Salford Area Health Authority (Teaching)

Royal Manchester Children's Hospital

(University of Manchester School of Medicine)

Pendlebury, Near Manchester M27 1HA

17 JUL 1978

Your Ref.

Telephone 061-794 4696 Ext.

Our Ref. DIKE/BB

Please ask for: Dr. Evans.

12th July, 1978

The Senior Educational Psychologist,
5 Durnford Street,
Middleton.

17 JUL 1978

Dear Sir,

GRO-A

These two boys have severe classical haemophilia and have been patients of mine for many years.

GRO-A first saw me when he was a baby. He came to hospital with what was thought to be meningitis, but it rapidly became apparent that he had haemophilia, and that his symptoms were due to bleeding in the central nervous system and spinal cord. He was successfully treated, but the illness left him with a weakness of bladder and bowel control and some clumsiness. Over the years these symptoms have improved enormously, but three years ago he also developed fits. They have been successfully controlled with drugs, and his main problem now is that his judgement is not as good as it should be and he is a little clumsy. He still gets occasional haemophilic bleeds in the subcutaneous tissues, muscles and joints, but has no serious problems with any systems outside the central nervous system. He is a bright, cheerful boy to talk to: he takes a keen interest in what goes on, and intellectually has managed well at a normal primary and junior school.

His younger brother GRO-A was diagnosed at an early age as we looked for the disease once it had been recognised in GRO-A. GRO-A is a more ebullient personality, and over the years has suffered several bleeds into the right knee joint, with the result that he now has a chronic arthritis of the joint which will not straighten fully. From time to time he has further bleeds into this damaged joint, each of which must further make a slight and additional damage to the joint. He has no central nervous system disease, and although he has had more bleeds in other joints than his brother, the knee has borne the brunt of the damage and is the main problem. He too goes to a normal school.

Recently, the GRO-A and their mother has been left to look after them, together with their young sister. She has been giving them injections, bringing them to hospital for clinic visits, physiotherapy and emergency treatment. GRO-A is now due to transfer to a secondary school. The boys' present school is on one floor and they have been able to go there on crutches or in a wheelchair if necessary. In changing to a secondary school the boys will have to travel further, and mix in a larger and less sheltered environment. They will not be as easily able to go if they have had a recent bleed. They are both capable of going to a normal school as their problems are mainly intermittent, but the school needs to be physically suitable. For instance, they will need to be able to get about

on crutches or in a wheelchair from time to time. Smaller schools where the staff can make sure the children are not being knocked over in the rush to different classrooms. The journey to school should not be too long or too tiring.

In my opinion there is no secondary school in GRO-A which is suitable for them. Furthermore, GRO-A, the responsibility of looking after two boisterous lads who need regular hospital and medical attention, and frequent intravenous injections of special products to treat their bleeding episodes, is too much for their mother to cope with unassisted. We have already had once to admit the boys to hospital to give the mother a rest as there is no-one else who can care for them. Consequently, after discussions with the family, I have come to the conclusion that their needs are best met by education at a boarding school.

Unfortunately, there is no suitable boarding school nearby. In their case, haemophilia raises problems which can only be met in a school with suitable facilities. In this country there are two such schools, and the best facilities by far are available at the Lord Mayor Treloar College at Alton, in Hampshire. This school has a Haemophilia Centre on site, with medical and nursing staff experienced in the management of the acute and long term problems of the disease. Such facilities are available nowhere else in the country. Although there are other boys under my care with the disease in normal and special schools, both residential and day schools, none presents quite the same combination of problems as these two brothers, and I consider that no other school is really suitable for them. For GRO-A, we are forced to make a decision now about his education, as the Lord Mayor Treloar College is the only school which can provide the comprehensive facilities he needs. We will have to make the same decision about GRO-A in two years' time. It is preferable for both boys to be together as they can help each other.

I understand from the Headmaster at Treloar that there may now be no vacant places for this September unless a child already accepted drops out. If this is so, I should prefer GRO-A to transfer to another residential school rather than to go to a local day school in GRO-A. As a short term arrangement the Children's Convalescent Home and School at West Kirby might be suitable.

Yours faithfully,

GRO-C

D. I. K. Evans,
Consultant Haematologist
Director of Haemophilia Centre.