Witness Name: Katherine Victoria Burt

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The Bulletin

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

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Annual Report 1979 – "FORWARD INTO THE 80'S"

When commentators wrote their annual reviews for 1979, they generally remarked on its significance as the end of a decade and then gazed into their crystal balls to see what the 1980's might have in store for us.

For the Haemophilia Society, 1979 marked the end of a momentous decade in which striking advances were made in the comprehensive care of people with haemophilia. In these ten years, we have probably seen the most significant advance ever in research and treatment facilities.

At the beginning of the 1970's, plasma was still used frequently for the treatment of bleeding episodes with 'Cryo' gradually becoming available at the Centres. By the end of the decade, Cryoprecipitate is being replaced by concentrates which are used increasingly by our own members for self-infusion.

The Society itself has made much progress in developing the support provided for our members. The minutes of the monthly meetings of the Executive Committee show the wide range of matters brought to our attention by individual members, the Groups and others who seek our advice and support.

In the last year, the style of the regular Council meetings has been changed to allow the business affairs to be conducted as expeditiously as possible so that the greater part of the agenda may be given to the study of a particular subject. So, we have on one occasion heard of the work of Sister Sheila Dykes and Sister Gill Davis as Regional Co-ordinators. On another occasion, Dr. R. B. Mibashan of King's College Hospital gave a fascinating, illustrated talk on his work involving 'Pre-natal diagnosis of Haemophilia'.

A new form was adopted as well for the Annual General Meeting so that, after the necessary formal business, a panel of specialists discussed the psychological aspects of haemophilia.

These examples demonstrate our concern to give greater attention to educational aspects of our work. First, the psychological factors associated with haemophilia are becoming more evident, now that general treatment facilities have improved.

NATIONAL AWARDS FOR ACHIEVEMENT IN EDUCATION AND IN SPORT BY HAEMOPHILIACS

In response to a number of requests the closing date for entries has been extended to 30th September. Full details and information on how to apply appear in the last Bulletin.

Secondly, the advances in the pre-natal diagnosis of haemophilia have begun to offer new hope to many who are anxious about the future. However, we are well aware that, while research in such diagnosis may give more factual information about the condition of the foetus, at the same time it raises major ethical issues to be considered by the parents. The Society's sense of responsibility for parents required to make such vital decisions has fortified our resolve to see that facilities for Genetic Counselling are available freely. We regard it as the right of parents to be given sufficient information to enable them to make informed decisions and then to be supported once their decision has been made.

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APOLOGY

In the last issue of the Bulletin we referred to Mrs. Jean Spooner as "Mrs. Jean Spoore" in one of the photo captions – we apologise for this error.

CONTENTS

The Research Social Worker

After five years with the Society, Mrs. Victoria Stopford felt it was time to move on to other work. Vicki came to us in 1974, after working with Local Authorities and having a special concern for Mental Health, but she soon became familiar with the needs of people with haemophilia.

Vicki was the first Social Worker to be appointed to a full time post with the Society and it was evident that she would be a pioneer in this field.

Her greatest contribution was in the promotion of a series of seminars for Social Workers, nurses, and others involved with haemophilia. She was held in high esteem by her peers who, as a result of the seminars, were better qualified for their work in their own Centres.

Vicki also compiled a comprehensive series of booklets providing essential information for specialists such as Careers Officers, Employment Officers, Teachers and, most important of all, for parents! She has accepted an appointment as a lecturer in Sociology at the North Tyneside Polytechnic and she carries with her our warm good wishes for the future as well as our gratitude for her having served the Society so well.

In the course of the year, the first meeting of a British Association of Social Workers Special Interest Group on haemophilia was held. We shall no doubt derive much benefit from Social Workers meeting in this way to discuss professionally matters concerning haemophilia.

The Groups

The Group Liaison Officer reports that four new groups were formed in the course of the year, making twenty seven in all and that generally all groups were active. They have helped the Society immensely by raising funds by a variety of imaginative projects.

Group representatives met three times during the year when most groups sent members to take part in the discussions which were lively and prolonged. The Group Liaison Officer visited ten groups during the year and undertook other engagements on behalf of the Society.

Finance

The work of the Treasurer was complicated last year by increasing inflation,

higher Value Added Tax and rising expenses.

The general running expenses were more than £22,000, an increase of 19% over the previous year. However, income from donations also increased and this, together with two substantial legacies, led to the excess of expenditure over income being kept down to £1,900.

At the Annual General Meeting a Research Appeal for £250,000 was formally launched with the Treasurer appropriately making the first personal donation to the Fund! By the end of the year £38,000 had been received in response to the Appeal.

The World Federation of Hemophilia

The Society has continued to play a prominent part in the work of the World Federation of Hemophilia with five of our members being officers, one as a Vice-President and another as Chairman of the European Advisory Board.

The outstanding event was the XIII International Congress held in Tel Aviv, Israel in July. The report from our Voting Delegate appeared in an issue of the Bulletin, when he testified to the value of these occasions when opportunity is provided for sharing experiences with members of other National Societies. At the same time, the Congresses keep delegates informed about the advances being made in research and treatment throughout the world.

The R. G. Macfarlane Award

The R. G. Macfarlane Award for 1978 was presented to Dr. Rosemary Biggs. At a memorable ceremony in Oxford, Professor Macfarlane himself presented the Gold Medal and Citation to Dr. Biggs with whom he had worked at Oxford. It was a moving occasion. For the first time since his retirement, Professor Macfarlane, Dr. Biggs and other doctors and scientists from the laboratory met together. The Citation for Dr. Biggs' award is recorded in an issue of the Bulletin.

The Katharine Dormandy Centre

An important event in the year took place in January 1979 when the Katharine Dormandy Haemophilia Centre and Haemostatis Unit was opened at the Royal Free Hospital, Hampstead, by the Chairman of the Haemophilia Society.

The building of the Centre was made possible by a donation of £200,000 from Mr. Laurence Knight and a guarantee of £30,000 from the Society to ensure the inclusion of the Centre in the plans of the new Royal Free Hospital.

The Centre was named after Dr. Katharine Dormandy who had established the hospital's first haemophilia centre nearly fifteen years before. Dr. Dormandy, who died in 1978, had been a member of the Society's Medical Advisory Panel and an enthusiastic supporter of all the Society's endeavours.

Addendum

From this report, it will be clear that the Society is active, effective and ever alert to find new ways to improve the facilities available to our members.

At the same time, we are very conscious of the fact that not all people with haemophilia are in a position to take advantage of the major developments in haemophilia which have been made during this last decade.

From time to time, we hear of someone who lives a lonely, isolated life, or of a family which struggles on alone, unaware of the facilities provided by a Centre, or unable to reach one easily.

It is our firm intention to search for these isolated families, to bring to them the good news of this support which is now more readily available for all.

We are no longer surprised by hearing of people with haemophilia who achieve academic distinction, success in sports, or who make their mark in industry and in other ways. As we move into the 1980's we carry with us a message of hope and encouragement. To all who set their sights high, great goals may be achieved. To others, who cannot aspire to such heights or who falter on the way, let them know that the Society is here to help them.

Details of the talks on Pre-natal diagnosis of haemophilia, by Dr. Reuben Mibashan and Mr. Charles Rodeck, both of King's College Hospital, and of the following discussion, will be given in the next issue of The Bulletin.

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"DOES HE TAKE SUGAR?"

"DOES HE TAKE SUGAR?" is a BBC Radio 4 programme of special interest to disabled listeners. As from 29th June 1980 it has a new transmission time of **7 p.m. on Sunday evenings.** The programme is presented by Marilyn Alan and has two handicapped reporters – GRO-A and GRO-A

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THE SOCIETY WANTS MONEY

It is needed for research, grants to hospitals for equipment, to meet costs in passing on news and information from the London Office to members, for the day-to-day running of Society affairs, amongst many other worthwhile activities.

We all know this.

How can you, yourself, help?

In the next few editions we shall be providing you with an A-Z of helpful fund-raising suggestions. Meantime, we shall be focussing on just one idea to help achieve the Society's fund-raising target of £250,000. £50,000 has been raised already in one year; but much more is needed, and quickly. We have to continue to give practical, financial support to those who are already helping haemophiliacs to lead normal lives.

Do-It-Yourself Jumble Sale

You don't have to be an expert to raise substantial sums of money, but you do need lots of energy. These are the ingredients for a successful jumble.

1) ***A suitable hall.*** It should be sufficient to hold 200-300 people – say about 60 ft. square. Hiring the hall can be expected to cost between £10-£30 for 24 hours,

which could be say Friday 4 p.m. – Saturday 4 p.m. or all day on a Saturday.

In the first case the jumble could be set up on a Friday evening and early Saturday morning, opening the sale itself at about 11.30 a.m. on the Saturday morning. Where the hall is hired for the whole of Saturday, the setting up would take place on Saturday morning with the sale starting at 2.30 p.m.

2) ***Lots of black plastic sacks.*** Friends and other members of the public are happy to clear wardrobes, garages, lofts and other hiding places to provide jumble for the benefit of a national charity. Lots of it is needed for a successful jumble, at least enough to half-fill a garage from floor to ceiling (in the sacks of course!).

You will find that toys and sports goods of all description will disappear incredibly fast at the sale, followed by electrical items, bric-a-brac, kitchen and other household goods, ladies handbags, clothes, with shoes being the slowest to go.

3) ***Coloured felt-tip pens.*** About 3 or 4 will do. They are used for a) Posters. Put them in shops, libraries, on notice boards, telegraph poles or anywhere they will be seen and effectively advertise your forthcoming event. b) Pricing your wares and producing notices for the day.

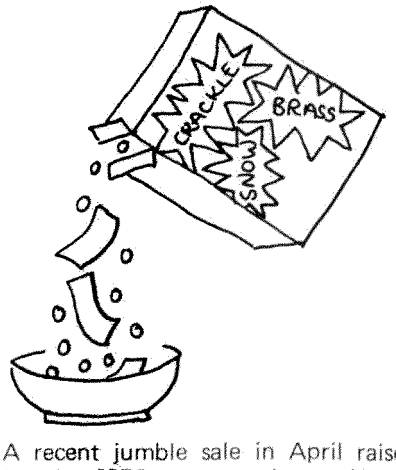
4) *A **telephone.*** Phone all your local newspapers, the free handout ones as well as those you pay for. Many of the papers will insert under "What's On" or "Forthcoming Events" details of your jumble sale at no cost. If you have to, then pay for two or three adverts. It will bring handsome dividends. Your local radio station will also announce details quite happily during the week or on the morning of the sale itself.

. . . the helpers after the sale

5) *A minimum of a dozen enthusiastic helpers.* The jumble itself can be collected over a longish period provided you have somewhere to store it. However on the day lots of bodies are needed for pre-sale sorting and to take the money from the hoards of marauding would-be purchasers. Eagle-eyes have to be on the look-out for articles disappearing into numerous plastic bags without money changing hands.

6) ***Lots of sandwiches, flasks of tea or coffee and cakes.*** These are needed to sustain the helpers after the sale and before the clearing-up process.

Helpers enjoy what they have done for you. Jumble sales engender a great feeling of camaraderie and satisfaction especially when the crackle, the snow and brass is added up prior to going into the bank.



A recent jumble sale in April raised just under £350 — you and your friends could do it too!

Happy jumbling — more next edition.

Illustrations © Helena Miller

Executive Health
THE YELLOW PERIL
by Dr. David Carrick

Many is the time I have heard or read that someone is "suffering" from jaundice.

Jaundiced the patient may be, but any suffering he may experience has little to do with his colour. Jaundice is not a disease any more than the rash accompanying measles is a disease. Both are the visible evidence of a disorder — the real cause of suffering.

Jaundice, in which the skin and whites of the eyes are stained yellow, can be the result of a number of disorders, most of which involve the liver.

There are certain diseases (including malaria) and accidental treatments (as with the transfusion of incompatible blood) in which a massive destruction of red blood cells takes place. The liver can cope with a moderate problem of this nature by converting the ruined cells and their contents, and excreting them as conjugated bilirubin; but excessive quantities lead to the pigment finding its way from the blood to the skin and staining it yellow. This type of jaundice is rarely intense.

Most causes of jaundice arise from an interference in the flow of bile from the liver into the duodenum. Bile is a yellowish-green fluid secreted by the liver and it is made up of salts, cholesterol, pigments and other elements which are employed in the emulsification of dietary fats. It is worth adding that, whereas bile flows steadily, a certain quantity is diverted into the gall-bladder which, under emergency situations — when great quantities of fat have to be managed (e.g. after a large meal of greasy fish and chips) — contracts and ejects considerable quantities of concentrated bile to reinforce the regular supply from the liver.

Obstruction of bile can take place outside the liver, as with impacted gallstones or pressure from an enlarged structure. But the bile is still being produced and eventually spills into the bloodstream and arrives in the skin and the sclerae of the eyes. Pigments enter the urine and change it to a mahogany colour, and the unemulsified fats passing through the bowel lead to clay-pale stools.

A similar picture arises if there is internal trouble with the liver, as with certain poisons and injections. It is with two of these causes that many people are most concerned.

Infective hepatitis, found world-wide but particularly common in areas bordering the Mediterranean, is caused by a virus (Virus A) and is passed from person to person as a result of poor hygiene. The virus is excreted from the bowel and in the urine, and the disease can be contracted from dirty lavatory seats and flush handles or soiled towels used by sufferers or carriers.

Indirect infection can come from water, milk and food that has been contaminated. Flies may carry the virus on their feet from rubbish dumps to food; and shellfish existing in polluted water have also been incriminated.

The incubation period is from 15 to 35 days. Then, several days before jaundice appears, the patient suffers from headache, malaise and chills. There is no appetite. Nausea and vomiting are usual and abdominal pain is common. The urine is discoloured shortly before the jaundice appears and the stools are pale.

The jaundice is intense and lasts for several weeks, but recovery usually takes place within three to four weeks and it is rare for permanent liver damage to occur. There is no specific treatment except bed-rest. A special diet (there are various views on the best form) is important.

When can a normal diet be resumed? Again ideas differ, but I believe that nature is a pretty good judge and (apart from liver function tests) a returning appetite is usually an excellent sign of recovery.

The disease caused by Virus B (the Australian antigen) arises from contamination of the blood by infected needles used in injections; from blood transfusions with blood from carriers; from unhygienic ear-piercing or acupuncture; and even, some believe, from blood-sucking insects such as fleas or bugs. The incubation time with this type is much longer — from six weeks to six months. The clinical picture is similar but the disease is much more dangerous than that caused by Virus A and sometimes carries a fairly high mortality.

Prevention of infective hepatitis is with gamma globulin (which must be given ***before*** the first symptoms appear) but, unfortunately, this prophylactic is less effective in preventing the disease caused by Virus B.

Evidently patients "suffer" from these illnesses (particularly as alcohol is banned for months after recovery) but their jaundiced colour is the least of their complaints. Their one compensation is that they need never feel guilty about not acting as blood donors; indeed, they must never be so generous as to pass their quiescent disease to the innocent.

by kind permission of the Editor
London Financial Times,
3 December, 1979.

WORLDWIDE

W.F.H. News

A SUMMER CAMP FOR HAEMOPHILIACS IN NORWAY
John Prothero, Chairman, European Advisory Board of the World Federation of Hemophilia and European Liaison Officer, The Haemophilia Society

In August 1979, I was invited to Norway for the Summer Camp organised by the "Institut for Blodere" — the Institute for Haemophilia. Each year the Institute holds a two-week camp, one year for adults and the alternate year for boys under 13 with their parents, which was the one I attended. Situated 20 kilometres from the centre of Oslo, the Camp combines an assessment of the problems and needs of each haemophiliac and his family with a fortnight's relaxation and recreation.

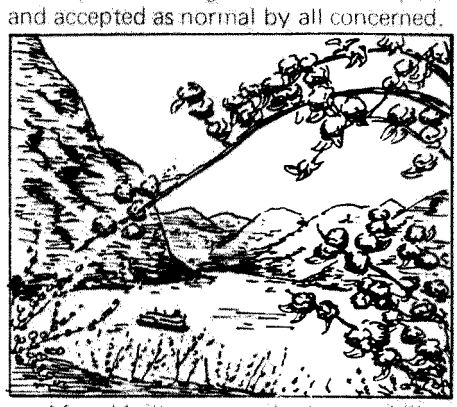
To call it a 'Camp' is to conjure up thoughts of camping and tents, whereas in fact it is held at the Frambu Helsesenter, which is a complex of buildings set beside a lake in a pine forest. It was built with financial backing from the Oslo City Council, and in its present form was opened in 1975, although it has existed for 20 years as an information and recreation centre for the handicapped. It is an independent institution financed by the Norwegian health service and all the expenses, including travel, are covered for the patients, and, if necessary, their parents, for with children the attendance of both parents is encouraged. If the parents have to stay away from work, they are entitled to sick leave with full pay. In some cases, brothers and sisters are also accepted. The Centre is not only for haemophiliacs, and during the year courses are run for sufferers from other complaints, such as cystic fibrosis, asthma and epilepsy. There is a permanent staff of experts at the Centre, which, when the haemophiliacs' camp is held, is supplemented by staff from the Institute for Haemophilia.

During the fortnight of the haemophilia camp, each haemophiliac and his parents are seen individually by the various staff members to ensure that any problems they might have are dealt with in the best possible manner. They see about two members of staff each day and the parents and sometimes the older boys are also invited to attend informal talks and lectures on a variety of topics. When the parents are at these, and indeed for most of the day, the children are looked after by young would-be university students and spend the time painting, playing games, swimming and generally having a marvellous time. The parents can relax knowing that treatment is available within minutes if a bleed occurs.

Each member of the team was kind enough to outline his views, activities and roles at the Institute or the Camp and it may interest members to have some of these outlined.

Dr. Anders Glomstein explained how the Institute maintains files for all the severe and moderate haemophiliacs in Norway, and also for the mild haemophiliacs who have been in contact with the Institute. The files include details of diagnosis, together with family, school and social security details etc. Within each file is a series of colour coded folders for reports from the staff members, the doctor, social worker, physiotherapist etc. In addition to the normal continuing notes, there is also a report of the assessment of each haemophiliac when they attend the Camp. Each of the staff at the Camp prepares a report and these are amalgamated. A summary is sent to the haemophiliac's doctor and the hospital where he receives his normal care. The extent of Dr. Glomstein's involvement with, and examination of, the boys at the Camp depends on how often the haemophiliacs have been seen at the Institute. Those on home therapy go to the Institute once a year for a day or so to be seen. If any problems arise in between visits, they can come and stay for a few days and, in some more difficult cases, haemophiliacs stay for longer periods. Some young haemophiliacs going to college or starting work find it difficult to make the break from the care of their family, but by staying at the Institute they can make a gradual entry into "the outside world". Some haemophiliacs are cared for by their local doctors and some by the nearest hospital, and the Institute tries to liaise with them over its findings and recommendations. When the haemophiliac is first seen, whether at the Institute or the Camp, a full medical history and examination is taken and the social background of the family is examined. A family history is compiled and a geneticist goes into this and the problem of carriers. A social worker carries out an appraisal of the family and the physiotherapist assesses joints and muscles. At each Camp attendance a haemophiliac has a full and comprehensive range of blood tests. Dr. Glomstein sees each patient for a minimum of an hour, and much more if it is the first time he is seeing him , or if there are any social problems. Apart from his examination, he sees it as an important part of his job just to talk to the family and give them general, overall information. Parents especially seem to need some points going over several times in order to explain them so that they may fix them in their minds and some seem to like to have even basic points reiterated at each Camp, as a reminder or for reassurance. All patients are given, free of charge, a looseleaf handbook of practical advice produced by the Institute team. This has sections on haemophilia and other bleeding disorders and their treatments; heredity and genetic counselling; the family; schooling; employment; the Social Security system; the Institute, the Norwegian Haemophilia Society and the Haemophilia Council; the World Federation of Hemophilia; medicines; advice on travelling; lists of literature available, and useful addresses. Patients on Home Treatment are instructed on the possible allergic reactions to their treatment and the use of the various drugs to combat them, which are contained in a special Allergy Set which is brought up on each attendance for checking. The clotting factors used are from the Norwegian Red Cross and in part from the Finnish Red Cross. The Norwegian freeze-dried cryoprecipitate is in bottles of 6 donor units, which is equal to about 420 international units of Factor VIII, and also in 3 and 12 donor units. The Norwegians like to be self-sufficient and in trying to work to that end, use no commercial clotting factors.

Ms. Ragnhild Molland will be remembered by delegates at the 3rd European Regional Congress of the World Federation of Hemophilia in 1976, as she presented a paper on the Institute and its work. She has been a social worker there since 1975 and when she then attended her first Summer Camp she found a lot of problems which the Institute has since been able to resolve. There were many haemophiliacs in bad or unsuitable housing, and many were in need of advice on Social Security benefits and rights. Education and employment were the cause of many problems, as indeed they are in most countries. Many haemophiliacs had moved to Oslo to try to get jobs and to be close to treatment, but things have changed substantially since then, especially since the advent of Home Treatment, and today haemophiliacs live and work all over Norway, which involves her in a great deal of travelling in visiting them and dealing with problems. Initially, she found a lot of the small children were over-protected, and it was felt it would help if they could be placed in normal kindergartens, but much persuasion had to be used on the parents and, of course, on the kindergarten staff, who were, in the main, ignorant of haemophilia and had heard only the usual "old wives' tales" about it. She provided the kindergartens with general information on the nature of haemophilia and the special information they needed relating to each child, from the files at the Institute. Some kindergartens would initially only accept the child if an extra staff member was employed solely to care for the haemophiliac and she had had to make applications in these cases for the necessary funds. Now the attendance of haemophiliacs is regarded as commonplace and accepted as normal by all concerned.



After kindergarten, the haemophiliacs often had problems with schooling, with many schools reluctant to accept them. Their ability to cope normally at school was demonstrably better if they had been at a normal kindergarten. The new school year in Norway starts in August, so she goes to see the school involved in the April before the boy starts. She also tries to arrange for the school to give him extra lessons if he is away at all, for she has found that generally schools take the attitude that a day or two off doesn't affect the boy's studies, but in many cases these days can build up to a large number over the course of a year, although of course the advent of Home Treatment has reduced the number of absences. Some haemophiliacs need to use wheelchairs from time to time and she tries to arrange for this as it necessitates the school co-operating in arranging as many lessons as possible on one floor. At first it was difficult to persuade schools to allow the haemophilic boys to do gymnastics, or play any sport, but now they will allow this, except for sports such as football, and this has been much better for the boys, both mentally and physically. If Ms. Molland has to make a trip, to talk to school staff for example, then she tries to visit other people in the area such as

haemophiliacs and their families, Social Security officers, family planning consultants, etc. Once a boy is at school, the Institute stay in touch with the school staff and can provide any advice they may need.

After school, the next problem sometimes encountered is with employment and she visits potential employers to explain the situation to them. Naturally these vary from banks to factories depending on the aptitude and ability of the haemophiliac. Often, she finds, employers are a little reluctant to employ a haemophiliac, but she has found that they can usually be persuaded. Sometimes they agree to a trial period in which the haemophiliac can prove his ability and worth, and in this case the employer will receive a State subsidy of the salary paid. If the job is in State employment then the subsidy will cover the full cost of the salary for a year, and may be extended for a further year; if the job is in the private sector, then the subsidy covers 50% of the salary for 6 months. If the man has then proved himself, he is taken onto the payroll in the normal way. As a result, the majority of haemophiliacs in Norway are in employment.

Ms. Molland also does a lot of follow-up and counselling work with families, especially those of newly diagnosed haemophiliacs where this has led to stress and strain on the family relationships. As a result, the staff of the Institute get to know the families really well and as there are about 150 severe haemophiliacs in Norway, the staff feel their patients receive a better level of care than a larger group located at a large hospital might do. There are in fact two social workers at the Institute and her colleague deals mainly with the problems of those who are at the Institute while she deals with those in the rest of Norway.

When a family arrives at the Camp, she sees only the parents and talks over with them any problems that they or their son may have and establishes if there is any action that could be taken to resolve them. She deals with the haemophiliacs direct only when they have left their parents' care.

Haemophiliacs' housing in Norway, generally, is of a high standard and they receive help by way of loans for home purchase at a much lower rate of interest than unaffected people. These loans are also available to enable house extensions to be built to give areas with no, or fewer, steps, if this will assist the haemophiliac. Previously, this facility was provided by Social Security, but now is obtained through the housing bank, which as it is also a source of funds for non-affected people, is preferable.

The average family with a haemophilic son has, at present, an annual average earned income of Kr.90,000 (£8,180) against a national average of Kr.55,000–Kr.60,000 (£5,000–£5,455). A few of the families with a haemophilic member had incomes of over Kr.100,000 (£9,090) which tended to push up the average, but even excluding those, the income still averaged above the national level. Each family with a haemophilic member automatically qualified for Kr.500–Kr.600 (£45–£55) a month from Social Security to cover the extra expenses involved. If the mother of a haemophilic boy was working and had to give up her job to look after her son, she would receive an allowance of up to Kr.2,000 (£182) a month, to cover extra costs and to make up for the lost earnings. This continues until the boy is 18 and is then reassessed. Usually the allowance for lost earnings is then discontinued, but if the haemophilic is still living with the family, the extra costs are still covered.

INTERNATIONAL HAEMOPHILIA CONFERENCE

This Conference is being organised jointly by the German Haemophilia Society and the World Federation of Hemophilia, and will take place in Bonn, West Germany, 3rd to 7th October 1980. Emphasis will be on the haemophiliac as a person and an entire session will be devoted to discussing a "Comprehensive Care Programme".

Special arrangements have been made for haemophiliacs (reduced registration fees, treatment facilities etc.) and anyone interested should write to the Society's office asking for a copy of the brochure which is now available.

Most haemophiliacs' families have a motor car supplied by the Government. This is not a general issue, but is supplied if a need is demonstrated because of the severity of the condition. Normally it is issued to the mother until the haemophiliac is old enough to be assessed on his own merits. The cars cost up to Kr.50,000 (£4,545) and a new one is supplied every 6 years. The family, or later the haemophiliac himself, pay the tax and insurance themselves, but the allowance they get for the extra costs of haemophilia takes this into account.

One member of the staff at Frambu Helsesenter who sees all the haemophiliacs is the dentist! Dr. Kari Storhaug is the full-time dentist there, and is assisted by a part-time colleague and a full-time dental hygienist. When the haemophiliacs arrive they have a full assessment which initially covered the condition of their teeth and gums and any abnormalities, but for the last three years has involved much more. The parents are also seen so that the dentist can build up background information on each patient and establish such things as their general attitude to dental care, and the dental services they normally received. At Frambu they have found that handicapped people, generally, have a worse dental condition than non-handicapped and they are trying to establish why. It may well be that those born with a handicap have their teeth adversely affected by different diet; by their medication, especially if it involved sugar when they were young; by the use of some drugs which, as a side effect, dry out the mouth; by over-protection in childhood resulting in the child receiving sweets and food on demand. After assessment, they try to establish why parents have not arranged proper dental care for the child, if this has been lacking. This usually comes from a variety of causes, such as being ill at the time the school dentist was calling, or when a private dental appointment had been made, and without any subsequent appointment being arranged; or it could be a fear of hospitals, doctors and, hence dentists, arising from the experiences of their condition; or it could be that parents see dental care as a small matter in comparison with the main handicap facing their child, so they don't bother; or it could be that the dentist is afraid to treat the child and if he is the only one nearby, as in a small place, the temptation is to do nothing as it could cost a lot of money to travel to another area to another dentist. There is a general lack of information and at Frambu they are hoping that the results of their work can be used to encourage the Government to do something to help resolve the problems, by, for example, extending the age range for free dental treatment, as Dr. Storhaug has found that earlier diagnosis is needed, more preventative measures are needed and better education of dentists in the care of all handicapped people would help.

At Frambu, after her assessment, any necessary treatment is given, as far as is possible. A lot of work is done by the dental hygienist on the preventative side, showing how teeth should be cleaned properly, the use of fluorides and a lot of time is spent in conditioning the children to accept dentists. This involves sitting them in the dental chair, letting them play with the equipment such as the water jets, etc.

As well as the haemophiliacs, if they have time, they try to look at the other family members, especially the mothers, who usually have least time to go to the dentist and who can sometimes have a low Factor VIII level which can give rise to bleeding problems.

A talk on dental health is given at the Camp, and she tries to pass on to parents as much information as possible, including the use of chemical tooth cleaners, as it had been found that if brushing sometimes made gums bleed, then the parents of haemophiliacs tended to cut back on the brushing which in fact worsened any infections present. If a chemical cleaner was used at such times, it would kill bacteria and after a while brushing could be resumed.

After the Camp, details of the assessments and treatments are sent to the haemophiliacs' dentists and they try to ensure they are seen regularly. They have found it gives better results if all the haemomphiliacs in one town are seen by one dentist.

The role of the dental hygienist is expanding. They do a 2-year course at university, and a large part of the course, especially in the final year, is devoted to dental care of the handicapped. Where the staff know of a good hygienist in a town they often refer the haemophiliac to her and leave it to her to find a suitable dentist for him. If his dental condition is good on referral, then the hygienist can ensure it remains so for a very long time.

The role of the physiotherapist in the care of the haemophilic child was discussed with me by both Ms. Liv Kjustad, from the Institute and Ms. Marianne Ziesler Berge, one of the physiotherapists from Frambu. One difference they have noticed over the last few years is that haemophilic boys now play much harder than before during the Camp. During the Camp, each haemophiliac is talked to and assessed. Because of the number present and the other calls on them, often each can only be given 30 minutes, but if time permits, or a case is particularly serious, extra time is given. This is workable only because of the knowledge of the Institute's physiotherapist about each case. If the need is urgent, they will start treatment during the course of the Camp, but normally the case is referred to a local physiotherapist near the haemophiliac's home, as the Frambu staff cannot follow up cases and although some follow-up work can be done by the Institute staff it is necessary for a local physiotherapist to be involved. As far as possible, the problems are discussed with the local physiotherapist before any course of treatment is suggested by the Frambu staff in order to ensure that it has not been tried unsuccessfully before. In addition to any course of exercises started at Frambu on some haemophiliacs, all the children have a session in the swimming pool and in the gymnasium every day and any brothers and sisters present are involved in the programme, as at Frambu they feel it is imperative that these matters are treated as one for the family. It is necessary to have sufficient children there to enable them to gain advantages from interplay between themselves and the parents, as this helps overcome over-protection. I was able to watch the gym sessions for the two age groups into which the children were split. They all greatly enjoyed them and as none of the exercises seemed to be other than part of a game, nearly all entered into them with enthusiasm. The exercises for the younger group varied from chasing games, various rolling games, ball games, swinging games and games on benches and various singing games involving simple actions. The older group's activities had rather less of a 'games' flavour, but they took turns at a variety of activities changing every few minutes. They climbed, balanced, wriggled, threw, ran and somersaulted their way through an amazing variety of exercises on apparatus and equipment with great vigour, with the help of the staff at Frambu.

It is not only the problems of haemophiliacs that are examined by the physiotherapists. Parents often have problems, usually involving their backs and necks, resulting from lifting their haemophilic sons, and from stress. Some are so exhausted when they arrive at Frambu that it is not possible to start any exercises until they have recovered and some parents find they are under so much stress that it is difficult for them to manage to fit in exercises at home.

I was also able to attend many of the talks given to the participants and I am most grateful to the members of the staff from the Institute, especially Ms. Eva Semb-Johansson, the Camp leader, for providing me with a whispered simultaneous translation. The wide range of the talks may be appreciated if I summarise some of them.

The first talk was given by the Frambu [redacted] outlined with a description of the adverse effects of doing it the wrong way, and the application of the principles to everyday living was given. After the theory came the practical and the parents had an amusing time in trying to put into practice the information they had been given, on a variety of weighty objects, including medicine balls, weights and, in some cases, their own children!

One of the few talks for children alone was given by Dr. Glomstein on the blood system and haemophilia. The children were seen in two groups, 4–7 and 8–12 years old. The younger group was shown just what blood vessels were, how people bleed, how blood clots and why, and the role of Factor VIII. To the delight of the children, Dr. Glomstein had a blood sample taken to provide a practical demonstration of clotting. The older group were given the same information, but in addition they were shown the structure of joints, and a model of the knee joint was examined. The muscles and the work they do was outlined and the effect of bleeds on both muscles and joints was described. Steps that could be taken to strengthen them, especially after bleeds, were suggested. Another blood sample was taken, this time from physiotherapist Kiv Kjustad, and as its clotting was watched, the way in which cryo-precipitate was prepared from blood was described.

Dr. Kari Storhaug spoke to the older children and the parents on dental health. She outlined the structure of teeth and the effect on them and on gums of decay, and how this happens. The benefits of correct brushing with a satisfactory toothbrush were outlined and the harmful effects of sweets and soft drinks on teeth were described. The need for parents to be responsible for brushing their children's teeth until even mid-teens was emphasised and the use and effect of fluorides discussed.

A very interesting evening talk was given on children's needs and development by Dr. Hilchen Sonmerschild Sundby who has been working with children since 1957, although recently she has been looking at them in the context of the family rather than as individuals. She was interested in what was inborn in children and what was a result of their environment. She felt that about 10% seem to have inborn problems. They just seemed to be born difficult and parents with such children should not feel that it is their fault, as there was nothing they could do about it, but it was necessary to recognise these cases. As babies they do not settle into regular habits and rhythms of eating and sleeping as most children do, and when they are older they exhibit strong reactions to new things. Often they flare up in anger at home, although they may seem normal outside it. Most children tend to be untidy and to spill things in their early years, but from the age of about 5 they tend to become more tidy, but the problem 10% don't! It was important to recognise this minority so as to give them special consideration. It should not be considered "spoiling" them if they were allowed to "get away" with some things, as it was just not possible to make strict rules for them. Conflict situations were avoided if they were left to be themselves. As they grew to adulthood they would still have the same tendencies, but they would learn to live with them, although they are more prone to develop other problems.

Learning opportunities were good for modern children, but unconscious learning was also important, and this children get from adults and the people they are with, but this opportunity is often lost with the difficult children. It is the sort of learning children get from being with their parents as, for example, when they cook or do repairs. It has been found more and more that where this has been missed, children lose their self-respect as they find they alone among their friends don't know about these matters which they cannot learn at school. School education tends to be of the 'sit down and learn' variety, and those who do learn are regarded as a success. If they don't they are called a failure, but if they have had some unconscious learning, they will at least have had some learning even if they fail at school, although often the difficult children do not even have that. It is important for parents to have their children with them, not only to read and talk to them, but to let them see how parents perform the various tasks they have and to help with them, although it is important to take care not to make it conscious learning, as this will make them "switch off". It is important also to suit the task to the age of the child and to take into account problems that can occur with such things as hot plates, tools, etc.

She felt children today face a lot of problems in establishing standards of morality and behaviour. It is difficult for them to find out what the rules are, as the standards they experience at home are different to those they see on television and those they encounter at friends' houses, and so they can become confused.

Twenty years ago the problem children were shy, anxious and introverted. Now they don't know what rules to follow, they have not been able to establish an inner morality, so they do just what they fancy. The most important thing to do is to establish rules within the family and to stick to them. Put words to them and call them rules. It doesn't matter if different families have different values, at least the children will have something definite.

Children also need to be taught to be thankful. Often parents had felt guilty, as though they were doing something dangerous to their children's wellbeing if they demanded gratitude, but it now seemed this was not so. One of the problems in teaching them gratitude is that so many things come so easily. Families are much better off these days and so, to a child, a gift of a toy or a bicycle seems to be nothing. It is important therefore to do things with the children, to take them to places and teach them to be grateful for this, for Dr. Sundby felt it would not just be a mere form of words as had once been thought.

A lot of research had been done on children whose mothers went out to work, to see if they differed from those whose mothers did not. It has shown that if the mother really wants to go out to work it will not damage the child. That is not to say that mothers have to work, but if they want to it is acceptable. It is important, however, to ensure that there are suitable arrangements for the children's care. It is not now thought necessary to follow the old rule about "one person contact" in the first year of life, which often stopped mothers working, but it is essential that whoever is looking after such babies really cares for them and nurses and cuddles them, rather than just being mechanical minders. If this is in order and the mother really wants to work, it will make her feel freer and she will then be able to give more to her children. There can be no set rules and Dr. Sundby stressed that it is important that each family must decide what it feels is best for it.

There were other talks which I was not able to attend, on the work and function of Frambu Helsesenter; general information on haemophilia; the care of joints and muscles on a day to day basis and after bleeds; why some haemophiliacs seem to react differently to bleeds and treatment; the life and experiences of a modern adult haemophiliac and current research projects around the world.

During the two weeks of the Camp, the parents had time for a trip to Oslo while the students baby-sat for them. On normal evenings the students provided a listening service in each corridor for signs of young distress, which enabled the parents to chat and play cards and even dance to music provided by some of the parents and staff of the Institute. Although the Frambu Helsesenter rules do not permit alcohol, everyone seemed to find the evenings very happy and jolly and I am very grateful to all my new friends who showed me Norwegian variations of card games and taught me, or tried to teach me, Norwegian folk dances!

I must again express my gratitude to Eva Semb-Johansson for all her patient help, to all the staff of the Institute for Haemophilia and to the parents at the Camp, for answering my many questions, and to the Norwegian Department of Foreign Affairs for meeting my expenses in Norway.

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£250,000 RESEARCH APPEAL

As at 1st June 1980 the total raised was £58,337 and grateful thanks go to all concerned.

Almost all of this figure has already been given or is earmarked to support a variety of projects at various hospitals.

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ANNUAL GENERAL MEETING – APRIL 1980

Following the new pattern, the Society's Annual General Meeting, held this year at King's College Hospital, London, was a mixture of the formal business of an AGM with news of exciting new work being carried out in the pre-natal diagnosis of haemophilia, and with the affectionate and grateful presentation of the Society's R. G. Macfarlane Award to one of the great workers in the world of haemophilia, Professor G. I. C. Ingram, who very recently retired from the post of Director of the Supra-Regional Haemophilia Centre at St. Thomas' Hospital, London.

Mrs. Pat Ingram, Professor Ingram and Alan Tanner examine the award citation.

R. G. Macfarlane Award, 1979

In introducing the Award presentation, the Honorary Chairman of the Society, the Reverend Alan Tanner, recalled how last year Professor Macfarlane himself had been able to make the presentation of the award named after him to Dr. Rosemary Biggs. He would have liked very much to have been able to have been present for the presentation this year because he held Professor Ingram in equal esteem and affection, but alas, was unable to come, so Rev. Alan Tanner said he had the great privilege of standing in his place and, to begin with, passing on Professor Macfarlane's very good wishes for the occasion to Professor Ingram.

Mr. Tanner said he thought most people would know about the Award itself, which perpetuated the name of Professor Macfarlane, one of the pioneers in work with haemophilia and a great friend and supporter of the Society and its work, and who was today one of our Vice-Presidents. The Award could be given to a doctor, scientist or other person who had been involved in research, in the management of haemophilia, or in the more general care of those with haemophilia or related disorders. The first Award had been made in 1977 to Dr. Katharine Dormandy, the 1978 Award had been to Dr. Rosemary Biggs and now the Award for 1979 was to Professor Ilsley Ingram.

The Rev. Alan Tanner continued that a very considerable amount of time would be needed to read through Professor Ingram's curriculum vitae, or to go through the list of his achievements, but he selected a few items from Professor Ingram's life and work and pointed out that, before he retired, Professor Ingram had been Professor of Experimental Haemoatology in the University of London at St. Thomas' Hospital Medical School and the Director of the Supra-Regional Haemophilia Reference Centre and the Supra-Regional Centre for the diagnosis of bleeding disorders at St. Thomas' Hospital.

Professor Ingram had held Wilkie Research Scholarships at the University of Oxford under R. G. Macfarlane in 1949 and from then until 1956 he had been in the Wilkie Research Institute of the Department of Surgery at the University of Edinburgh, where he had been a member of the external staff of the Medical Research Council, after which he had gone to St. Thomas' Hospital. In 1960-61 he had been a Wellcome Travelling Research Fellow in the Department of Pathology in the University of North Carolina at Chapel Hill, under K. M. Brinkhous and J. B. Graham, two names very well known in the whole international field of haemophilia. He had been a founder member of the College of Pathologists in 1963 and had become a Fellow of that College in 1969, and had been elected to a Fellowship of the Royal College of Physicians in 1972.

The Chairman said that his eye had been caught by another piece of small print in a summary of Professor Ingram's work which said, very simply, that Professor Ingram had published about 100 papers in books and journals on the subject of haemophilia and related matters and was co-author, with R. M. Hardisty, of "Bleeding Disorders; Investigations and Management" in 1965. He said that this small, cold print did not however tell one very much about the Ilsley Ingram whom the Society had known as a great friend and an enthusiastic member of the World Federation of Hemophilia, and one who had been keen to be involved with all the work the Society had done over the years. The summary only gave the achievements of Professor Ingram as the scholar, the research worker, the one with an enquiring mind, who fortunately for us had included in the enquiries that he had conducted, haemophilia and the care of individual haemophiliacs as a personal concern. All those achievements had been recognised widely at home and abroad, and Mr. Tanner said he had been impressed at seeing the great international esteem in

which Professor Ingram had been held by his peers.

The Rev. Alan Tanner then turned to the Award itself. He said we could have offered the Award to Professor Ingram on the grounds he had already covered. In addition, one of Professor Ingram's great gifts was his ability to translate, into terms which could be understood by lay people, some of the most complicated medical matters. That was a great gift, and Mr. Tanner said we had often gone to Ilsley Ingram to have something explained in simple terms or even to learn how to pronounce a medical term and Professor Ingram had always been very ready to do that with humility and without any sense of condescension, which was a sign of a person who was very much master of his subject and was keen to have others introduced to an acquaintance with it as well. Professor Ingram had for long supported the Society and had been a member of our Medical Advisory Panel. We would all remember for a long time the paper on 'The History of Haemophilia' which he had read at the World Federation's European Congress in 1976. We thought it would prove to be the definitive document on the subject. He kindly allowed us to have it printed and it has now circulated very widely, not only among our own members, but also abroad, and we were very grateful indeed for that, and on that count alone, his name would be linked with the Society for many years to come. Mr. Tanner then said that he would like to add a personal note and said that the members present would gather that he was deeply indebted himself to Ilsley Ingram, not only for helping him with the understanding of medical matters, but for the ease and the friendship which he had allowed us to enter into with him, and which we all valued very greatly indeed.

HISTORY OF HAEMOPHILIA

Copies of this most interesting and informative booklet are still available and will be sent on receipt of 20p in postage stamps.

The author is Professor G. I. C. Ingram, recently retired Director of the Haemophilia Centre at St. Thomas' Hospital, London.

Lastly, the Chairman warmly welcomed Mrs. Pat Ingram who had often been closely associated with our own Society affairs and who had travelled widely with Ilsley Ingram. He then read the citation for the Award which said — "The R. G. Macfarlane Award 1979 presented to Ilsley Ingram by the Haemophilia Society in acknowledgement of his unique achievements in the study and management of haemophilia, which have gained international recognition, and in gratitude for the sustained personal support he has given to the Society for many years" — and presented it to Professor Ingram to the accompaniment of prolonged applause.

After accepting the Award, Professor Ingram said he was overwhelmed by the kindness of the members of the Society. He felt that he could not express the honour that he felt the Society had done him, which he felt all the more because of its association with three people whose kindness and friendship and professional collaboration he had so much valued. As the Chairman had said, he had been sent to Professor Macfarlane, while still wet behind the ears, to learn his trade and of course he would never forget all that Professor Macfarlane had taught him, rather more than 30 years before. Dr. Dormandy worked first with Professor Hardisty, before she went to the Royal Free Hospital and, at that stage she, Professor Hardisty and he had collaborated in a scientific paper. He had been closely in touch with her, had very much valued her friendship, and greatly admired her over the years; he mourned her loss very deeply. Dr. Biggs had, of course, been at Oxford when he had been there and he had worked closely with her and he had gone back to her and Professor Macfarlane on a number of occasions with his problems, to pick their brains and receive the stimulus of their enormous intellectual ability. He had marvelled over the years at the stream of top-level work which came from their collaboration together and with the other members of their team. He said that the audience would see how moved he was to be associated with the names of those three wonderful people. He was also very moved that the members had chosen that way of saying 'thank you' from the Society, for he knew that was what it was. Really it was he who should say 'thank you' to them and all the haemophiliacs he had known and whose friendship he had treasured over the years. To be able to get to know a group of haemophiliacs very well and to feel that they were all working together to try and achieve the amelioration of such a very trying disorder had been such a wonderful partnership and so often he had marvelled at the courage and resourcefulness with which his patients had met the enormous challenge before them. The Award was a link with all that he would treasure for the rest of his life and so he would just like to say "thank you very much indeed" for having chosen to cement the friendship through the years to come in such a marvellous way.

Professor Ingram's typically modest speech of thanks was received with great warmth and depth of feeling by the audience which numbered among it colleagues who had worked with him on various projects, haemophiliacs who had been his patients, their families and friends and some haemophiliacs who now benefited from care at Haemophilia Centres whose Directors had been trained by Professor Ingram.

The Annual General Meeting

The Minutes of the Annual General Meeting will be presented to members at the appropriate time. Suffice it to say here that the Annual Report and accompanying Accounts were accepted by the Meeting and the Reverend Alan Tanner as Chairman of the Society announced that the Council of the Society, meeting that morning, had re-elected as the Society's President, Sir Weldon Dalrymple-Champneys, who continued to give us the benefit of his wisdom and advice. The Vice-Presidents, R. G. Macfarlane, Neil Marten, Robert K. Massie, Lord Rawlinson of Ewell, H. F. Rutherford, J. F. Wilkinson and Lord Willis of Chislehurst had been re-elected. There had, however, been a change in the Medical Advisory Panel. Because of his retirement, Professor Ingram had asked not to be included as a full member, but had agreed to act as a consulting member from time to time. The Panel that had been re-elected was Dr. H. Davis, Dr. Rosemary Biggs, Professor A. Bloom, Professor R. M. Hardisty, Dr. P. Jones and Dr. C. Rizza.

The Chairman declared elected the following Honorary Officers and Members of the Executive Committee:—

Chairman:	The Revd. A. J. Tanner
Vice Chairman:	J. R. Hunter
Secretary:	K. R. Polton, MBE
Treasurer:	H. Abrahams
Committee:	Mrs. M. I. Britten, C. Knight, Dr. L. Kuttner, K. Milne, J. Prothero, J. Ritchie, D. Rosenblatt.

ANNUAL DRAW

The Annual Draw will take place at a meeting of our East Kent Group on Thursday, 16th October 1980 at 8 p.m. The venue is the Kent Postgraduate Medical Centre, Canterbury Hospital.

ANNUAL SUBSCRIPTIONS

Although most of the money received goes straight into the Research Fund, to be used to help those doctors working on research and problems relating to treatment of haemophia, we still rely upon Annual Subscriptions and donations to keep the Society functioning, pay for the cost of the Bulletin etc.

If you have not yet sent your Subscription for 1980 please do so as soon as possible. Also, we would welcome hearing from members who would like to donate by covenant or who would like some Collecting Stockings for display in shops, clubs, canteens etc.