

## **Proposed National Paediatric Hospital at Eccles Street, Dublin.**

### **Submission to the Oral Hearing by Ciara Gilmour, Parent Representative (North-West) of The New Children's Hospital Alliance.**

Madam Inspector,

My name is Ciara Gilmour. I am a member of the New Children's Hospital Alliance executive, and am the parent representative for the North-West. I am a primary school teacher, and I live in North Donegal. I am mother to three boys, and during the period from August 2003 to March 2007 I spent a lot of time with my eldest son, Eoghan, in Crumlin Children's Hospital.

Eoghan was born with a number of health problems, the most life-threatening of which was a severe congenital heart defect. He spent a considerable amount of time as an inpatient in Crumlin, as well as having to make many trips down to outpatient clinics. Eoghan passed away in Crumlin Children's Hospital on the 15<sup>th</sup> of March, 2007.

I would like to speak today about the major issues that affect families travelling to Dublin for tertiary care for their children. These are:

1. The fact that this is to be the *National Children's Hospital*
2. Access to the hospital
3. Parking
4. Accommodation for parents and families
5. Outdoor space

#### **1. The National Children's Hospital.**

Dr Curtis, in the introduction to her submission, paragraph 3.2, states that the hospital will have two crucial functions. The first is to provide secondary level care to children from the Greater Dublin Area (GDA). The second is to provide tertiary level care to children from all over Ireland. However, as this project has been granted the status of a National Strategic Infrastructure Development, surely its primary function is that of tertiary level care.

Statistics have been quoted during this hearing which state that 76% of in-patients and 65% of patients admitted for day-care procedures will be from within the GDA. I find this figure quite misleading. The GDA, as pointed out by Dr Curtis, includes Dublin City and County, as well as counties Meath, Wicklow and Kildare. Difficulties with access which will affect parents from outside Dublin will also affect a significant proportion of this group. It would be much more meaningful, therefore, to compare the number of anticipated attendances of patients living within the M50 area to those living beyond its reaches.

Of the patients who will travel to the hospital from outside the GDA, it should be emphasised that almost **all** of them will be tertiary care patients – i.e., patients who have been assessed as requiring more specialised care than can be provided for in local, general or regional hospitals. (These patients will obviously present with minor ailments to their local hospitals). Due to the nature of their illnesses, many of these patients will be frequent attenders, both as in-patients and for out-patient visits. While the group coming from within the GDA will include such tertiary care patients, a significant proportion will be patients with much more “normal” or “everyday” complaints – appendicitis, broken bones, gastro bugs, etc. Many of these patients will only have to visit the hospital once or twice, and for this group, ease of access will be less of an issue. I would like to re-emphasise that this is to be the *National Children’s Hospital*, and as such its primary role is to provide tertiary level care to children from all over Ireland, and statistics such as the one I have mentioned above are therefore really not relevant.

## **2. Access**

For patients travelling to a tertiary care centre for treatment, clinics, etc., access to the hospital becomes an issue before they even leave their own homes. Living in North Donegal and travelling to Dublin for outpatient appointments, I was unable to travel to Dublin and back again in one day, both because Eoghan often had numerous appointments on one day, and also because the journey was just too much for him. He was fed via a “peg” into his stomach, and for much of his life his feeds were given continuously, using a feeding pump. This device was battery-operated and as such had to be plugged in every so often to be recharged – something that could not be done while driving. I mention this fact only in order to try to explain how difficult travelling with a sick child actually is – it cannot be compared in any way to travelling with a healthy child. On top of a four-hour journey to Dublin in these circumstances, and the accompanying stress of attending hospital with your child, often to see more than one team of doctors as well as speech therapists, dieticians and other disciplines all in one day, parents do not need to then have to try to negotiate city centre traffic as well. We were obliged to attend the Mater hospital on a number of occasions before Eoghan’s cardiac surgeries, as this was where his surgeon’s clinics were held. Even then, without the new hospital in place, attempting to access the hospital was very stressful for me as the parent of a sick child. I can honestly say that knowing we were attending the Mater, rather than Crumlin, for clinics, made the prospect of the journey ahead much more stressful. This problem would only be exacerbated in future for parents from all over Ireland attending a children’s hospital at the Mater site, and this causes me great concern.

## **3. Parking**

Having eventually accessed the Mater hospital for clinic appointments, one then has to try to find a parking space, and as has been attested to here by local residents as well as others, this is all but impossible. In fact, after the first time that we attended the Mater for clinic, I always made a point of leaving home at least half an hour ahead of time, knowing that I could quite feasibly have to spend that amount of time trying to find somewhere to park where I wouldn’t find on my return to the car that I had been clamped. This is not an acceptable situation for the parent of a sick child, and with fewer than 1,000 spaces allocated to the new hospital to service the projected 6,000 daily users

of that hospital, the stress levels for parents bringing tertiary care patients to the hospital will be unacceptably high.

Also on the issue of parking, I would like to stress that I have been unable to find out how wide the parking spaces in the planned hospital car park are to be – it should be accepted that all of the parking spaces should be wide enough to allow the doors of each vehicle to open fully, in order that parents will have room to fold out pushchairs for younger children and babies, and wheelchairs for older children. Anything less than this in the parking lot of a children's hospital is not good enough.

It is important to point out that, for tertiary care patients, public transport is simply not an option. Sick children have to be transported to hospital by their parents, and adequate, safe parking must be provided.

#### **4. Accommodation for parents and families.**

I am aware that pull-out beds are to be provided in patient rooms for parents, and that the Ronald MacDonald foundation are looking into the possibility of acquiring a building nearby. However, from my own experience, two serious questions about accommodation arise. The first question relates to families of children in the wards – one pull-out bed in the child's room is not enough when there are two parents who need, and are entitled, to be accommodated. Article 3 of the European Association for Children in Hospital Charter (EACH) states that “accommodation should be offered to all parents and they should be helped and encouraged to stay”, and also that “parents should not need to incur additional costs”. The hospital **must** provide adequate accommodation for all parents.

There are to be 62 Intensive Care beds in the new hospital, and my second question is whether there will be **enough** parent beds to accommodate these. It should be borne in mind that parents whose children are in intensive care are extraordinarily vulnerable and stressed, and the very thought of there not being enough beds in the parent accommodation wing to house them is truly awful. When your child is in intensive care, your first priority is to be as near to them as possible at all times – I cannot stress enough how distressing it would be to discover that you had to leave the hospital and go elsewhere at night to sleep. Please also bear in mind that a high percentage of parents of sick children tend to separate, and therefore it should be imperative that **more** parent beds than ICU beds be provided in this wing.

Recreation space for families of children who are in hospital long-term is also critical. The emotional well-being of parents and siblings cannot be over-estimated as a crucial determining factor in the convalescence of a sick child, and as such parents and families should have access to adequate recreation space within the hospital – sitting rooms, kitchenettes etc.

#### **5. Outdoor Space**

Although much emphasis has been put on the outdoor spaces that have been included in the design of this hospital, it is important to note that there are no real outdoor, ground floor garden areas. Article 4(2) of the EACH states that “steps should be taken to mitigate physical and emotional stress”, and it is well documented that outdoor space – in particular green areas – have a profound

effect on patient recovery times. Many studies have found that exposing patients to nature has a significant effect in alleviating pain. From the perspective of the parent of a young child in hospital, I can say that it is vital to have outdoor spaces to escape to, for example when your young child is having a nap. These spaces do not have to be large, but they do have to be outside the hospital, and they do have to be green and at least relatively free of noise from traffic, etc. None of this will be possible with this new hospital, due to the nature of the “gardens” that are included, but also due to the city-centre location. The spaces provided for will be hemmed in and will, in my opinion, only serve to contribute to patients’ and parents’ feelings of claustrophobia.

Madam Inspector, I thank you for hearing my submission today and ask, if it is your finding that the issues I have raised warrant further investigation, that the planning application be rejected. Thank you.