The Bulletin

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Patron, H.R.H. The Duchess of Kent

Member of the World Federation of Hemophilia
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THE HAEMOPHILIA SOCIETY
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A.G.M. REPORT

ST. THOMAS' HOSPITAL

The Society's Annual General Meeting was held at St. Thomas' Hospital, London, on Saturday 24 April 1982.

The Annual Report and Accounts were presented and adopted by the meeting. Professor R. G. Macfarlane was re-appointed President and the following Vice-Presidents appointed:

Dr. Rosemay Biggs
Dr. S. H. Davies
Professor G. I. C. Ingram
The Rt. Hon. Neil Marten, PC, MP
Robert K. Massie
Dr. J. F. Wilkinson
Lord Willis of Chislehurt.

The Chairman reported that the following had been appointed to the Medical Advisory Panel:

Professor A. L. Bloom
Dr. B. Colvin
Dr. C. Forbes
Professor R. M. Hardisty
Dr. P. Jones
Dr. E. Mayne
Dr. C. R. Rizza
Dr. E. G. D. Tuddenham

and they were welcomed by the Annual General Meeting.

Honorary Officers were re-elected unopposed for 1982-83, and they are as follows:

Honorary Chairman:
The Rev. A. J. Tanner
Honorary Vice Chairman:
J. R. Hunter
Honorary Secretary:
K. R. Polton
Honorary Treasurer:
H. N. Abrahams.

After election the following eight members were elected to serve on the Executive Committee:

Mrs. M. I. Britten
W. Johnstone
C. Knight
Dr. L. Kuttner
K. Milne
J. L. Prothero
J. Ritchie
D. Rosenblatt.

The Chairman then presented the Catherine Cookson and Brendan Foster Awards for 1981 as follows:

The Catherine Cookson Award

Senior: GRO-D — for achievement in examinations

Junior: GRO-D — for academic achievement.

The Brendan Foster Award

Junior: Not Relevant — for achievement in sport.

Photographs of the recipients appear elsewhere in this Bulletin.

Following the formal business the meeting adjourned for lunch in the Postgraduate Centre, which has inspiring views across the Thames to the Houses of Parliament.

The afternoon session of the A.G.M. was devoted to a panel discussion entitled **"JOINTS — Care & Repair"**, chaired by the Reverend Alan Tanner, Chairman of the Society. The panel consisted of:

G. F. Savidge, MD Senior Lecturer and Director of Supraregional Haemophilia Centre at St. Thomas' Hospital. Before joining the staff at St. Thomas', Dr. Savidge worked with the eminent Dr. Blomback at Karolinska Institute in Stockholm where he gained 10 years' experience working with haemophilic patients. He is a graduate of Cambridge and St. Bartholomews Hospital.

M. E. Smith, FRCS After Trinity College Cambridge he came up as a Medical Student at St. Thomas' Hospital. Having completed his general training he went on to St. Thomas' Orthopaedic rotation. He took fellowships in Hongkong and America and immediately prior to his appointment as Consultant Orthopaedic Surgeon at St. Thomas' Hospital, spent a year in research on Fracture Healing. He has published on the orthopaedic aspects of haemophilia and paediatric orthopaedics.

J. C. A. Madgwick, MB, BS, FRCS Senior Consultant Orthopaedic Surgeon, The Royal Free Hospital. Co-founder with the late Dr. Katharine Dormandy, in 1967, of the joint orthopaedic/haemophilia clinic. Author of papers on various orthopaedic subjects, chapters in a textbook of orthopaedic surgery, and co-author of a Haemophilia Handbook.

Brenda Buzzard, MCSP, SRP Senior (1) Physiotherapist at the Newcastle Centre in the Royal Victoria Infirmary. Mrs. Buzzard trained at the RVI, qualifying in 1976. She has worked alongside the staff in the Centre for 3½ years and makes a specialty of the haemophiliac's problems.

It is hoped to publish the contents of this interesting and stimulating session at a later date.

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Not Relevant

Not Relevant

Dr. Peter Jones and his family with the R.G. Macfarlane Award.

R. G. MACFARLANE AWARD 1981

The R. G. Macfarlane Award for 1981 was presented by the Reverend Alan Tanner to Dr. Peter Jones at a buffet supper, organised by our Northern Group, on Friday 19 February 1982.

The Award, first presented in 1978 to the late Dr. Katharine Dormandy, is made annually to recognise officially Professor Macfarlane's work in the study and management of haemophilia and to register the appreciation of the Society for all the support which he has given to it for many years. The Award itself may be given to a doctor, scientist or any other person who has been involved in research, in the management of haemophilia or in the more general care of those with haemophilia or related disorders. In making particular reference to Dr. Jones and his vast enthusiasm for patients and relatives, the Chairman recalled with pleasure the long and happy association which has been enjoyed between the Society and the Newcastle Centre. The presentation of the Citation and medal was received with much warmth by the large company of guests and Dr. Jones replied in suitable vein.

A number of colleagues shared in Dr. Jones's delight and expressed this in the form of further presentations, which included one from the Northern Group.

The Society – represented by Alan Tanner, Ken Polton, Jim Hunter, Ken Milne, Mr. and Mrs. John Prothero, Mrs. Peggy Britten and the Co-ordinator – are indebted to the Northern Group for their immaculate plans for a superb evening.

Not Relevant

Not Relevant

DISABILITIES AND HOW TO LIVE WITH THEM

This article originally appeared in THE LANCET of March 10 1982 and is reproduced here with grateful acknowledgements to The Editor.

I am a 36-year-old haemophiliac with a coagulation factor level of less than 1%. Diagnosis was established when I was 2 years old after I had fallen and cut my forehead. Haemophilia was nothing new to my mother. Two of her brothers, now deceased, were severe haemophiliacs. She had discussed with her doctor the possibility of transmitting the disease to her children. His advice was that such transmission was most unlikely since haemophilia usually misses a generation.

My childhood bleeding was primarily to knee, elbow, and ankle joints, with nosebleeds and bleeding from superficial cuts and abrasions. I could always recognise a bleed by a bubbling, a tingling, or simply an awareness that all was not well around the area concerned. Each joint bleed followed the same depressing, predictable sequence of events: the early warning sign would be followed over a 3–6 hour period by a gradual loss of movement and an increase in pain and discomfort. My mother was usually the first to be told of a bleed and accepted the news in her usual calm, matter-of-fact way. This reassurance was of the utmost importance as it helped me to accept and cope with each incident. The reaction of my father was always of surprise and disappointment for me that I was again out of action, but he would quickly accept the situation and, like my mother, get down to giving me the care and attention I needed. My parents and I soon found that the local hospital had little understanding of the disease and was unable to provide any treatment. The local general practitioner was similarly out of his depth and was able only to advise rest. As our experience increased, we realised that we were the only ones who could decide what to do each time. Each bleed prompted the familiar question: "How did it happen?" Most of the time, it was impossible to remember. We did not appreciate that with such a low clotting level, trivial incidents could trigger off a bleed and bleeding could also occur spontaneously.

For bleeds in joints it was necessary to immobilise the limb completely until swelling and pain had subsided. Each episode took weeks and even months before full movement was regained. As

the frequency of bleeds into knee joints increased, there was a gradual loss of full bending movement. I particularly dreaded bleeds into the knee or ankle joints as either rendered me almost helpless. My parents' lives were constantly disrupted with one or other having to stay with me during the night. Hot or cold compresses were applied, pain killers given, and anything that might ease the continuous agonising pain was done. Recovery was always slow and my days were spent propped on a sofa or bed, filled with boredom, loneliness, and an intense feeling of isolation from the outside world. Friendships with other children were difficult because of prolonged absences. When I was with them I was always torn between the irresistible attraction of joining in the more hazardous pastimes and the warnings from my parents.

Primary education proved impossible. Frequent bleeds resulted in poor attendance at school and after two years my education ceased. It was not until I was 12 years old that the education authority arranged for me to have home tuition. During those few years I reached a reasonably high standard of education. I later attended two colleges where my training was completed for future employment. At the age of 15 I had teeth extracted for the first time. Prior to admission to the local hospital, gum shield impressions were made of both sets of teeth. Immediately after the extractions the shields were firmly inserted, a method which fortunately proved successful, since there was still no known treatment. As I entered adolescence, the number of bleeds into joints began to decline because of my more leisurely adult pursuits, such as drinking and girls.

At the age of 18 I started my first job in the costing department of a civil engineering company, and the following two years were quiet so far as bleeds were concerned. I had finally to join another company when mine went into voluntary liquidation. I sustained my worst bleed ever when, at the age of 20, I strained my right hip. I had a massive haemorrhage which resulted in swelling from hip to knee, loss of sensation along the top of my thigh, and extreme pain. After five months I was mobile again, but had lost my job meanwhile, because of the injury. Later that year the same leg gave way and I was back where I started. A year later it happened again. This time I developed haematuria and was admitted to the local hospital. Fortunately, one of the doctors had heard of treatment at the Royal Infirmary, Sheffield (now transferred to the Royal Hallamshire). Soon after arrival at the Infirmary I was put on an intravenous plasma drip. I was overjoyed with the result; the discomfort began to ease and the swelling soon became softer to the touch. From that day I was registerd at the haemophilia centre. Therapy continued to improve, and the advent of cryoprecipitate factor VIII and fibrinogen extracted from plasma reduced treatment to an injection on an outpatient basis. Ironically, in 1973, after an injection of cryoprecipitate, I developed serum hepatitis. During my recovery, chickenpox added to my troubles. I was in an isolation ward for six weeks. It is unfortunate that serum hepatitis remains a risk of replacement therapy, yet it is a risk I am sure that most haemophiliacs are prepared to take in view of the tremendous advantages.

At the age of 29 I was fortunate enough to be chosen to administer my own treatment, which consists of an intravenous injection of dried factor VIII concentrate reconstituted with sterile pyrogen-free distilled water. My lifestyle since home treatment has improved dramatically. I am now able to treat each bleed immediately, and so avoid discomfort, inconvenience, and reduce future damage to a minimum. Over the past two years the single injections have totalled an average of two bottles per week (one bottle contains 260 I.U. factor VIII). My daily routine is rarely disrupted and my employment in administration with a local bus company is no longer at risk. During 1981 I was off sick for a total of seven days, of which two were because of influenza. Holidays present few problems, provided I choose appropriately and I take sufficient supplies of factor VIII with me. My wife, whom I married when I was 24, despite her family's misgivings regarding my condition, and I have recently returned from three weeks in Thailand. I consider myself fortunate to have loving parents and a wife who have helped me through the darker days of my childhood and adult life. The only reminders I have of those days are reduced bending from a straight position in each leg and a weakened right thigh muscle, but my general appearance gives no indication of these restrictions. I am an avid snooker player enjoying the game's competition and skill. Golf is my other game which I play whenever I feel up to a round during the summer. I also

GRO-C

My wife and I have not had children because we did not want to add to our difficulties during the early days of our marriage. In view of present-day treatment and the promise of tomorrow, I do not consider that the possibility of transmitting haemophilia to future generations should deter any married couple from having children. My lifestyle is now as normal as possible within the confines of the disease.

GRO-A

Not Relevant

WORLDWIDE
W.F.H. News

HAEMOPHILIA: STATE OF THE ART II 1981

A Report presented at the W.F.H. XIV Congress held in San José, Costa Rica

Scientific discoveries and subsequent clinical developments in the field of haemophilia have evolved rapidly in the past two decades. The undersigned Committee of the World Federation of Hemophilia submits this status report in light of these developments.

GLOSSARY

1. *Haemophilia* — Refers to Factor VIII deficiency (*Haemophilia A*) or to Factor IX deficiency (*Haemophilia B*).
2. *Plasma* is prepared by the deep freezing of fresh plasma or as a by-product of red blood cells or cryo-precipitate production.
3. *Cryoprecipitated Factor VIII concentrate or cryoprecipitate* is prepared from fresh frozen plasma. It may come from one blood donation (*single donor*) or more than one (*pooled*), and may be frozen as freeze-dried (*lyophilized*).
4. *Factor VIII concentrates* are more highly purified and may be identified as intermediate purity (0.3 to 0.8 units Factor VIII/mg protein) or high purity (0.8 units Factor VIII/mg protein). Factor VIII concentrates are always freeze-dried.
5. *Factor IX complex concentrates* (coagulation factors II, VII, IX, and X) are freeze-dried and used chiefly for treatment of severe Factor IX deficiency.
6. *"Supervised self-treatment"* is equivalent to *"home care"* and implies that the patient has been trained to evaluate the type of haemorrhage and establish the dose of factor replacement to be infused **under the responsibility/supervision of a physician**. Supervised self-treatment may also refer to injection of a child by the parent, or technical help given by family members or other medical personnel.
7. *Prophylactic factor replacement therapy* is equivalent to *maintenance* treatment and implies administration of plasma products to *prevent* bleeding rather than for treatment of a bleeding episode.
8. *Inhibitor* is a circulating antibody to a plasma clotting factor or factors.
9. *Factor VIII unit* is the amount of Factor VIII in one ml. of fresh pooled normal plasma.
10. *Factor VIII:C* is Factor VIII coagulant activity as measured by a functional assay. This entity reacts with other plasma clotting factors to convert fibrinogen to fibrin, and is defective or deficient in haemophilia A.
11. *Factor VIII:CAg* is Factor VIII coagulant antigen, that is, the Factor VIII coagulant entity as measured by an immunologic test which detects both active and inactive entities. This is a small-molecular-weight portion of the Factor VIII molecular complex.
12. *Factor VIIIR:WF* is Factor VIII-related von Willebrand factor, the functional activity of which facilitates platelet adhesion and which is defective or deficient in von Willebrand's disease.
13. *Factor VIIIR:Ag* is Factor VIII-related antigen, as measured by an immunologic test for the von Willebrand factor and associated with the large-molecular-weight portion of the Factor VIII molecular complex.

I. DIAGNOSIS OF HAEMOPHILIA

Precise and accurate diagnosis of haemophilia can only be performed by laboratories recognized for their ability by peer evaluation. All diagnoses must be made by specific factor assays. Laboratory determination of Factor VIII antigen levels, Factor VIII and IX coagulant activity and von Willebrand factor levels is necessary for precise diagnosis of haemophilia. Inhibitor assays must be performed by standardized methods at intervals according to treatment schedules, usually yearly, or when the patient's clinical course indicates.

II. GENETICS OF HAEMOPHILIA

Genetic counselling for Factor VIII and IX deficiencies, including carrier testing and laboratory determination of Factor VIII antigen, must be an available service of major haemophilia centres.

Centres performing carrier testing must have enough known carriers available to standardize their tests. Although diagnosis of the carrier state has reached a high level of confidence, a female cannot currently be absolutely assured she is *not* a carrier. Continuing efforts must be directed toward the improvement of carrier tests. The availability of peer-recognized carrier testing must be expanded. At this time, prenatal detection of the haemophilia state in a male foetus is a promising technique but is not yet widely available.

Differentiation must be made between genetic information and genetic counselling. Decisions regarding highly personal issues like child bearing, contraception, and abortion must be the responsibility of the haemophiliac and family members. Professional staff members must respect this ultimate right of decision of the haemophiliac and his family and not attempt to influence these decisions.

III. TRANSFUSION OF THE HAEMOPHILIAC

The goals of treatment are: 1) prevention of mortality and morbidity; 2) general social and physical well-being; and 3) achievement of the person's full potential. The major disabilities of haemophilia result from repeated haemorrhage into the musculoskeletal system; therefore, the prevention of these problems is a major goal of therapy in the growth years. A single haemarthrosis in a major weight-bearing joint may initiate a vicious self-perpetuating cycle of rebleeding leading to haemophilic arthropathy.

HAEMOPHILIA HOME THERAPY

by Dr. Peter Jones

A **limited** number are available at a cost of £8.00 (incl. p & p) to Society members. This book will be of special interest to Centre staff and others involved in the professional care of haemophiliacs. Please order your copy from the Co-ordinator, at 16 Trinity Street, London SE1 1DE.

Timely and adequate replacement therapy is the key to haemostatic therapy. Supplies of Factor VIII and Factor IX complex concentrates, cryoprecipitate (for Factor VIII deficiency and von Willebrand's disease) and plasma (for mild Factor IX deficiency) must, therefore, be adequate, available, and affordable. Factor VIII and Factor IX complex concentrates offer the advantages of potency and stability; they require only small volumes of diluent for reconstitution and can be injected by syringe; their high purity reduces the incidence of immediate adverse reactions; storage, handling, and administration are convenient for the patient. These properties give lyophilized Factor VIII concentrate a particular advantage over cryoprecipitate for use in supervised self-treatment.

Availablility of concentrates is limited in most countries by economic factors. ***Therefore, a goal for the future is the general availability of concentrates; meanwhile cryoprecipitate can be used for Factor VIII replacement therapy when concentrates are unavailable.***

Experts are not in agreement concerning dosage schedules in the treatment of haemophilia; most developed nations provide as average 20,000 units of Factor VIII per patient per year and report satisfactory clinical results. Clinicians in certain haemophilia treatment centres in the United States and the Federal Republic of Germany have experienced an increase in Factor VIII dosage to an average of 50,000 to 200,000 units of Factor VIII per patient per year. Certain patients may require much higher doses for clinical benefit.

Mild haemophilia patients should avoid pooled plasma because of the risk of hepatitis. Recommended therapeutic materials are:

1. Small-pool or single-donor cryoprecipitate for mild Factor VIII deficient patients.
2. Plasma for mild Factor IX deficient patients. Plasma is needed as a source material for products to Factor VIII deficient patients and is wasted if transfused to other patients.

Early plasma episodic infusion therapy is the general basis of treatment, but maintenance (prophylactic) therapy is used at some centres in childhood, during the period when growth is most rapid and until the musculoskeletal system reaches maturity. Maintenance therapy may also be considered in the adult patient, if frequent haemorrhages occur into one or multiple joints, when one target joint is apparent, or in situations of major psychological and physical stress to permit active rehabilitation.

Infusion therapy should never be withheld from a haemophiliac because of fear of developing an inhibitor or because of the risk of hepatitis. Haemophiliacs may understand their symptoms better than medical personnel. The judgment of the haemophiliac should be respected and replacement therapy be provided upon request, even if clinical signs of haemorrhage are not apparent to the observer.

IV. DELIVERY OF CARE

Medical care for patients with haemophilia requires 1) experienced and competent medical and paramedical personnel; 2) an educated patient population; 3) adequate supplies of concentrates (frozen or lyophilized) and plasma; and 4) affordability of numbers one and three.

A. **Identification of Patients and Physicians** — Haemophilia is a rare disease, so low population areas may not have physicians experienced in its diagnosis and treatment. Efforts should be made to identify and register all patients with haemophilia and assist them and their physicians in finding professional care.

B. **Supervised Self-treatment** — All patients with haemophilia should have access to a supervised self-treatment programme. Selection and training of patients and families and comprehensive medical and orthopaedic examinations are essential. The patient must comply with the requirement to keep adequate records and to remain in communication with the supervising physician.

C. **Hospital/Medical Facilities** — The haemophiliac must have an appropriate medical facility available at all times and someone skilled in the therapy of haemophilia and able to treat acute illness or bleeding problems. Supplies of plasma replacement products must be available.

D. **Surgery** — Surgery on patients with haemophilia and carriers requires the collaboration of an experience haematologist to test the patient to ascertain that no inhibitor is present, and supervise replacement through surgery and during convalescence. *Sufficient supplies of lyophilized concentrate or cryoprecipitate for replacement therapy must be assured before elective surgery is undertaken.* General principles of factor replacement therapy require a peak level of the missing factor immediately prior to surgery and then a minimum haemostatic level until primary wound healing is complete.

E. **Inhibitors** — The treatment of the haemophiliac with an inhibitor remains a challenge. No single method can be recommended at this time, but several promising avenues of treatment are under active investigation. For example, several investigators have demonstrated the elimination of a Factor VIII inhibitor in both low and high responders using concurrent infusion of high-dose Factor VIII and "activated" Factor IX complex concentrate transfusion over a period of several months. Use of this technique mandates adherence to a detailed and strict protocol. Highly purified porcine Factor VIII concentrate is available and use of this product appears promising. "Activated" and "non-activated" prothrombin complex concentrates have been reported to be useful in the treatment of inhibitor patients. It is essential that the treatment of patients with inhibitors be managed by physicians experienced in this serious complication.

F. **Comprehensive Care** — A patient with haemophilia must have periodic reviews for assessment of general health as well as haemophilia status and possible periods of growth or complicating illness. They are best achieved by a team of individuals skilled in general medicine/paediatrics, nursing, orthopaedics, physical therapy, rehabilitation, dentistry, genetic, and psychiatric/psychological services. The haemophilia patient must be an active member of the team. Continuity of care requires a long-standing patient-physician relationship.

Shelby L. Dietrich, Chairman

Committee:

Dr. J. P. Allain	Dr. M. J. Inwood
Dr. H. H. Brackman	Dr. Carol Kasper
Dr. A. F. H. Britten	Dr. P. H. Levine
Prof. H. Egli	Prof. P. M. Mannucci
Dr. F. Etzel	Prof. K. Schimpf

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Not Relevant

THE FUNCTIONS OF THE HAEMOPHILIA SOCIETY

by Mr. J. Prothero

The Haemophilia Society in the UK is a unique combination of lay and medical skills. The lay side mainly comprises our Headquarters organisation and the 26 local Groups around the country. The medical side basically comprises our Medical Advisory Panel and our links with other medical and para-medical staff.

The Headquarters organisation based in London relies on a full-time, professional Co-ordinator and two part-time paid staff who between them man our Southwark office five days a week and process information, bank incoming money and act as the liaison between members, local Groups and the Honorary Officers and Executive Committee to ensure that the most appropriate person deals with unusual requests and the non-routine problems and queries that come to us. The Officers and Executive Committee are either haemophiliacs or are closely related to a haemophiliac and so are well aware of the problems of the modern haemophiliac as well as those he has had to surmount in the past.

The local Groups of the Society deal with local fund-raising projects and with the support of local haemophiliacs who have particular problems.

We have found that the quality of the link a Group has with the Haemophilia Centre or Centres in its area, and especially the link with the Director, is often of key importance to the ability of the Group to fulfil all its functions. Fund-raising can be accomplished even when there is no link with the Centre, but the other roles a Group can play in supporting haemophiliacs and their families and helping sort out problems that may arise for them from time to time, can only really satisfactorily be handled if there is good communication, understanding and a mutual desire to act together between the Group and the Centre Director and his staff. The forging of this link can provide all parties in haemophilia care with certain problems, but once it is established the benefits are great.

The Medical Advisory Panel has no executive role in the Society, but we would ignore their advice at our peril! There is a fairly continual exchange of information and advice between the Officers and the Panel, although the formal meetings with them, as a Panel, are few. Their support has enabled us to open many doors that would otherwise have been closed to us.

With that necessarily very brief outline of our organisation, let me turn to some of our functions.

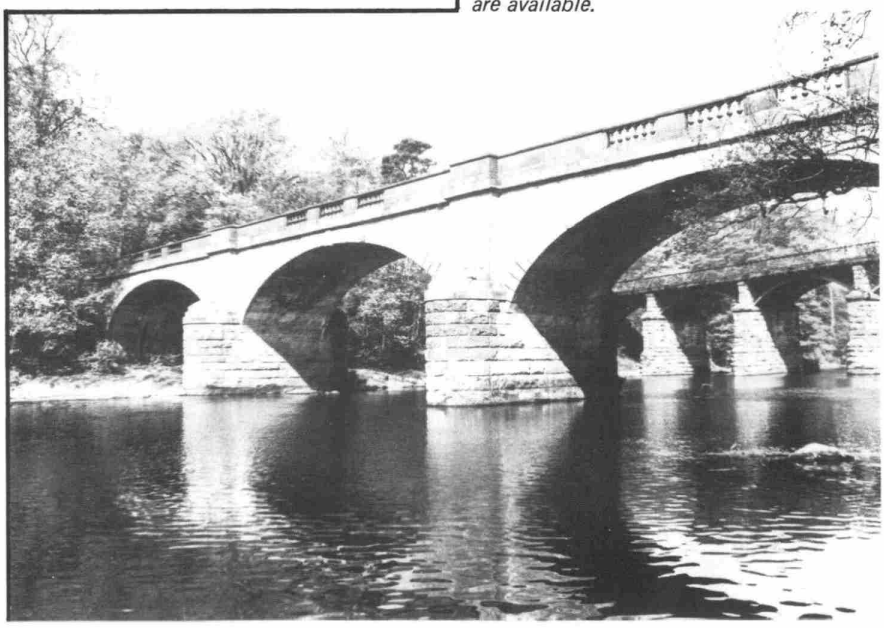
Perhaps the most important of them is, as our Rules and Regulations put it, to provide a fellowship for sufferers from haemophilia and allied conditions (and whenever I mention haemophilia again, you should read into my words . . . and allied conditions'), their families and those concerned with their health and welfare. It was to provide fellowship that the Society came into being. We have found that the fellowship aspect is called on most especially at times of change: for example, at the time of diagnosis; when the new treatment methods or materials are introduced; often in adolescence and early manhood and frequently at times of personal stress.

We feel another important function is our role in assisting in education and employment. All too often the parents of a haemophiliac infant will be unable to explain to a school exactly what haemophilia is, what its care is and what the needs of a young haemophiliac are, always assuming they know themselves! It is

Continued on page 7.

Not Relevant

On the River Lune — 25 yards from Caton Park, Lancaster. Fishing permits are available.



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often helpful for the Society to add to, or amplify the parents' explanation and often we have been able to help in working out, with the local Haemophilia Centre, the school and the parents, the best way of coping with bleeding episodes at school, both in obtaining treatment for them and ensuring loss of learning is kept to a minimum. This often needs to be repeated when secondary education is commenced. Where a local Group exists, or if contact is made with the Society officers, then often it can be brought home to schools and parents at an early stage the desirability of trying to relate the subjects the boy studies to some realistic job prospect in that particular area.

Employment is a very difficult problem, especially in areas of high unemployment. Groups can more readily contact local businessmen's organisations to explain the nature of haemophilia and its control and can encourage them to give haemophiliacs a chance. It is only through this slow, educative process that any satisfactory results will be achieved.

A further function of the Society is to safeguard the social and economic interests of sufferers. We do this by looking out wherever possible for changes in conditions which could affect haemophiliacs' lives, either through changes in new legislation, or by trying to change existing laws, or, more easily, local rules.

We do also have a practical approach to economic problems and make cash grants to members to assist them with almost anything from meeting overdue bills, installing telephones or having a holiday.

We do not believe, however, that merely handing out cash is the answer to all, or even many problems. We recognise that usually there are serious underlying problems that should be resolved if members approach us, or are referred to us for a grant. Interestingly, we have found that overall we have made fewer grants and for smaller amounts in recent years because we have found that greater benefit can be achieved by resolving such problems, especially in co-operation with local agencies, and it is far more satisfactory to reach a permanent solution than just to pay out cash for a temporary alleviation of the problem.

The most expensive of our functions is in promoting the study of the cause and treatment of haemophilia. This takes an increasing amount of funds and whereas in the past we tended to buy bits of equipment for doctors and scientists and Centres, now we tend to support whole projects. Obviously we are not in a position to fund everyone who comes to us, but we try to select projects that are breaking new ground and which we feel, often after consulting our Medical Advisory Panel, will be of benefit, so if they are demonstrably successful others will join or preferably take over the funding.

Gathering and publishing information useful to sufferers and others is another important part of our work. Where more people are on Home Care Programmes the contact they have with their Centres is greatly reduced and so they tend to get less and less information. We try to remedy this. At least our new-style Bulletin looks attractive and we have made great efforts to ensure it does have valuable information as well as more parochial items, such as the proceeds of a Group's sponsored swim, etc. We commission articles especially for it, or reprint items of particular interest from other publications not normally seen by haemophiliacs. In addition, we have produced a

collection of pamphlets, papers etc., specifically for particular groups of people concerned with haemophilia from parents to social workers, from teachers to health visitors.

We feel that we have an obligation to assist in raising knowledge and standards of haemophilia care, but do not see this function as being restricted to this country, as much of our work obviously must be. Although we work at this here, we also do provide a lot of information and help to Haemophilia Societies, doctors and individual haemophiliacs throughout the world, either direct or via the umbrella of the World Federation of Hemophilia. We work direct or especially in those parts of the world that were, or still are, painted pink on maps and in some other areas where Haemophilia Societies are only just beginning to achieve results. We have a firm commitment to the World Federation of Hemophilia, to which are affiliated all the active Haemophilia Societies in the world. We were one of the founding members and it has now expanded to nearly 50 members. The extent of our involvement can be demonstrated if I tell you that apart from their regular job and their roles and work for The Haemophilia Society, we have among the Officers and Committee of the Society, the Chairman of the World Federation of Hemophilia, the Chairman of the World Federation of Hemophilia's European Advisory Board, who is also Secretary of its Home Care Committee, both these members are also on the Advisory Board of the World Hemophilic Youth movement; the London Secretary of the World Federation of Hemophilia, the Chairman of the Insurances Working Group of the European Advisory Board and a member of the World Federation of Hemophilia Constitution Committee.

Not Relevant

Not Relevant