



**Gutsy Kids-Parents Advocacy Group**  
[www.gutsykids.ie](http://www.gutsykids.ie)

To whom it may concern

We are a diverse group of parents who have one thing in common. We all have a child who suffers with the severely debilitating condition that is Inflammatory Bowel Disease (Crohns Disease and/or Ulcerative Colitis being the two most common conditions). We have come together to give a voice to our children who, whilst enduring often painful, stressful and in some cases life threatening effects of their condition, have also to contend with poor and often inadequate services. We would prefer to work with the OLCCH to improve the plight of children with IBD attending there.

Our Advocacy Group is called Gutsy Kids and our main initial concerns that we wish to draw immediate attention to are as follows:

- Limited Clinical Nurse Specialist support – we have only 1 nurse working part-time with the IBD team in Crumlin, even though given the patient numbers, there should be 3 full time IBD nurses to provide a basic service. Whilst Mary does a fantastic job it is unacceptable that she should be tasked alone to cater for approximately 450 families of children with IBD. We had an additional support in Karen, who job shared with Mary. Karen is currently signed off ill and is pregnant. (her replacement nurse covering half of Karen's hours). We require an immediate fulltime replacement for Karen and request further full-time resources be provided to support IBD children and their families with immediate effect.
- Proper facilities – a child who is enduring a 'flare up' or has just been diagnosed with IBD requires toilet facilities as a matter of course on a very regular, immediate and prolonged basis (up to 20 times in a day in the middle of a flare up). There is a dignity and respect aspect here that demands that we should be able to provide a hospital room with an en suite for any child suffering with IBD who requires hospitalisation.
- Planning and Development – as a group with the best interests of all our children at heart we want a voice and representation to help facilitate best planning and outcomes for children when they are admitted to hospital and for future planning of Crumlin and its replacement.

We would welcome an early meeting with you to discuss these matters further.

Regards

Clare Farrell

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On behalf of Gutsy Kids Parents Advocacy Group