



An Operation which would not have been done Without Factor Donation by (WFH)

I am Agbar [REDACTED], 34 years, from Sudan. I suffer from moderately severe hemophilia. I live in a remote area with no access to hemophilia medical care. I have to travel for 2 days by road to Khartoum where there is the only hemophilia treatment unit in the whole country. So, I do not always receive factor replacement for my bleeds and let them resolve spontaneously. Two and a half years ago, I had bleeding in a muscle on the anterior part of the thigh (quadriceps muscle). I had pain & stiffness for a few days & then I resumed my normal activities. The swelling did not subside completely and with time it became progressively larger with increasing difficulty in bending the knee joint. A year later, the swelling became quite big and my walking was affected. I went to the Hemophilia Treatment Unit in Khartoum, the only one of its kind in Sudan. A diagnosis of a haemophilic pseudocyst was made. I was told that surgery was needed but there was not enough factor to cover the operation.

As the symptoms became worse I had to seek treatment outside Sudan. There, I was told that the cost of the factor concentrate to cover the operation was \$11,000. I phoned the Hemophilia Treatment Unit in Khartoum and was

told a factor donation from the WFH was expected in Sudan in a few days and was advised to come back .So, I was back in Sudan in 2 days and the donated concentrate arrived the same day. On 19/7/2005 I , at last, had surgery. 63 bottles of FVIII concentrate were used to cover surgery and the post operative period. I was shown simple exercises to do at home. Now I am out of hospital and back to my village and at work . My leg is now almost normal.

If not for the WFH donation, I might still have been waiting. I am thankful to WFH & the staff of the Haemophilia Treatment Unit in Khartoum & Soba University Hospital, where the operation was done.