

26 October 2010

Mr. John Moloney, T.D.  
Minister of State  
Department of Health & Children  
Hawkins House  
Dublin 2

Dear Minister Moloney,

I write in follow up to our meeting in Leinster House on 12<sup>th</sup> October and to let you know how things stand from our point of view. I know from Janette that you are planning to call us over the coming week and she is keeping you up to date on a weekly basis regarding our over 4's.

However, while the over 4's is of real concern and costing Jack & Jill €280,000 per annum right now, it's the bigger question of sustainability for the 0 to 4 year olds that is of most importance.

Can I please say again that it makes sense on EVERY level for the HSE to invest the additional €750,000 into Jack & Jill in 2011, as it will save millions and prevent our babies from ending up in hospital beds – beds that simply aren't there. While we have been able to survive on less than 20% support from the State up to now, our reserves have run out and the money coming in from 1<sup>st</sup> January is less than the money going out. That's a fact and again I would suggest that we throw our books open to the number crunchers in the HSE, any time and the sooner the better.

Jack & Jill is not looking for a handout and I am very concerned that we are lumped in with other charities desperately looking for more money. All good causes I know, but ours is a unique case. Why?

- There is nobody else doing what Jack & Jill does. That's a fact.
- We do what the HSE should be doing and we do it faster, better and it works. It's got the five star rating from our families and been thoroughly checked out by the Trinity Health Economists.
- Ours is a real value for money proposition and the HSE should be embracing this model of care and ensuring that Jack & Jill is sustainable into 2011. Otherwise, it's a false economy and ignoring the SOS (Save our Service) funding request will mean more babies in hospital at a cost which is nine times more expensive than our model.
- We're NOT looking for a handout, rather an investment and ANYONE who sees the Jack & Jill figures understands that this is a real Return on Investment story.
- We do not sit on our hands when it comes to fundraising and we are well able to raise the other 50% we require. However, we simply can't survive on less than 20% funding from the State – it's simply not possible and it's wrong.

Due to our unique schools "Phones for Boards" campaign during the last scholastic year we were able to donate over 400 interactive whiteboards to schools all over Ireland thereby saving the Department of Education a retail spend of €1.2 million – a feat not replicated by any other charity.

Right now, our families are angry and stressed about this funding crisis and the fact that we're still looking at the diabolical prospect of cutting their hours from 1<sup>st</sup> January, which will force at least 100 of our babies back into hospital and will push many of our parents over the brink.

This is our reality Minister. "False Economy" is what Prime Time called it and I'm sure you've seen some of our families on TV3 and in the national newspapers like today's story in the Irish Times, see attached. Next stop for us will be Liveline and we have a growing number of families suggesting that our Christmas Book Launch in Buswells on 17<sup>th</sup> November is turned into a proper

Rally.

I've seen the letters going to you from consultants and I'm hoping that these are convincing you that investing in Jack & Jill makes sense. Who is the real decision maker in the HSE when it comes to Jack & Jill funding for 2011? I'm planning to meet Cathal Magee soon and these are questions I will pose to him too.

Lastly, please tell me what else can we give you to help you to come to the right decision. Please call me any time.

Yours sincerely

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Jonathan Irwin  
C.E.O

c.c. Mr. Cathal Magee, Chief Executive, HSE, Dr. Steevens Hospital, Dublin 8  
Mr. Sean O'Fearghail, T.D., Dáil Eireann, Leinster House, Kildare Street, Dublin 2  
Mr. Alan Shatter, T.D., Dáil Eireann, Leinster House, Kildare Street, Dublin 2

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## On borrowed time



[Jack and Jill foundation nurse \(right\) Caroline Thomas with baby Annie Matthews and her parents, Suzanne Matthews and Carl Brennan, at their home in Skerries, Co Dublin.](#)

[Photograph: Alan Betson](#)

KITTY HOLLAND

One family describes how the Jack and Jill Foundation has helped them cope with their seriously ill child and take care of their other four children

SUZANNE MATTHEWS and her partner, Carl Brennan, know their one-year-old daughter Annie will not live to her second birthday. She was not expected to live to her current age and some nights, as she struggles to breathe, they wonder whether she will see the morning.

She has a rare neurological condition, schizencephaly, which means she has clefts, or holes, in her brain. She has cerebral palsy, is tiny for her age, is almost totally blind and is unable to sit up unaided.

She also has up to 50 severe seizures a day, each one of which makes the clefts bigger, the brain damage worse and brings death a little closer.

Sitting in her parents' home in Skerries, north Co Dublin however, one can see there's a little girl behind all that disability who feels pain and hunger, who laughs when tickled and who snuggles into Carl's shoulder for comfort as he holds her. The young couple – who have four other children

– want her to live, and die, at home with them.

“At first we just didn’t want to accept what had happened to her,” says Suzanne.

“She spent five weeks in intensive care (ICU) because she was so sick and so small – 3lbs 9oz – when she was born. We were in the Rotunda where they were brilliant. After five weeks, when they got her weight up to four and a half pounds they told us she didn’t need to be in ICU anymore.”

And so they brought home a “tiny, tiny bundle”, were told to keep an eye on her seizures, do her physiotherapy, manage her medications and keep her away from infections. They needed to bring her to Temple Street children’s hospital regularly for check-ups.

Suzanne details Annie’s daily routine – how two people are needed to bath her each morning given that she cannot sit up alone. “Then she needs to be dressed and fed.” She is fed through a tube as she cannot swallow properly and could choke if spoon-fed. The tubes need to be changed and sterilised daily.

“She has floor-time then, which involves stretches and exercises for her muscle tone.”

Through the day she has eye stimulation to help encourage her vision, more physio in the afternoon and feeds, and they have to keep an eye on her breathing and seizures, as well as make sure she gets all her medication.

“It is round-the-clock, constant and, of course, there are the other kids’ school runs and that.”

It was a social worker in Temple Street who, when Annie was six months old, felt the family would benefit from the help of the Jack and Jill Foundation. “She could see we weren’t coping very well,” says Carl.

The charity provides nursing, palliative and respite home care to more than 300 families, like Annie’s, for children under four years of age with severe developmental delay.

Caroline Thomas, liaison nurse with the foundation, visited them, talked them through what they could offer, and assigned a nurse to cover 10 hours a week of Annie’s care.

“It was like a whole new world opened up for us,” says Suzanne. The couple’s world had closed in around their desire to protect and care for their seriously ill baby. “But now, well she is just so involved in our family, she takes such good care of Annie, we can get on with other things, take small breaks and just feel a bit reassured about everything.

“Having the little bit of time free has given us the space, I think, too to accept what has happened to Annie. It’s only in the past few months we’ve been able to make peace with what has happened. We wouldn’t change a thing about her now because if she was any different she wouldn’t be ours.” The charity is, however, like many others, under grave financial pressure, with a current funding shortfall of €750,000.

If this is not bridged by the Department of Health, it will have to pull nursing care from about 100 families in January. These families’ babies will almost certainly have to return to emergency hospital care, at a cost to the State of €14 million, says Jonathan Irwin, chief executive and founder of the charity.

Irwin pleaded for the €750,000 plug at a recent meeting with the Minister of State with responsibility for disability, John Moloney, but has yet to learn the outcome.

The department said Mr Moloney “hopes to be a position to make a comment in the next week or so”.

Suzanne can hardly bear to think what would happen if the family lost the 10 hours a week they get from Jack and Jill.

“I know two things: We couldn’t cope without the nurse and I’d be so fearful we’d in the end have to let Annie go to hospital.

“I know we are on borrowed time with Annie. Keeping her comfortable now is the most important thing. She seems to struggle more with her breathing at night, and that is the most frightening time, because every time you do get frightened, you think is she going to pass on now, and you are blessed every morning she is still here.

“When God does take her we don’t want her taken from a hospital.

“We want her here with her brothers and sisters and her toys and her cot, where she is loved.”