

30<sup>th</sup> March 2005

GRO-C

## RE RECOMBINANT FOR ADULT HAEMOPHILIA PATIENTS

Dear Sister Julie (Voles),

Peter and I are writing with regard to our telephone conversation of 30th March 2005. We request that you pass this letter on to the relevant medical staff.

We are pleased that the RVI Primary Care Trust is finally catching up with other Trusts in Scotland and Wales with regard to safety, and finally financing recombinant products for ALL haemophilia patients, and not just under 16s who have been funded for recombinant since 1998, and the younger generation of haemophiliacs.

It is a great pity that the Trust refused to listen to us in 1995 when we first wrote and asked for Peter and others to be given the safer recombinant product, and that the Trust turned Peter down for recombinant in writing in March 1996. Peter and other haemophiliacs were repeatedly exposed to v CJD after that period and this exposure to vCJD could have been avoided in many cases. It is very sad that such penny pinching by the PCT could once again cost the lives of haemophiliacs who may yet go on to develop vCJD.

As you are aware Peter has been on treatment strike refusing human plasma on the grounds of safety for over 5 years now. Nothing we have learnt in the past 5 years has led us to believe that safety regulations regarding the collection of human plasma are being strictly followed. We are certainly aware of numerous recent safety violations in the collection of U.S. plasma, where UK donors visiting America on vacation, or studying in the U.S. were allowed to sell their blood in the United States. (UK donors were supposed to be banned from donating plasma in the U.S. because of the vCJD risk). We did in fact bring this to the attention of the FDA, via Bill Freas, at the FDA regular blood safety meeting in Maryland, and as a result certain safety rules that were about to be dropped were kept in place. I have since been e-mailed to say that further restrictions have now been put in place. It's a pity it takes a lay person on another continent to point out safety violations, and shows that little has changed over the years with regard to screening of donors!

Peter will come off treatment strike as soon as he has been given recombinant from the RVI haemophilia centre after 1<sup>st</sup> April 2005. Peter remains in St Oswald's Hospice where he is receiving excellent care. As you are aware we have been able to access some emergency supplies of recombinant over the past five years from our own sources. The hospice staff kindly allowed me to treat Peter with our own supplies of recombinant on the premises. They are aware of the politics surrounding Peter's contamination with viruses through plasma treatment, and the fight for recombinant. We have provided staff with information where they have asked for it. We have not expected hospice staff to get involved with these issues and have been very happy with the care and support they have shown us in looking after Peter.

Peter was taking Kogenate initially for bleeding episodes but for the past few months I have treat Peter with Baxter's Advate, 1000 unit bottles. I am happy to show you our remaining unused bottles of Advate as evidence of this fact. Advate works

well for Peter and we find it works better than Kogenate. Peter is stabilised on Advate. We request that he continue on Advate as we understand it is the RVI policy not to swap haemophilia treatments and risk a patient developing inhibitors. We believe that although staff at the RVI may dislike Peter, as professionals you would not want to risk causing inhibitors.

We do not require lessons in administration as we have been using Advate for some time already, so that is a waste of your time and ours. You are as you said the experts in haemophilia treatment but as the RVI has had little active involvement in Peter's haemophilia treatment for the past few years, as most bleeds have been managed by us at home with our own recombinant supplies, we have had no choice but to become expert haemophilia patient and carer. This is a role that is now recognised by NHS that are promoting the very issue of "expert patients" as described in the latest haemophilia literature.

We understand that staff from the RVI wish to take a blood sample to check clotting levels before putting haemophiliacs on recombinant, and to monitor for inhibitors. We would like to state that any blood given for this reason does not mean that Peter gives consent to any other blood tests such as tests for infectious diseases or any trial tests for vCJD. We are aware that RVI haemophilia centre staff have a history of testing haemophiliacs for infectious diseases without their knowledge and permission, against General Medical Council guidelines, and have then withheld positive test results for years, (now the subject of a two year GMC investigation).

It would be helpful if someone from the RVI could come to the hospice to carry out any blood tests, rather than Peter travel to the RVI, as it would be more comfortable for Peter. He has only recently been taken off traction, and I understand that the fracture of the femur has not quite mended completely.

We anticipate that Peter will need prophylaxis several times a week and extra treatment should he bleed. Peter has had far less bleeds than normal during the last 6 months only because he has been in bed on traction for some time. He is now learning to walk again, and has already experienced some bleeding on exercise. He does not wish to see Dr Hanley with regard to haemophilia treatment, and neither do I after our past experience of him putting pressure on Peter to accept human treatment whilst Peter was depressed and intermittently confused as a result of liver deterioration due to hepatitis C infection, facts supported by an independent psychiatric report which we commissioned. We do not feel Dr Hanley respects our wishes and we do not like his sarcastic attitude. Although Dr Hanley expressed his thoughts that Peter would probably not be alive by April 2005, we are glad to say he is alive, and still campaigning for justice, even if it is from a hospice bed.

Please place this letter in Peter's medical records. Thank-you.

Yours sincerely

GRO-C

Carol and Peter Longstaff

GRO-C

Cc Hospice

Dr Schmid

Prof Bassendine, Freeman