Haemophilia Centre and Thrombosis Unit

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Our Ref: ACN/zg/DICT/Patient MRN no. GRO-C
Clinic Date: 26/08/2014
Date: 28/08/2014

Private & Confidential
Dr Liam Byrne
Rowe Avenue Surgery
17 Rowe Avenue
PEACEHAVEN
BN10 7PE

Dear Dr Byrne

Re: Mark WARD – DOB: GRO- 1969
GRO-C

Diagnoses:
1. Severe haemophilia A, on demand treatment with ReFacto.
2. HIV, on antiretrovirals with a viral load of less than 40 transcripts/mL.
3. Hepatitis C, natural clearer.
4. Haemophilic arthropathy with left total knee replacement, left ankle arthrodesis and a fused right elbow.
5. Atrophic right kidney.
6. Dyslipidaemia.
7. Hiatus hernia.
8. Osteopenia.

Mr Ward attended the review clinic this morning accompanied by his mother. He complained of pain in his joints, especially the right ankle. As you know, Mr Ward had local steroid injection of
his right ankle earlier this year. I believe that some of his metacarpal joints were also injected at the same time. These injections appear to have been ineffective.

Mr Ward was also concerned about the lack of efficacy with ReFacto. He mentioned that he had a bleed some six weeks ago which he treated with 3,000 iu of ReFacto daily for five days but without observing any clear benefit.

ReFacto was commenced earlier this year because he reported reactions to infusion of Helixate, the FVIII formulation that he had used for some years previously. Those reactions which consisted of muscle spasm and twitching, palpitations and exaggeration of

all his senses, appeared to be limited to times when he had continuous infusion of Helixate during surgical procedures.

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Interestingly, Mr Ward did not have these reactions when he had a general anaesthetic in 1984, thus excluding drugs used during anaesthesia. In addition, they are unlikely to be related to Morphine as in 2005, in the midst of such reactions, he had asked for the Morphine infusion
to be taken down post-surgery but without alleviation of his symptoms. These reactions have been reported to the company and regulators.

During the consultation he described a sensation of swelling in his feet and, upon further questioning, also mentioned pins and needles in both hands.

His current medication for pain consists of Dihydrocodeine and Paracetamol. He has previously tried Celebrex for pain but this, apparently, made him bleed.

I note that his venous access is good, as he has a couple of good veins in his left cubital fossa.

On examination today, Mr Ward was able to walk unaided. His pulse was 60 beats per minute and regular. He has normal heart sounds. Chest was clinically clear. Examination of the joints showed reasonable movement at most joints, except left ankle and right elbow, but no evidence of ankle swelling. Overall however, joint function appeared to be similar to that observed during previous clinic visits.

In terms of actions from today's review clinic, I have given Mr Ward the option of changing from
his current treatment of ReFacto to Advate, which is the another recombinant product. Another alternative is plasma-derived FVIII which now has a very good safety profile, despite the theoretical risk of blood-borne infections. In addition, based on some of the symptoms described by Mr Ward, I wondered if he is suffering from peripheral neuropathy which sometimes occurs in patients on long-term antiretroviral therapy. I have offered to refer him to Simon Mead at Queen Square
whom he has seen before. Furthermore, we could get a Rheumatology opinion in case some of the joint pains are due to non-haemophilic causes.

We naturally recognise that Mr Ward comes a long way for these reviews, and he asked if we could meet some of the travel costs, or arrange to review him when he attends for some of his other appointments at the Royal Free. I explained to him that the MDT review clinic is designed to provide comprehensive haemophilia support by bringing together Physiotherapist, Nurse Specialist, Psychosocial Support, as well as the Medical Team, in one room. These clinics, consequently, are very popular but could not be easily organised on other days as several individuals across different disciplines are involved.

Therefore I could not offer a multidisciplinary review appointment on days other than

Tuesdays,
but offered the option of seeing Mr Ward on an ad-hoc basis outside the MDT review clinic. We also discussed the time frame for an MDT review appointment and that it was important to keep to a review slot of 20 minutes so as to not inconvenience other patients. If there are problems that require extended discussion, then these could be done with an ad-hoc appointment outside of the MDT review.

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He seemed dissatisfied with this and, therefore, I also offered him the option of having his haemophilia review done locally, as this would reduce the need for the rather long commute
to the Royal Free. This was perceived as me trying to get rid of Mr Ward, which is clearly not my intention. Our intention is to give him the best possible medical care and this is something that
I discussed with him at the outset of the clinic and also at the end.

We have made a review appointment to see him again in six months' time and, in the meantime,
we await his instructions as to which specialist he would like us to refer him to and where.

Yours sincerely

Professor Amit C Nathwani MBChB, FRCP, FRCPath, PhD
Director, Katharine Dormandy Haemophilia Centre & Thrombosis Unit

cc

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Mark Ward

GRO-C