

5 August 2012

**Request to have our names confidential please but happy for our submission to be published.**

To the Parliamentary Inquiry Committee

As a family we have experienced first-hand care of a child with chronic illnesses, disability, frequent hospitalisations and all related health services. My child, T [REDACTED] [REDACTED] has 1P36 Deletion Syndrome, resulting in a life limiting condition Chronic Lung Disease and Bronchiectasis. T [REDACTED] is 3 years old and was born on [REDACTED]

Our experiences caring for our child T [REDACTED] have prompted us to provide you with our story and our comments regarding paediatric palliative care & home and community care services 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

[REDACTED]  
[REDACTED]  
[REDACTED]

To the Parliamentary Inquiry Committee

Further to my introduction letter, I would like to submit further details about our family and also about our hopes and dreams for the future of palliative care, home & community care services, disability, mental health care support and chronic health care in Queensland.

I will endeavour to respond to the Terms of Reference supplied.

I will also use the WHO definition of Palliative Care for children as my basis of what we should be aiming for in Queensland. I note that this definition was NOT included in your Terms of Reference.

*As parents, we hope our children will experience a wonderful life journey on our planet.*

*For T [REDACTED], we have the same dreams.*

*But, we recognise that his future is uncertain. During these uncertain times, this is what hope looks like to us...*

#### *WHO Definition of Palliative Care for Children*

*Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):*

*Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.*

*It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.*

*Health providers must evaluate and alleviate a child's physical, psychological, and social distress.*

*Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*

*It can be provided in tertiary care facilities, in community health centres and even in children's homes.*

## Our Journey

### The beginning

On 22 April 2009, we welcomed our fragile yet determined little boy T [REDACTED] into the world. At 3 weeks of age, T [REDACTED] stopped breathing at home and turned blue very quickly. My husband resuscitated him with the help of the ambulance over the phone. T [REDACTED] went on to spend months in PICU and the Mater hospital. We almost lost T [REDACTED] again due to life threatening seizures. We baptised our baby in intensive care and we were told he would probably not make it.

### The happy times

In April 2012, we celebrated T [REDACTED] s 3rd birthday! Over this last year, T [REDACTED] has learnt to weight bear for short periods and to get from sitting on a chair to standing with some support. There were tears of joy when he first started to take some intentional steps in a supportive walker device. He has started to enjoy drinking water from a sippy cup (T [REDACTED] is tube fed) and he continues to develop his own beautiful communication style - with sounds, eye contact and a whole lot of expression!

Reflecting on what T [REDACTED] has achieved this year, rather than what hurdles life has presented, has reminded us that while T [REDACTED] is a little boy with so many challenges in life, therapy is the key to helping him develop and we must never stop doing all we can to give him the opportunities he deserves. T [REDACTED] s neurologist continues to report that T [REDACTED] is evolving - meaning his brain is developing all the time which is so wonderful because who knows how far T [REDACTED] could go with the right therapy and early intervention.

### The diagnosis

T [REDACTED] has 1P36 Deletion Syndrome, which means he is missing a very tiny part of Chromosome 1. There is no known reason why this happened to T [REDACTED] - except that it's a small spelling mistake in T [REDACTED] s genetics, resulting in specific symptoms and major challenges.

As a result of this syndrome, T [REDACTED] suffers hypotonia (very low muscle tone), seizures, hearing loss, vision delays, difficulties with communication (absent speech) and inability to feed orally (T [REDACTED] is fed via a tummy button into his small intestine), painful reflux, developmental delay and other health issues. For T [REDACTED] one of the side effects of low tone and developmental delay is a very weak respiratory system that has led to a diagnosis of Chronic Lung Disease.

T [REDACTED] has suffered many episodes of pneumonia and other respiratory illness in his life. He is oxygen dependent much of the time. He has Chronic Lung Disease caused by continuous aspiration of saliva, repeated respiratory illnesses causing damage to his lungs and low tone issues.

This year delivered a new diagnosis of Bronchiectasis for T [REDACTED] - it's an obstructive lung disease, resulting in airflow obstruction and impaired clearance of secretions. It means that T [REDACTED] needs a lot more therapy and aggressive intervention when he is sick - and when he is well, he has daily treatments at home to slow down the progression of this disease. Given the nature of this condition, doctors are unable to give us a predicted life span for T [REDACTED]

However, given the uncertainty, we are meeting with Palliative Care Qld this week so that we can build a relationship with them now and ensure that T [REDACTED] is supported from a "pain & anxiety" perspective in his future life.

### What he does

T [REDACTED] s busy week involves attending Xavier Conductive Education twice a week to help with his development, weekly appointments with his privately paid Physiotherapist and Speech Therapist and attending regular appointments with specialists and doctors.

**What he needs**

There are many adults and children in the world with 1P36, so we can learn from them and we know he needs the following:

- \* Lots and lots of Specialists! Including Neurologist, Pediatrician, specialist dental work, Gastroenterologist, Orthopedic specialist, ENT, Respiratory specialist, Ambulatory Care Services and more! All of these specialists help to keep him well and make him comfortable.
- \* Specific therapies including Physiotherapy, Speech Therapy, Occupational Therapy and other Alternative Therapies.
- \* Specialised disability equipment.
- \* Suitable, flexible intervention for his chronic health condition.
- \* A life that provides opportunity, stimulation, variety, inclusion, love and friendship.
- \* To live a pain-free life.
- \* Healthy, mentally stable, happy parents who can continue to meet his high-care needs.

## What we, as T [REDACTED]'s family, need in relation to the Inquiry into palliative care services and home and community care services in Qld

### Good mental health support

- From the moment a family is given a diagnosis of a life limiting disease or disability for their child, there needs to be outstanding mental health support. There needs to be a program put into place urgently so that families can survive this journey without experiencing health issues themselves caused by chronic, unrelenting stress and pressure.
  - Personally, I have experienced a range of health issues related to the stress/grief that the last 3 years have delivered to us. Including depression and anxiety. These led to unusual symptoms involving body numbness that led to MRI's etc checking for MS, stroke, etc. The tests were clear. The neurologist diagnosed chronic stress as the cause. My nervous system had reached its peak. The next step was a break down if I didn't do something.
  - I have endeavoured to access respite to enable us to get sleep 1 night per week, but we could never find a suitable carer. I wonder how my husband G [REDACTED] actually gets out of bed each day and goes to work and manages to function in a stressful job after sharing the duty of getting up to T [REDACTED] throughout the night on a daily basis.
  - I have engaged the services of a private psychiatrist. It is extremely beneficial, however, almost impossible to get to the appointments in the city due to T [REDACTED]'s ever changing health and finding suitable Carers. How can we do this better? Offer services in the home?
  - I now understand that as a parent of a child with chronic illness/disability, we are on a constant journey of grief that started with an initial diagnosis and has not stopped. It is a rollercoaster of emotions and it's very difficult to understand. You think you have a hold on it and you have beaten it, then you get a new diagnosis of illness for your child and the grief process starts again.
- The worry of what will happen to your disabled child if something happens to us as parents is debilitating. Someone needs to be there to help parents through these concerns.
- The rate of divorce for couples that have children with disability is very high. Education and support for couples on what they will face on this journey is very important and is NOT available.
- I have met many couples who both parents have had to stop working as the high care needs of their child, lack of sleep, lack of respite and chronic stress has made it impossible to work. My husband G [REDACTED] has a good job and works very hard. But I understand how it could become impossible for families to maintain a job. I imagine it must be impossible for those families who are outside of the "Brisbane catchment areas" also.
- Please note, that the type of psychologist/psychiatrist needed for parents in this situation must be someone VERY skilled in this area of work. [REDACTED] [REDACTED] however, we did access a wonderful Counsellor in the hospital very early on in our journey and we may not have got through those first few months without his support. He was able to educate us that what we were experiencing was "grief" and we were experiencing it very differently - as men and women often will.

## Siblings

- Implement a range of suitable education, support and inclusion groups for siblings of children with life limiting illnesses and disability. These MUST continue to be accessible if the sibling passes away.
  - Our other son H [REDACTED] is almost 5 years old. He loves and accepts his little brother completely. However, we are just starting to see some behaviour that may (or may not) be related to the stress of the uncertainty that is unavoidable in our home.
  - I fear that the sadness, uncertainty, isolation, and anxiety that H [REDACTED] WILL experience as he gets older and realises the full extent of his brothers disability and life limiting disease, will lead to depression for him later in life. We need help to understand what we can do NOW and in the future to help our son avoid this.

## Grief and Bereavement

- From the moment you have a diagnosis of chronic illness and/or disability, the grief cycle starts.....and it doesn't end.
  - There are times when T [REDACTED] has been doing so well, and we have allowed ourselves the joy of "looking to the future" with hope. Then we received a diagnosis of Chronic Lung Disease. This was the first time the "Palliative" word was discussed with us.
  - [REDACTED]
  - We got through that time, and once again started to look forward and be hopeful. Then the diagnosis of Bronchiectasis was given and we fell into the grief cycle again. And the "Palliative" word was discussed again.
  - I am pleased that we are being given the opportunity to meet with Dr [REDACTED] [REDACTED] at Ambulatory Care Services at Royal Brisbane Hospital so that we have made contact and have someone to look to if T [REDACTED] does become more ill in the future. In the mean time, we need to find a way to continue on, be positive and never lose hope, while all the time, being honest with ourselves that our time with T [REDACTED] could be short. These feelings are very difficult to deal with and there needs to be strong support for families through this time.

## Hospital Admissions

- As a privately insured patient, I have unfortunately had the sadness to learn that we have been missing out on some publically funded services. HITH is not the only service we have missed out on.
  - You will see in Attachment 2 a letter that is self-explanatory and was written by me not long after we received a diagnosis of the life limiting disease "Bronchiectasis" for T [REDACTED]. The energy it takes to write a letter like this is exhausting. **It's as if you have to reach breaking point and have unusually high adrenaline levels to get to the point that you can write these letters. Then you slump. And you wonder why you have to "fight" the system like this all the time. All we should be focussing on in a time of gut-wrenching heart ache, is caring for and loving our children.**
- On the other hand, having private health insurance has been a blessing for us. The Mater Private Hospital has been our "home away from home". A mostly kind, welcoming and safe place for our child and family. Having the space to be with family in a private room has been a blessing. Having the option of buying a parent meal has been a

blessing. I believe that had we been in a shared public room on these very regular and long hospital stays, it would have added an enormous amount of additional, unnecessary pressure.

- I am already fearful of the new hospital that is being built. [REDACTED]
- We have heard that there will not even be enough beds in the new hospital for the children who will need them. I am very fearful of what this will mean to our future care. I am fearful of what will happen to emergency waiting times in the new hospital if we lose the Royal Brisbane Hospital.
- WE are the clients of the hospital. WE are the users of the service. I hope we can have some clarity around what the new hospital will provide soon.
- Every time T [REDACTED] is sick enough to go into hospital, we have to go via Emergency. There have been many times that we have sat for 8+ hours until we have been admitted - and that is as a Red Star/Complex Care patient. The stress, anxiety and ill health this causes are tremendous.
  - **PLEASE PLEASE PLEASE have a fast-track system put into place for chronically ill children who present at Emergency. If T [REDACTED] presents with low oxygen saturation above the level we can deal with at home, we need to be admitted! It should not take 4, 5 or 10 hours to get to that decision!**
- Looking back, we were sent home from hospital with a very, very sick and undiagnosed child. Then, after T [REDACTED] had been resuscitated at home and we had gone through weeks in PICU, we were once again discharged from the hospital with a gravely ill child. Because we were Private patients, I NOW realise that is why we had not been offered home support, which is unacceptable. T [REDACTED] went on to stop breathing on us time and time again and we would always land back in Emergency in an ambulance.
  - There was never any official dissemination of information on which departments would assist us/we had to register with, available supports within the community and what to expect with our little boy.
  - The link between Health and Disability is poor and is failing people on a daily basis. We were the lucky ones. We had the ability and the resources to find the information. It almost sent us to breaking point, but we just got through - so far. What is happening to other people who do not have this ability? The system is built to confuse - from where we sit, that is how the Government is managing costs in certain departments.
- The option of In-Home Care for people who wish to access services that way MUST be developed further. If we have the option of in-home care in the future, supported by quality, consistent respite, it helps things to run more smoothly and helps to avoid job losses for spouses and mental health issues for siblings and parents.
- In USA and UK, children are being diagnosed with rare chromosomal disorders at 2 weeks of age. In Australia, this takes months before you are even offered the testing, and then months to get the results. My understanding is that it is due to lack of funding and resources for Micro-Array Testing. I hope the importance of early diagnosis will be discussed. While Micro-Array testing does not provide an answer for everyone, it does for many.

## Service Providers

- I cannot speak highly enough of groups like Xavier Children's Support Network who have been a valuable support to us, especially in our earlier years. I honestly do not know how we would have survived without them when we first brought home our sick little boy.
  - I sincerely hope that easy access to Xavier Children's Support Network will not change and I fear that they will have to become a "business" in the future

structure, rather than a not-for profit charity that receives some Government Funding.

- I support the Mamre structure that allows people with chronically ill children/disabled children to access self-managed funding that can support the “entire” family and not just the disabled child.
- HACC flexibility is a positive thing and maybe one of the few things that “works” in a very much broken system. PLEASE don’t change this flexible and supportive way.
- Funding needs to be structured to address individual circumstance - disability, disability with life limiting illness or life limiting illness/palliative care with no disability. Needs may vary.
- [REDACTED]
- The option of In-Home Care for people who wish to access services that way MUST be developed further. If we have the option of in-home care in the future, supported by quality, consistent respite, it helps things to run more smoothly and helps to avoid job losses for spouses and mental health issues for siblings and parents.

## Hospice Care

- The last link in the chain is one of the most important.

*“With Australia’s population of almost 23 million there are only 2 children’s hospices nationally and none of them are in Queensland. The UK’s population of almost 63 million boasts 44 children’s hospices.”*

- Our son T [REDACTED] has a syndrome that is estimated to be 1 in 5,000 to 10,000. Early on, I found other families with 1P36 in the UK and USA. I remember wondering why they had these beautiful respite homes in the UK and why there was nothing like that here.
- Early in our journey, we were offered overnight respite for T [REDACTED] - we could send him to a stranger’s house, with beds in a room that conjured up images of institutions to me. It never made sense to me to even consider sending my critically ill child to a stranger’s house, where there would not be a trained nurse on 24 hour watch. This was NEVER the answer for me personally.
- However, over time, we realised that if we didn’t get some sleep, we would break down. I often joked that Belmont Private Hospital was a nice potential mini-break destination. Sadly, this was more of a fear than a joke. I know of mothers in our situation who have had breakdowns, and I was frightened. When I think too far into the future, I become frightened again.
- Thankfully, we built a relationship with one of T [REDACTED]’s Carers and over time, we had the confidence to let him have an occasional overnight stay with her.
- Very recently, we have been offered a once a month overnight stay with this Carer and it does provide some relief. But my heart still breaks every time because I have to separate my two little boys for overnight care. H [REDACTED] has recently started to ask if T [REDACTED] can go to Gran and Grandads with him. We have to say that unfortunately, it is too much for them to care for T [REDACTED].

**\* But this is not a soft place to fall for our family \***

- 12 months ago, we had the wonderful experience of visiting Bear Cottage in Sydney. We drove down there (as T [REDACTED] is too unwell to fly) and spent a few days there. It is a sanctuary for palliative children and their family AND children with life limiting diseases and their families. It gave us the opportunity to have a few days away with H [REDACTED] on our



own also and do some things that T [REDACTED] is not well enough to do. It gave us much needed rest and respite. It allowed G [REDACTED] and I the chance to just talk again, and in doing so, is nurturing to our marriage.

- We were able to take T [REDACTED] out in the day, but sleep well at night. When we did leave T [REDACTED] at Bear Cottage, we felt so confident and not guilty like we usually do. He had music therapists, beautiful volunteers to play with him, he went on walks, and he was surrounded by colour and sunshine and warmth. And he had 24/7 professional nursing care in a beautiful home with a Labrador called Frankie. We weren't handing him over to "respite" so we could sleep. We were giving him a life outside of us. A chance to belong too and a chance to experience new and wonderful people.
- Our son H [REDACTED] still speaks about Bear Cottage and asks to return. He didn't notice the very sick children who sat quietly in their chairs. Because they were at peace. Not screaming like in the hospitals. He didn't notice that the nurses caring for T [REDACTED] were nurses, because they were dressed in plain clothes and smiled and played with him too. Frankie the dog became his best friend very quickly. And as much as my heart was aching, we had found a place that, as a family, we belonged.
- A mother arrived while we were there with a small baby deemed palliative. She was very frightened and distressed. We sat and talked a lot that day and I think, in some small way, I gave her a soft place to fall.
  - I hope and pray that the Queensland Government will provide on-going and generous funding to Queensland Kids so that they can build the only hospice in Queensland to help children and their families with life limiting illnesses. I hope this will be done with little need for continuous "review" and "interference" from people who do not understand.

*As parents, we hope our children will experience a wonderful life journey on our planet.*

*For T [REDACTED], we have the same dreams. The Queensland Government can help us with this - please support Hummingbird House. And give families who have children with life limiting illnesses much needed respite, a place to belong and a soft place to fall when we need it.*

## ATTACHMENTS

### Attachment 1

Link to the video that supports our story and in support of Queensland Kids and Hummingbird House - G [REDACTED] and I, along with our son T [REDACTED] appear in this video.

LINK:



### Attachment 2

Letter that I sent to the Mater Hospital regarding Hospital In the Home Program and the issue with Privately Insured patients being unable to access this program. This letter has been included in the Federal Inquiry into Palliative Care.

### Attachment 3

Photos of our family

**COPY OF LETTER THAT EXPLAINS THE ISSUE OF HITH NOT BEING ACCESSIBLE TO PRIVATELY INSURED PATIENTS.**

11 June 2012

To the Mater Director of Allied Health and DAART Paediatric Program

**Regarding T [REDACTED]  
Hospital in the Home Program (HITH)**

I am mum and full-time Carer to my son T [REDACTED]. T [REDACTED] is 3 years old and has 1P36 Deletion Syndrome. This syndrome results in severe hypotonia, epilepsy (controlled currently), inability to feed orally (fed continuously via jejunum), oxygen dependency (on and off), Ebstein's anomaly, poor immune system, severe reflux, hearing loss, vision delays, etc. T [REDACTED] also has a diagnosis of Chronic Lung Disease caused by complex chronic aspiration and regular respiratory illness. On our recent stay in hospital, he was given a further diagnosis of Bronchiectasis.

We have a Private Paediatrician and we are public patients with the Mater Children's Respiratory. We have private health cover with Medibank Private and T [REDACTED]'s extensive and complicated medical history has always been with the Mater Children's Private Hospital on Level 8 who we are forever grateful to for their support.

I am writing in regards to our recent stay in hospital. T [REDACTED] was admitted via the emergency department with suspected pneumonia. After staying a few days, we went home with T [REDACTED] and our usual care plan, however, he did not pick up as he normally would. We were re-admitted directly into the Private Hospital and stayed another week. The Mater Children's Respiratory Team was then able to explain to us that T [REDACTED] very likely has Bronchiectasis and that is why he was not picking up as he normally would. While this news was heartbreaking for us as parents, our doctor was able to teach us how best to care for T [REDACTED] and avoid/delay further damage to his lungs. We always appreciate our doctor's open, honest and sensitive approach with us.

However, we soon realised that while T [REDACTED] was not especially "unwell", he was certainly going to need another week or so of "specialised treatment" that did not necessarily need to be done in the hospital. To help us to get home, we were offered the services of Hospital in the Home (HITH) to enable us to get home. My husband and I had never even heard of this wonderful service before (which is surprising given we have a chronically ill child with complex disabilities) and it was wonderful to learn of it.

However, we were soon to learn that we, as privately insured patients who stay in the private hospital, were not "entitled" to access the services of HITH. HITH is a service that only public patients are allowed to access. On top of the recent 2 week stay in hospital and being delivered the news that our little boy's lungs are even sicker than we were already aware, we now had to be told that we could not access a "public service".

Over the next few days, we were left in limbo wondering if we would be able to access HITH, and if we could, who was going to fund it. The discussions were about our private health insurance, Mater Private hospital funding it, etc.

Eventually, we were grateful that the Mater Private Children's hospital offered to fund a nurse to visit our home for 7 days to administer IV antibiotics for T [REDACTED] and a physiotherapist to visit twice a day for 3 days, then daily for 2 days to do chest physio for T [REDACTED]

This brings me to the reason for my letter. Given T [REDACTED]'s diagnosis of Bronchiectasis, it is likely that T [REDACTED] will need this same specialised treatment in the future. And if T [REDACTED] is well

enough to actually be at home, that is where he should be. **Therefore, we need to understand who is going to fund HITH for our family going forward please?**

A few important points I should mention are:

- Becoming a patient of the public wards is not an option for us. We have paid \$40,000 in private health insurance to enable us to access the services of the private health system. It is our right to remain a private ward patient.
- Becoming an intermediate patient is not an option for us. T [REDACTED] has a very weak immune system and one of the most important things to us is that we have a private room when we he is a patient on the wards. This privacy protects T [REDACTED]'s health. It also protects our sanity. T [REDACTED] cannot sleep any outside stimulation and he would struggle to ever get rest in a room with other children/families. We always ask to be discharged as soon as T [REDACTED] is well enough as staying in hospital for too long always means he ends up contracting a new infection or illness. He keeps much healthier at home. It also means that we try to limit long hospital stays as it puts our other child under a lot of stress when T [REDACTED] is in hospital and it makes it hard for my husband to maintain his own job during these difficult times.
- As with any family who has a child with a chronic illness or disability, T [REDACTED]'s condition and admissions do mean my husband and myself are under an extreme amount of stress and pressure. It is important that I stay as healthy as possible to be able to keep up with the demands of a high needs child. The issues surrounding who was funding HITH put both my husband and myself under a great deal of unnecessary stress and caused much upset. It is hard enough as it is, without having the humiliation and stress of knowing that departments are arguing over who will fund treatment for our son.
- I am completely at a loss to understand why HITH is only offered to public ward patients and why private ward patients are not eligible. I am intelligent enough to understand that this is a funding issue and no one wants to pick up the cost of HITH for private patients. However, from where we sit, this is very much a discrimination issue and our family is being discriminated against because we have private health insurance. While I have not sought legal advice, I feel very confident that this is a discrimination issue. While we hold private health insurance and while we choose to stay on the private wards during our admissions, it should not mean we are exempt from accessing public health systems and programs. We already do access public health systems and programs - so why is the HITH program any different?

I was told that I should contact our private health provider and the Mater Private Children's hospital about this issue, however, while I have copied them on this letter, I do not see it as their issue. Our health system is largely funded by the Federal and State Government and is supported by private health insurance. Both the private hospital and Medibank Private are businesses and they are in the business of making money.

This issue is about our family accessing Federally and State funded public health systems. And about our family having the freedom of choice to do what works best for OUR family and our sanity and health. This issue is about both our public and private health systems working together to avoid these types of unproductive and highly stressful obstacles for patients and their families.

Finally, I ask that someone makes a decision as to how this will work going forward so that the next time we have a need to use the HITH program, there is no confusion or upset please.

We look forward to hearing from you.

Yours sincerely, N [REDACTED]

