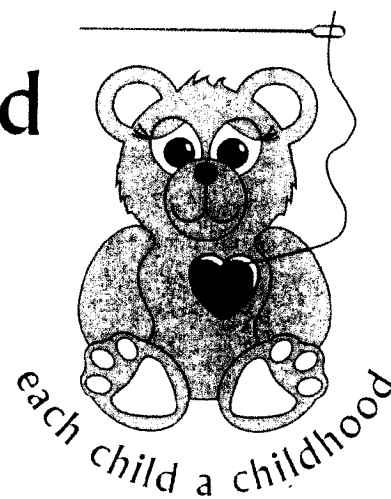


Children's Heart Surgery Fund

September 12th, 2013

Bill McCarthy
National Director for Policy
NHS England
Quarry House
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Dear Bill

Thank you for inviting comments on the new Congenital Heart Disease (CHD) Review from interested groups. I feel obliged to raise some strong concerns I have regarding appointments to the Congenital Heart Disease Clinical Reference Group (CRG), including Anne Keatley-Clarke, Chief Executive of the Children's Heart Federation; Suzie Hutchinson, lead support for Little Hearts Matter; and Samantha Lloyd, a parent and carer representative. I am deeply concerned about the impact which these appointments will have on the new CHD Review.

You will recall that the Independent Reconfiguration Panel (IRP) criticised the role of the Children's Heart Federation in the Safe and Sustainable Review. The IRP reported that "*a number of parents and some charities raised concerns about the role played in the process by the CHF in undertaking surveys that influenced the weighting given to the access criterion and the fact that this organisation was the sole voice for children and parents inside the process. For many parents who spoke to the Panel this arrangement become more problematic after the CHF itself issued public statements critical of those challenging the proposals.*" It concluded that the Charity's role in the Review was as "*a source of unhelpful divisiveness that undermined achieving the necessary engagement rather than delivering it*" and said that it "*found some of the media statements issued by the CHF... were seen to be combative in style, serving to polarise the debate and unnecessarily antagonize those raising their concerns.*" Whilst I of course do not object to CHF contributing to the new Review, the same as any other organisation, I do believe that to afford a specially created place (affiliate membership without voting rights) to Ms Keatley-Clarke who as Chief Executive was primarily responsible for CHF's behaviour during the Safe and Sustainable Review, is hugely inappropriate and risks discrediting the new Review in much the same way as its predecessor.

Ms Keatley-Clarke's appointment is especially alarming in the light of the fact that in January 2010, she co-signed a controversial statement in which she pre-determined the outcome of the Safe and Sustainable Review by setting out which children's heart surgery units should remain open (see enclosed). This was also signed by Suzie Hutchinson, another Patient Experience appointee to the CRG, who wrote to Professor Sir Bruce Keogh as recently as April 17th this year, making allegations against the Leeds Unit on specific medical cases which she is neither qualified nor informed to comment upon. I was dismayed that she chose to raise her concerns in this way, without taking

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them up with staff at the Unit or going through the appropriate channels at the Hospital, and as a result her actions inflicted maximum damage on the Leeds Unit. Surely this demonstrates a bias against Leeds which is incompatible with occupying an important role on a neutral body? I was especially dismayed because at a meeting in the spring attended by Ms Hutchinson, myself and several clinicians, she did not raise the concerns which she then detailed in her letter (**enclosed**) to Sir Bruce shortly afterwards.

On August 7th, Samantha Lloyd attended the meeting which was arranged for local and regional charities and organisations to contribute to the CHD Review as spokesperson for Newcastle-based Children's Heart Unit Fund (CHUF). Ms Lloyd has pursued an active campaign against the Leeds Unit and publicly repeated her desire to see the Unit close. I **enclose** screenshots of her pronouncements on Facebook, where she is listed as a member of the Fragile Hearts and 'Support the closure of the children's heart unit at LGI', as examples of this.

The Children's Heart Surgery Fund (CHSF) wants the new Review to be a success for the sake of the patients and families we represent. We welcome the efforts you and your team have made to be open and transparent and to ensure stakeholders, including regional charities such as ours, are included in discussions. You will, however, appreciate that we are profoundly concerned by the appointment of individuals with a record of campaigning against the Leeds Unit on to a body which will presumably play a prominent role in the CHD Review. I hope you will also appreciate that this goes completely against the assurance given by NHSE at the August 7th meeting that it "*will seek assurance that the patient representation [on the CRGs] is broad enough to capture the full range of views.*"

I should therefore be grateful for clarification on the precise role which the Clinical Reference Groups will play in the new Review, whether as advisers or decision-makers, and for your assurance that none of these individuals will have a special position in the Review.

I look forward to hearing from you.

Yours sincerely



Sharon Cheng
Director

Copied to:
Jeremy Hunt MP, Health Secretary
Graham Stuart, Chairman of the Congenital Heart Services CRG
Mike Bewick, NHSE Deputy Medical Director for Northern England
Andy Buck, NHSE Director (West Yorkshire)
Cllr John Illingworth, Chairman of the Yorkshire and Humber JHOSC