



Gutsy Kids-Parents Advocacy Group
www.gutsykids.ie

Dear Minister,

I represent a group of parents who are deeply concerned about the management of Crumlin hospital and its failure to provide appropriate care and conditions for treating children with inflammatory bowel disease. All of us have children suffering in varying degrees from IBD (Crohn's & Colitis) and many of us are living in various parts of the country.

Collectively, we as parents have all experienced the situation at home when a concern arose for our child. We had each been advised to call the paediatric IBD nurse in such circumstances, to convey our concerns and obtain advice on how best to manage our child's condition, in the hope of avoiding hospital admission. The only alternative is to bring our child to A & E in Crumlin to access specialist advice.

In recent times we found it increasingly difficult to get hold of the IBD nurses. On further enquiry, we understand that nurse Karen Gleeson is on sick/maternity leave but the hospital management has failed to provide a safe level of cover in her absence. This is a totally unsatisfactory situation. When a call is now made, it is very likely that you end up speaking to a secretary or somebody without expert knowledge of your child. This is not the level of IBD nurse service our children deserve and need.

We are constantly being reassured by you and your officials that critical front line services are protected and have not been affected by cutbacks. That may be, but not if you are a parent of a child suffering with IBD. As you are aware, although rarely fatal, IBD is incurable and has devastating effects on a growing child's life. It is bad enough that our children with diarrhoea have to slop out like common prisoners when they are admitted to Crumlin because of their appalling toilet facilities.

It appears that both your Department and the Crumlin hospital management see little necessity to have the IBD nurse positions properly staffed. You are quite relaxed about the anxiety being suffered by the parents and their children, who in turn have to travel considerable distances at all hours to present at the hospital, all as a result of not properly filling an essential front line nurse position.

We await your meaningful response.

Yours faithfully,

*Rachel Kane on behalf of the
Gutsy Kids Parents Advocacy Group*