long one I'm going to sum this up for now. Today as I write it's been a year since transplant so a prefect day to end this part. All I can say is no one ever prepared us for the hell year that followed.

We still travel very regularly to starship and have close relationship with Invercargill hospital, weekly bloods and dr check, Monthly IVIG is still needed and monthly penatmadine, and whatever else comes along IV.

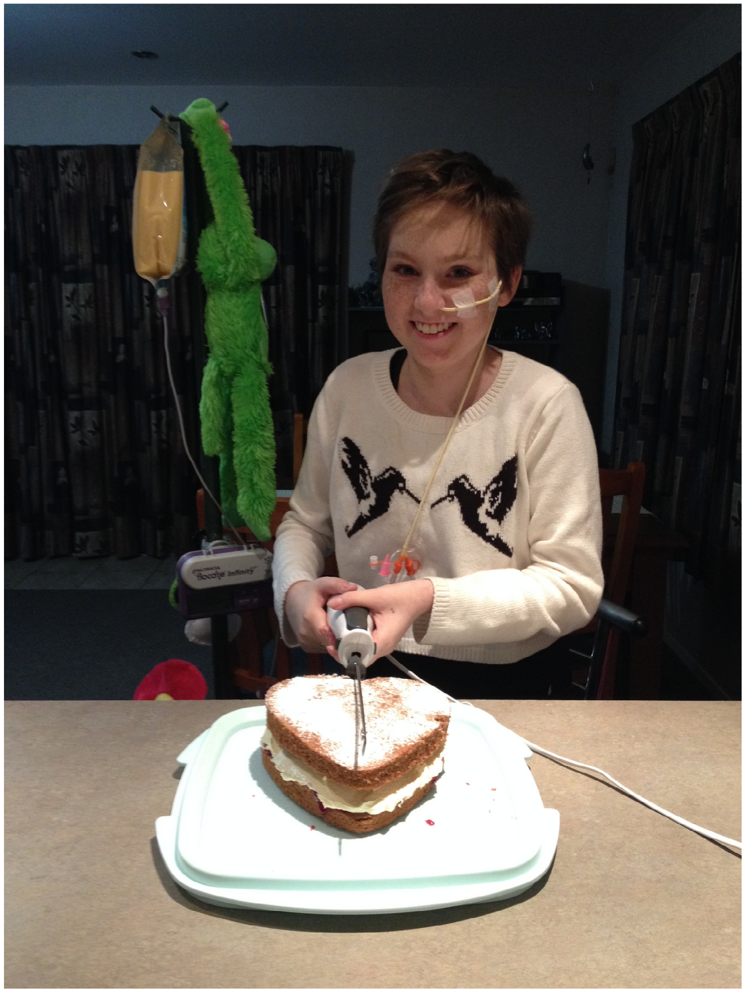
Understandably Hannah's a rare bunny so we and the drs always are prepared for anything out of the ordinary. We've been told that Hannah will basically have health problems for at least another 1-2 years!!. So I end this past year with her current (this weeks) issues in brief.

Platelets have dropped to 67 reasons Gvhd or virus or something else.
She was neutropenic 2 weeks ago but counts back to normal for the moment. Hannah's still 24/7 ng fed, but there are concerns as she's never got enough nutrition since transplant, she's probably only getting 60% of her daily requirements ,so awaiting test results and for all her vitamin levels etc. this could be the cause of some of her health issues. she's very stubborn and still turns feeds off or the rate down so becoming a real battle and her weight has been dropping. Drs do not know what the future holds for her with feeding or when or if she'll return to normal diet of real food, or what is going on inside her tummy.

Her physio is going well and she is getting a little stronger each month.
Still battling infections in toes on and off,and recently a slight line infection and the damn cmv virus keeps coming back but negative at the moment. Gvhd is in her mouth and eyes at the moment. And tummy pain still have bad days/nights needing morphine. School is out of the question still for a very long time could be 6-12 months , but is attending health school a few hours a week. Her broken arm is now out of cast but still in a lot of pain so just going to watch and wait.

She has days (most days) she's just feeling very ill, dizzy, headaches, in pain etc, nausea and nights she can't sleep also recent rough days of very low temperatures of 35.3.

But I will leave this past year on a positive note, we have our amazing girl home, she's still manages smiles and can be quite the joker. She likes to bake and help me in kitchen, she's such a strong girl and keeps us going as parents, as we continue this horrid journey what the next year will bring is totally unknown.



Beautiful Hannah with her cheeky smile