

Hannah Capil – Journey with PID .

Diary update by mum Lisa, May 2015. 5 years after diagnosis with PID Hannah and her family have been through bone marrow transplant and are still grappling with health issues . Lisa offers an update for all of those following Hannah’s brave story.



May 2015:

Wow I can't believe it's 2015 and it's been 7 plus months since the last update.

So here goes : basically Hannah has been battling weight, on NG feeds 24/7 , vomiting, bad mouth ulcers (Gvhd) extreme tiredness, trouble sleeping, still in wheelchair, damn CMV virus keeps coming back causing her to be more ill , been in cast for suspected broken wrist, still having monthly Ivig and penatmadine. Plus lots of other meds via her ng tube.

Life is still a day to day struggle and we wondered will this ever get better, even though she has come a very long way from this time a year ago.

1st October 2014 : no day time ng feeds Hannah's decision she was sick of being attached to it.. Drs said they will watch her weight etc.and to keep to night feeds she is finally starting to eat very small amounts....

Hannah's doing better more energy , went to the swimming pool (despite still having Hickman line in) no more cmv, less meds only on tacrolimus and antinausea, panadol when needed.. So Just when things were finally looking positive Hannah opted to have her Hickman line removed here in invercargill, well that did not go well what a horrible mess with huge cut and extreme pain... So took her home where the next day 24th October she vomited ng tube out, migraines, tooth ache, face looked irritated, eye sore, red spots on upper body then BANG admitted to hospital for 11 days with shingles. Hannah went down - hill very quick back on heaps meds back up to 10 a day at least from memory. And because she had no Hickman line in she endured over the 11 days several IV lines . Starship check - up was cancelled in November (she was too sick) as was our planned trip to drive our car from auckland home to Invercargill and to have some fun on the way back ,so Hannah was shattered as she had planned the trip and were finally looking fwd to a family holiday.

The rest of the year was battling the nerve pain from the shingles which was horrid., the odd vomit, low weight and energy and not happy.

By Xmas 2014: no more wheelchair, most meds weaned off.

We managed to get to The KIDS Foundation Holiday home with the boat for 4 nights. Then home to pack for Starship in January and finally the family trip home.

Starship went good the main concerns are her weight and feeds, and some Gvhd in mouth and possibly in gut.

Road trip home was great, was nice to see Hannah and Emma smile and have fun (and so did we) eg at rainbows end, Rotorua , Hastings etc .Hannah had no fear and did every extreme ride she could find .This time we treasured as you never know what's around the corner. But it was very tiring for Hannah , headaches, nausea so even though we had fun it's reality that Hannah's got a long way to go still.

Since March 2015 Hannah's done a few hours at real school which she hadn't been to for 2 years but finding it very hard/tiring so she's basically will be doing health school and do 2/3 hours a week of real school to just attend one subject she can't do as correspondence or with health school.

The days can vary with headaches and feeling sick and still very tired.. Recently, We've been having nights of random vomiting for 3-4 hours unsure why? drs watching . But for the first time in 2 years!!! She actually has put on 2kg and grown in height too, eating more and more energetic .

On the 1st may 2015 it will be 5 years since this horrid journey began....



So we will continue taking each day as it comes as she is still recently post bmt and still has compromised immune system...Lisa Capil May 2015