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University Hospital Birmingham

NHS Foundation Trust



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Strictly private and confidential

Mr. Martin Harvey
The McFarlane Trust
12 Caxton Street
London
SW1H 0QS

24. August 2005

Dear Martin,

Re: GRO-A

We would like to make an official complaint regarding the handling of this case.

We had requested on the 13th July 2005, a respite payment for GRO-A to visit his family in Spain. When we were made aware by another registrant of the summer payments we contacted the Trust initially yourself, to request what supporting information we could provide to ensure that this request would still be granted and not fall foul of the new criteria.

You put our call through to the Head of Support Services, Jude Cohen who we explained the situation to and she informed us that a letter of support from our consultant was needed. The supporting letter that was sent dated, 26-07-05, and was almost verbatim as requested. This letter was faxed through to be there for the NSSC meeting on 29-07-05

On Tuesday we called Jude directly to ask the outcome. We were told the request had been refused due to insufficient information. The Trustees were requesting a more detailed medical report.

There are two points firstly. Should not the Head of Support Services have informed the Trustees that the letter met the specific requirements as requested by her?

Secondly, we had already sent a detailed and up to date medical letter stating present health status. Was this presented to the Trustees as further support for our request?

We cannot craft our letters and requests if the Trust are changing the criteria on a weekly basis as in this case, without informing us of any changes. We are not opposed to change but, feel it would be more ethical if criteria changes are not implemented until after current applications have been processed under the existing guidelines at the NSSC meeting.

Chairman: John Charlton

Of late the whole process of making applications has become far more bureaucratic and complex. The amount of time spent on simple applications has at times meant a considerable delay in requests being processed. This case itself is a prime example with correspondence between ourselves and Dr. Wilde, with now a request from yourself for a further letter from our Consultant.

Although you are awaiting Dr. Wilde's reply he has made us aware of the content of your letter and so we would like to clarify some of the points raised as we were the authors of the original request.

We were aware of the £750 summer payment which came into being after our original application. We were only aware of this because another registrant had informed us. We also knew that the £750 would help GRO-A with his current cash flow problems, which I am sure Susan Daniels will be submitting a full report as she met with him on the 23rd August 2005.

Your comment which you thought might be seen as harsh was more disconcerting as it seemed to high light a lack of knowledge and understanding of respite. It is a well researched fact that people who have long term and life threatening conditions benefit from respite.

In GRO-A's case he was able to spend quality time with his parents to be away from the isolation of his home and the many health and financial problems he has there. The sad fact for all registrants is they can never leave their condition or conditions behind. Those conditions will always be apparent be it physically or psychologically.

As a lay person, we would be more than happy for you to visit us and we could discuss many of the issues raised in this case within a forum with other HIV and haemophilia professionals, in an informal setting, or organise a presentation at the Trust.

We understand that the Trust is going through a period of change and upheaval but we do feel that your managers need to manage and make decisions on criteria that they have set out.

It would be helpful if we were kept informed of changes in the office guidelines or grant application criteria. The only people to suffer as a consequence of this lack of communication are the registrants themselves.

We look forward to hearing from you and continuing to work with the Trust to the mutual benefit of the registrants.

Yours sincerely,

GRO-C

Tracey Dunkley
Clinical Nurse Specialist

GRO-C

Mark Simmons
Senior Social Worker

Cc Dr. Wilde, Peter Stevens, Linda Roberts