Date 05/08/2012

To the Parliamentary Inquiry Committee,

As a family we have experienced first-hand chronic illness and frequent hospitalisation services.
My child, Dion Jack Taprell, had a Mitochondrial Disease which was life ending without a cure. This Disease is known as Leigh's Disease. He was 3 years old when he passed away. 04/05/06 ~ 12/06/09

Our experiences caring for our child Dion, have prompted us to provide you with our story and our comments regarding paediatric palliative care in Queensland.

We acknowledge the difference that exists between disability and palliative care but we also recognise the cross over that is intrinsically linked for many children with complex medical conditions.

It is our hope that by sharing our personal experiences and recommendations we can contribute towards highlighting the need for continued change within the paediatric palliative care and disability landscapes.

Please find attached a more detailed account of my child's story that supports my comments.

Yours sincerely

Mr Warren Taprell & Mrs Tracy Taprell

Here is a little insight into our story.

Dion's story.

Dion was a surprise package from day one. I thought that I was having another girl but out came a boy with red hair.
I could not breastfeed either of my children due to having no milk so Dion went straight onto the bottle. He was classed as á lazy sucker' and would only drink half of his milk quota and that was pushing him.
As time went by his milestones were a bit behind but nothing to be worried about. Every second Thursday I would take Erin and Dion down to see our local health nurse to get them weighed. It was on one of these Thursdays that she mentioned to me that Dion had not gained any weight in eight weeks and to go and see our paediatrician.
Along came the roller coaster of a food diary, many blood tests, x-rays and ultrasounds to find a reason as to why.
Every test came back normal or negative and at this stage Dion's weight was just under seven kilos at 11 months of age.
We were booked into the hospital for Dion's first round of nasal-gastric tube feeding just two weeks before his first birthday.
That was a scary two weeks in hospital as no-one knew what was wrong with him and I had terrible thoughts that he would be taken away from me as I couldn't feed him and felt as though I had neglected him. At this stage Dion had virtually stopped eating all together and it became such a battle between us both that we hated the sight of food. He would cry and I would think(here we go again!) I had so many people trying to give me advice on how to feed him that I stopped trying to talk to them, because didn't they think that I had tried everything to get my child to eat?
We went home the day before his first birthday with his feeding machine that we have named

"Charlie' and that has been a constant fixture in our lives as Dion is fed via that three times a day for two hours at a time.
Dion was in and out of hospital every month for one reason or another until he became so sick and lethargic in September 2007 that we stayed in hospital for seven weeks.
Everything that went down his nasal-gastric tube came straight back up. The nursing staff would hand me up to 12 towels per day to catch everything that was coming up, and still no-one knew what was wrong. He was losing more and more weight as the weeks went on and I was very scared that I would lose him.
Dion finally had surgery to place a gastric tube into his stomach and to perform a fundoplication. That is where the stomach is twisted around the oesophagus to stop anything coming up through the throat, so he could never vomit again.
He finally stopped vomiting and began to gain weight so we could go home.
He went back into hospital over new year with a tummy bug so the doctors decided to do an MRI while he was in there.
My husband and I thought that the scan would come back normal just like every other test and scan he had had.
How wrong we were.
Our Paediatrician rang our room and said that the MRI had come back abnormal and he was on his way in to talk to us about 'LEIGH'S DISEASE'.
We didn't know what to say or to think but knew that our lives had been changed forever and we cried many rivers of tears.
We learnt that this disease is terminal with no medications, operations or cure.
I can still remember the feeling of what felt like my heart breaking and thinking that we had to start planning his funeral straightaway. The range of emotions we went through that day were amazing. Guilt was a big one as was the question Why us, why him.
Many specialists came to see us to offer advice, support and information on this disease.
Leigh's disease is a rare inherited nurometabolic disorder that affects the central nervous system. It is a mutation in the mitochondrial DNA from both my husband and I. As this disease progresses Dion will lose muscle tone, forget how to do things such as talk and move which will then affect his organs until they start to shut down where eventually he will forget how to breathe and end up on a ventilator until we decide it is time to say goodbye.
With Dion's strain of Leigh's Disease the age of dying is anywhere up to the age of six to seven. He will turn three in May.
Dion's big sister Erin (4.5) knows that her little brother is sick but not to the full extent. She just knows that he can’t eat like her and in her words"he has a sore head on the inside". The amount of time we have spent in hospital has been tough on her but we have had wonderful family support that she has been well cared for and loved.
Someone once asked me if I felt angry that an MRI hadn't been done sooner but the answer is no, as I had 20 months of not knowing my little boy was going to die.
It is sometimes hard to watch family and friends'kids growing up and running around as I know that Dion will never get to that stage in life. He cannot walk but can crawl and can talk enough that we can understand him but he does manage to annoy his sister and they fight just like any other siblings and it is these moments and memories that will keep us going.
We don't really know what is in store for Dion and we don’t plan too far in advance but we have been told to give Dion the best quality of life we can, so I take him out everywhere and give him as much normality in life as I can but within reason.
These are the times that will stay with me forever and I will give him and us as many fun memories that I can ...

Sadly Dion passed away 4 months after I wrote this story.

Dion NEVER received Palliative care until the day he died, so therefor we had to trust a Dr that we had never met before to help our beautiful child feel that it was OK to let go and die peacefully.
Dion NEVER received respite care yet he had a terminal illness.
There is currently NO children's respite hospice in Queensland.
We as a family NEVER got to go to a children's respite centre, to let Dion experience a fun time with help surrounded.

After Dion passed away all services stopped…..
That is something that is hard for a grieving family to accept. All the friendly people we knew were now no longer a part of our 'hospital family'.

If Queensland had of had a Children's respite hospice, then Dion could have died in a place full of love, care & comfortable surroundings, instead of a hospital room that had to be shut off to other people so no-one came in to interrupt our grieving.

Dion was our life and we wish for other families to have the help, care and assistance that were not offered to us.
There seems to be no WHO definition of Palliative care for Children.

I hope that our story helps in offering a Palliative respite hospice FOR CHILDREN IN QUEENSLAND..

Sincerely Warren & Tracy Taprell