MJ & TJ HEDDES
[redacted]

6 August 2012

To The Parliamentary Inquiry Committee
Health and Community Services Committee
Email: hcss@parliament.qld.gov.au

RE: PAEDIATRIC PALLIATIVE CARE IN QUEENSLAND

As a family we have experienced first-hand having a disabled child with frequent hospitalisation and now classed as Palliative care.

Our child, Bailey Heddes, has a life limiting condition known as Congenital Muscular Dystrophy Merosin Deficiency. Bailey is 12yrs old and was born on 10.11.99 at the Gold Coast Hospital, Southport.

Our experiences in caring for Bailey 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 and their families.

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 detailed account of our child's story that supports our comments.

Yours sincerely

TIFFANY HEDDES
Enc.
cc.
Premier Campbell Newman
Senator Susan Boyce

Rob Molhoek MP
Queensland Kids
Dr Anthony Herbert
Dr Margaret Harris
Dr David Pincus
Nicolette Thornton
Katie Bunch
Physio 4 Kids

MJ & TJ HEDDES
[redacted]

3 August 2012

To The Parliamentary Inquiry
Committee
Health and Community Services
Committee
Email:
hcss@parliament.qld.gov.au

[redacted]

This morning I am reminded yet again of the importance of having a Palliative Care Respite Facility in Queensland.

My friend has a 3yr old daughter who is Palliative Care and the only way the family can have a break is for their daughter to be placed in hospital once a month for a weekend and to be cared for by nursing staff that are not trained in Palliative Care management. Last weekend whilst in the care of the hospital incorrect medications were administered and now her daughter is critically ill. This simply should not happen and would not happen if there was a dedicated Palliative Care Respite Facility. How can parents rest easy and how can they get a break if this facility is not provided??? Imagine being on edge 24hours a day, literally living hour by hour minute by minute for a long period of time, it is darn right difficult, stressing and your body runs on adrenalin. You as a parent cannot continue to live like this, something has to give.

OK, so why am I telling you this. I too am a parent of a Palliative Care child, Bailey, 12yrs, who lives with a rare form of Muscular Dystrophy, a cruel muscle wasting disease that robs his body of any tone and strength.

Bailey is a gorgeous (yes we are biased!) bright and intelligent child, wise beyond his years. He simply is living in an extremely weak body.

Bailey faces many challenges every day and faces these challenges with unwavering courage and determination to make the most of every day, every moment. Bailey is ventilated (his lung function is down to 5%) fully PEG feed, has severe scolosis, many contractures, relies on regular sub-cut medications up to 6 times daily, requires ongoing pain management, relies on a power chair for mobility and requires full assistance for personal care and all daily tasks. Bailey is unable to lift his limbs against gravity. Imagine not being able to move on your own, next time you subconsciously take a step, imagine what it would be like not being able to roll, crawl, walk, run down the hall and throw your arms around your mum! These are things we all take for granted but are the everyday things Bailey is unable to do due to his weakness. I have attached his Daily Care requirements, although have struggled to list them as it is something we have done automatically for many years and we just don't think about it anymore!

For the past 2 years Bailey has been classified as Palliative Care....... **Palliative care** is **care** that is designed to relieve the symptoms of a disease rather than to cure it. It is used for the comfort of the person with the disease, especially if they have a disease that is incurable, and no further medical intervention can improve the disease. Palliative care is a matter of quality of life not quantity.

We have chosen to nurse Bailey at home, it is both his and our wish for him to pass peacefully at home. The care to date that

Bailey and our family have received from the Queensland Paediatric Palliative Care Service and other medical professionals is to be commended. A special thanks to Dr Anthony Herbert, Dr Margaret Harris, Dr David Pincus, Nicolette Thornton – Clinical Nurse Consultant, Physio 4 Kids, Blue Care and Katie Bunch, Clinical Psychologist. We are extremely grateful for their commitment to assisting us to give Bailey the best possible quality of life.

This team offers support by visiting Bailey at home, by regular tele-health conferences, providing scripts for ongoing medication, emotional support and by being available for the odd midnight and weekend urgent calls!!

Ongoing to assist us in caring for Bailey we would love more RESPITE. No, let me rephrase – WE NEED MORE RESPITE, it is not a luxury, it is a necessity for us to continue doing what we do. We do receive some funding through Department of Communities for in-home respite care and we as a family employ a private carer at a cost of $700 per week from our pocket. We can only afford to do this as we run our own businesses from home. My business is Special Needs Solutions and we provide equipment for disabled children throughout Queensland and New South Wales. This business evolved from my need to source specialised equipment for Bailey from overseas.

It is a tough gig, caring for a Palliative Care child, other family members (Bailey has an older Brother Sam 16yrs), my sister has an intellectual disability and is cared for by my ageing parents, running a business and keeping up with everyday life. We are always exhausted and tend to run on adrenalin but you do what you do to provide the best quality of life for your child, disability or not.

Hummingbird House is a necessity, not a luxury, we and many other Queensland families deserve some respite from the constant pressure and stresses of caring for a child with a life threatening illness. Life is so fast pace, crazy and busy for everyone, add to the mix caring for a child like Bailey – you cannot deny our family requiring a break.

To be able to send Bailey out of home for respite would be amazing. It would give us the opportunity to:

Have privacy in our own home (it can be challenging having constant carers in your home)

Time to re-charge and re-fresh

Allow us quality time and full attention for our other son, Sam

Allow my husband and I some “our time”

We could go out and visit friends and socialise

Go to a movie together

Go for a long walks along the beach

Just sit and relax and not be constantly on edge or we could be spontenous and do what we liked. This would be a novelty as nothing happens quickly with Bailey, it is a military operation and takes approx. 2hours to get Bailey ready to leave the home!

Having a disabled/Palliative care child at home is a hard task. Too large a task to be left solely to the parents.

Queensland Kids Vision Statement:

"Queensland Kids is a recently incorporated charity with the vision of creating an innovative and sustainable respite facility addressing a significant gap in Queensland's paediatric landscape. By establishing Hummingbird House, Queensland Kids will deliver a supportive home away from home for families impacted by a child's life-limiting illness."

Bailey is now 12 years old. A short life. But a long haul 24/7 for my family. We are not asking you to take over. All we ask for is a break. We have carried the load, done the hard yards and it has cost us serious money for the vital mobility aids and nursing care. He is our son, our dear boy and we love him and we will continue the, at times exhausting, full time job of providing him with the limited quality of life available to him.

A disabled child should be offered respite care. It is a community responsibility and should not be the sole responsibility of the parents. This view is shared by Senator Susan Boyce. In a recent tele-health conference with Bailey and I the Senator gave unequivocal support for continued funding to care for all disabled children.

This conference resulted in a personal letter from Premier Campbell Newman who stated that Bailey was a great role model for the community and truly an inspiration to Premier Newman him self.

These positive comments, plus the pleas of many parents of disabled children demonstrate clearly the need for this Parliamentary Inquiry and the need for Hummingbird House.

Yours sincerely

TIFFANY HEDDES

Bailey's Daily Care requirements:

1. Regular suction of secretions. Bailey has lost the ability to swallow

2. Daily medications administered up to 4 times daily subcutaneously, which is through a small needle inserted under the skin with a port that we are able to inject drugs through. Current medication:

   Midazolm for pain relief, anxiety and sleep

   Glyclopyrrolate to control secretions

   Cyclizine for constant nausea

   Fentanyl skin patches for pain management

   Lexapro – for anxiety and depression

   Movicol for bowel movements

3. PEG feed – Bailey is unable to take anything orally due to his inability to swallow. He is fully PEG fed – which means he lives on a special formula, known as Jevity to provide all his nutrition requirements. This feed is pumped continuously into his stomach via a tube that sits on the outside of his stomach and goes directly into his stomach.

4. Infection control is a must

5. Bailey requires full assistance for showering, brushing hair, cleaning teeth, dressing etc. He wears nappies for incontinence.

6. Bailey requires full assistance to be lifted out of bed and seated in his wheelchair. This is a process and can take some time to position him correctly.

7. Bailey predominately lays on his right side and is prone to skin breakdown and ulcers. He finds breathing difficult when laying on

his back for more than 15minutes and cannot lay on his left side at all due to severe scoliosis and his rib cage “squashing” his lungs.

8. Bailey can no longer use a computer but does access the internet through his playstation controller. We need to reposition his arms and the controller every half hour. Playing playstation and searching the web are the only independent things Bailey can now do. Eventually his muscles will weaken to the point that he will have this taken from him too.

9. Ensure his suction machine, bi-pap ventilator, PEG feeding pump and power wheelchair are charged at all times as well as back up batteries incase of power failure.

10. Monitor lungs and treat any infection aggressively

11. We are responsible for ensuring all medications and medical supplies are in stock in the home. This involves regular collections from Gold Coast Hospital on a weekly basis.

12. Bailey is in Grade 8 at Aquinas Catholic College, Southport, and requires full assistance to attend school as he can. He attends school approx.. 2hours per week. Bailey is keen to keep up his education and completes his favourite subjects at home by verbally telling his carers the answers and the carers filling out paperwork etc. He recently received an A for his Assignment on Dr Fiona Woods, Burns specialist.

The above is not a complete list but a summary that clearly demonstrates how full on caring for Bailey is.

TIFFANY HEDDES

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Edward Milwyn Spink
[redacted]

2 August 2012

Look upon a small disabled child. Body twisted and pain wracked. Big eyes wide. Trusting. Hoping. Oxygen tubes feed the struggle to breathe. To stay alive. A small face smiling against enormous odds.

Day after day, night after night, this uneven fight goes on as anxious parents look on. Knowing but never showing their dread. Gently moving a limb to a more comfortable position. Caring. Reassuring on the outside but weeping silently on the inside. As this painful drama drags on for years, the child's brain grows but his body stays unable to function.

This heart breaking scenario is the lot of parents with disabled children. They carry their heartbreak with a stoicism that is saintly through each distressing day and often sleepless night

Most have increased their mortgage by many thousands of dollars to pay for special equipment so vital to a disabled child. Mum is on duty all day every day. Dad comes home from work and takes over. They share the load. Their nights are broken sleep as they take turns to tend to their ailing child.

It's a big, expensive, tiring responsibility which they accept and handle without complaint. But the fatigue and debt grows for these Aussie Battlers. They are only human, they need a break. Some respite now for them to keep going.

That is why such a responsibility should be, must be, shared by the Community.

If we can give untold millions in foreign aid to countries which show no real appreciation, then surely we can help our own to share the load. To reward unselfish effort.

To look upon that child and turn your back is UN Australian. So STOP LOOK HELP. It is time to reach out. To help with a facility such as Hummingbird House.

TED SPINK

Disabled War Veteran

PS: I am not a politician

I am not a do-gooder

I am a friend and neighbour

But I have watched

And witnessed their daily heartbreak

Their cry for help is from their heart

Not their pocket

And what comes from the heart

Goes to the heart

Or should

I was in the war

When our mates were wounded

When they needed help

We gave it

We learned to STOP LOOK HELP

We ask our Country to do the same