THE
HAEMOPHILIA
SOCIETY

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Nick Fish
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3 November 2014

Dear Nick

Having looked at the information you sent, and discussed this with our Clinical Advisory Committee I am not convinced that this explains why there would be such a significant difference in the number of people differed or rejected from the bleeding disorder community. We would be interested to understand this better.

Please would share any analysis you have done on the decision making process, to ensure the bleeding disorder community are not discriminated against. You say, for example, that someone with a high BMI or alcohol intake can have their application deferred if their platelets and other tests are normal, even if their fibroscan score is higher than normal. However within our community if someone has received contaminated blood, has haemophilia and lives their life in fairly constant pain and with a major disability due to joint damage from their haemophilia, it wouldn't be unusual for them to have a high BMI and possibly due to the pain, isolation and the fact they have lost large numbers of friends to contaminated blood, they may also drink larger amounts of alcohol than those without a bleeding disorder. How is this taken into account and weighed in your decision making process? This should not exclude them from receiving payment. If there is any possibility they have cirrhosis we believe they should be accepted for stage two payment, using the balance of probability, rather than the beyond doubt principal.

Do you have a fibroscan score you use as a guide to say yes or no to applications? I appreciate there are other contributing factors but considering the WHO states that the risk of cirrhosis of the liver is 15–30% within 20 years for those with chronic HCV infection, and every one of the contaminated blood population will have had their infection for over 30 years and many are also co – infected increasing their risk further, yet only 18% of applicants are accepted as having cirrhosis by the Skipton Fund . This seems an astonishing difference.

I also understand that on appeal a large percentage of applications are overturned. This in itself suggests there is a flaw in the process, and knowing the challenges of everyday life for our community I would be very concerned. I suspect many of our patient group will not bother to appeal due the complexities of their health and life with a bleeding disorder. Can you please share with us the number of persons with and without bleeding disorders that have appealed and what was the outcome?

I would be grateful if you would provide us with a more detailed analysis of the reasons why the bleeding disorder community has such a low approval rate for Stage 2 applications.

Kind regards

GRO-C

Liz Carroll
Chief Executive