11 June 2012

To the Mater Director of Allied Health and DAART Paediatric Program

Regarding
Hospital in the Home Program (HITH)

I am mum and full-time Carer to my son . 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. 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 Bronchiectisis.

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 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. was admitted via the emergency department with suspected pneumonia. After staying a few days, we went home with 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 very likely has Bronchiectisis 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 and avoid/delay further damage to his lungs. We always appreciate our doctors open, honest and sensitive approach with us.

However, we soon realised that while 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 boys lungs are even more sick 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 and a physiotherapist to visit twice a day for 3 days, then daily for 2 days to do chest physio for .

This brings me to the reason for my letter. Given diagnosis of Bronchiectisis, it is likely that will need this same specialised treatment in the future. And if 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. 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 health. It also protects our sanity. 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 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 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, condition and admissions do mean myself and my husband 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 type 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