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Dr Gary Benson
Belfast Haemophilia Centre

20 February 2019

Dear Gary

Following the meeting held this week with Gillian Traub and Paula Scullin that I attended with our Trustee Paul Sartain, I wanted to write to express my apologies and sadness for the way the situation with our member and parent of your patient has developed.

As I explained to Paula and Gillian the initial phone call I had with our member, which was the first time we had any contact, came to me as the caller was exceptionally angry we had promoted an active lifestyle for boys with severe haemophilia. During the conversation I suggested if she were unhappy with the care her son received she should come and discuss it with you as her son's consultant as you may be able to answer some of her questions and concerns. This is our usual practice as we are not clinical advisors and in general this resolves any issues. At no point did we suggest treatment levels were far too low and she should change her son's dose. I understand this appointment with you wasn't at all what would usually be expected and was a particularly difficult meeting with several families. I am sorry, had I realised this may be the outcome I would have contacted you in advance.

Subsequently this mum posted on our closed Facebook group saying she felt her son was being undertreated (she appears to have searched for a dosing formula on the internet and found one in America), which as I explained to Gillian and Paula we didn't see for some time. Unfortunately, what I had said wasn't accurately documented in the post and I accept it could have read as if The Society were condoning her stance by not commenting. This was not my intention at all.

By the time staff saw the post a fair while later the post had dropped down the page, so was no longer prominent and had a number of more balanced comments where members talked about their doses and lifestyle that challenged the original posts perception of the care her

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son received. This is often what happens in a post. Unfortunately, we did not receive any notifications of a report to Facebook from anyone that this could be a post that needed reviewing (which sometimes happens) so we didn't see it until much later. A decision was made not to comment and bring the post to the foreground of the page again, and it was deleted as soon as possible. As I explained in the meeting either removal or posting was an option, but as it had dropped down the page and most people would probably have forgotten it by this time I decided to remove it rather than open the conversation again.

I contacted the original poster and explained that this post was not in line with our rules (pinned to the top of the group) as although you as a doctor had not been named it was mentioned they were attending the centre in Belfast and this was not appropriate or permissible on our group. I also explained that we did not and could not advise on doses as these are very specific to individuals.

I understand the mother had already spoken to other mothers in her local area which is why they had decided to come together to visit you in clinic, this was not due to the Facebook post.

Following this incident, I discussed our social media strategy with our Board of Trustees and we have reviewed our risk register and practice relating to this. We have a very small team and a significant number of posts so are not able to moderate, but have now a plan to review posts regularly, which we hadn't previously done. We also have agreed to add a sentence on the pinned posts to reflect our policy on not providing clinical information.

As I have said, I very much regret how this incident evolved and hope that we can re-establish the positive working relationship we previously had with you and the team in Belfast, as we know how passionately you feel about doing the best you can for your patients and we too want to do more for our members in Northern Ireland, hopefully in collaboration with you.

Yours Sincerely

GRO-C

Liz Carroll
Chief Executive

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