



The Bulletin

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

Member of the World Federation of Hemophilia
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As construction at Elstree keeps to schedule

UK SELF-SUFFICIENCY CONFIRMED FOR 1986

There are high hopes that the self-sufficiency deadline for the U.K. home production of Factors VIII and IX will be met after all.

Recently there had been considerable doubts that the Government's declared target of self-sufficiency would miss its 1986 target date.

The record of missed 'deadlines' in the past few years has not been a good one as forecast after forecast was overtaken by a variety of events which put the 'on-stream' date further and further back.

It started in 1976 when Dr. David Owen, then MOH in the Wilson Government declared that we planned to be self-sufficient in Factors VIII and IX within a few years.

IMPROBABLE

But 'within a few years' looked improbable until Lord Glenarthur, speaking for the DHSS in 1981 declared that we would be producing all the supplies we needed (an average of 32,000 units per patient per annum) by 1985.

Then 1986 became the projected date as the Government's new £32 million production complex at Elstree began to take shape.

However, according to Society Co-ordinator David Waters 'We are assured by the authorities that the 1986 deadline will be met'.

But even when the new plant

is 'up-and-running' there is some concern over where sufficient supplies of plasma will be found.

'It will take something in the region of 450,000 tons of plasma per year to produce the Factor VIII and Factor IX we need,' says David.

'At the moment we use 150,000 tons of plasma to meet 30% of our needs, and with 4/5,000 patients receiving regular treatment involving each of them in about 32,000 units, we need a lot of Factor VIII and Factor IX,' he added.

AIDS PROBLEM

'And although the press has been dramatizing the AIDS problem and the risk of imported blood coming into this country, I think it is very important not to forget that without the imported product the quality of life of those who need Factor VIII and Factor IX would have been much poorer.

'But having said that, confirmation of 1986 as the date for self-sufficiency is good news—although it may be December.'

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£5000 FOR COAGULATION METER



Jersey group presented a cheque for £5,000 to the island's public health committee in June.

The money will go towards the cost of a coagulation meter for use in the pathology department of the local hospital.

In this picture (kindly sent to us by photographer Barbara Pitman) are (left to right): Mike Entwistle (senior scientific officer), Jean Daghorn, Sheila Greenhough, Beryl Picot and Norma Toudie for the Jersey group, Deputy Robin Rumbold of the Public Health Committee and John Picot, chairman of the Jersey group of the Haemophilia Society.

CARIBBEAN HOLIDAY PRIZE

First prize in the 1985 annual draw will be a holiday for two in St. Lucia or Barbados. This generous prize has been donated by Lawson International Travel Services. Watch the post for your tickets!

£500 FROM OVER 30's

A £500-plus cheque was handed in to the North West group by a local haemophiliac member representing money raised from six months of special events run by Bowden Over-30's Social Club.

SOCIETY IN GOOD SHAPE

AGM was held in June

Over 40% of the financial surplus accrued by the Society last year came from the annual draw, while large sums from legacies and a substantial increase in donations all combined to put the Society's finances on a much more healthy footing.

At the Society's annual general meeting, held in the Nevin Theatre at St. Thomas' hospital in London, in June, the chairman the Rev. Alan Tanner paid special tribute to the work of John Prothero in his first year as treasurer, and coupling his name with 'the unstinting efforts of the office staff and the professional skill and dedication of the Co-ordinator David Watters', said that he could report with confidence 'that the Society has never been more efficiently organised than now, nor more readily poised to meet the needs of members in days to come'. The following were elected as your Executive Committee for 1985/86:- Chairman: The Rev Alan Tanner; vice chairmen: David Rosenblatt; Ken Milne; treasurer: John Prothero; committee: Howard Abrahams, Peggy Britten, Keith Colthorpe, Carol Holliday, George Kirman, Clive Knight, Dr. Kuttner, Diane Lewis.

CARDIFF FLAG-DAY

South Wales held a flag-day on July 4.

'We'd waited a long time for it,' says committee member Diane Lewis. 'There's such a heavy demand for flag-day permits that it's been five years since our last.'

They've always been good business in Cardiff and on previous occasions over £500 was taken.

'At one time we were wondering if our chance would ever come again, but it did.' Which was good news for the group—and the Society.



It looks sunny, but it was cold. Left to right, members of the Committee are Dr. Kuttner, George Kirman, Diane Lewis, Keith Colthorpe, Rev. Alan Tanner, Ken Milne, Peggy Britten, John Prothero and Clive Knight.

THE 'BULLETIN' IS BACK

After a long break, the 'Bulletin' is back in this new four column format! As many will have noticed there have been no issues since Ed34 No 1 early in 1984 and this is the appropriate time and place to explain why this was so.

During the course of 1983 it became increasingly apparent to the Editor and the Co-ordinator that a faster means of getting information to our members was essential.

The old 'Bulletin' appeared at approximately three monthly intervals and required that timespan for articles to be initiated, written, typed, edited, typeset, corrected and "pasted-up" to form a coherent issue. This process simply could not absorb last minute, and therefore up-to-date news, nor could it be significantly speeded up without devoting disproportionate amounts of money and time to the Bulletin production.

HAEMOFACT

Our answer to these problems was 'Haemofact' which is produced in our own office in response to the need of the moment. The aim of the Society has always been to keep its members as fully informed about haemophilia as possible and 'Haemofact' is the embodiment of that aim.

It enables the Society to

desseminate information quickly (with a production and distribution time of a few days) which has become so important in the light of the AIDS problem.

Our policy has been to respond to and sometimes to anticipate scare stories about AIDS and present the facts, always accepting that in a dynamic situation we will sometimes be proven wrong in retrospect.

EXTRA WORK

In 1984 the sheer volume of extra work in our office, generated largely by AIDS, and the shortage of cash available to the Society, led us to stop production of the 'Bulletin'. This break in production has enabled the Executive Committee to examine the future role of the 'Bulletin' and on the recommendation of the Editor it was decided to produce a new style 'Bulletin' in a new way. This issue is the outcome of our deliberations and we hope that our readers will approve.

The 'Bulletin' will remain as the document of record of the Haemophilia Society. It retains learned articles, useful information on mobility and welfare rights, a letters column, news about Society activities and personalities and, we very much hope, contributions from members. It will have more Group news, interviews, reportage and pho-

tographs than before.

We intend to produce three 'Bulletins' a year to a regular timetable.

To achieve these objects we have secured the services of a professional journalist, Ian Lucas, who will take over all the pre-publication work entailed, other than the editing. Ian travels extensively throughout the UK in the course of his business and so will be able to act as a reporter for the 'Bulletin'. We are confident that this will make our journal much more interesting to more of our members in the future.

EDITORIAL

There will be one more change in the 'Bulletin'. As from No 2 1985 each issue will have an editorial or leader column which will deal with a topical matter and explain the Society point of view on it.

On a personal note, as I have been editor since 1976, I look forward to the arrival of professional reinforcements and to new challenges and opportunities for the Bulletin.

Clive Knight, Editor.

FAIR EXCUSE

A number of the Lewisham group were missing at the AGM because the date clashed with their annual fund-raising tombola stall at the Blackheath Fair.

YOU MIGHT JUST BE LUCKY IF YOU WANT A CARAVAN HOLIDAY

Hurry, hurry, hurry if you want to book a Society caravan this season. Most of them have been gobbled up for July and August, but September is still available in most areas.

At Clacton there is a 6-8 berth van on the Highfields site (excellent social and leisure facilities), and living close by is member Joan Bleeze who dashes about settling people in and sorting out any problems they may have.

There are one or two dates available for the Pemberton Seacrest van we have at Pagham Village near Bognor. 'It's a lovely, secluded site', says bookings organiser Jean Copping. 'And there's St. Richard's hospital in Chichester where Dr. Bateman is on hand to help with any problems.'

There is a choice of two vans at Caton near Lancaster where



North West Group keep them in tip-top condition. Contact Keith Pope for available dates.

And out on the west coast of mid-Wales is an 8-berth caravan at Borth, close to the 'golden sands'. Your contact for this one is Kay Instone of Shirley (Solihull), who tells us there are September dates available.

There's plenty of room for children to play both at Caton (above) and Clacton (below). Note the ramps which have been built to take wheelchairs.

FLAG DAYS IN THE NORTH

There are so many charities seeking flag days that the Northern group has been finding it more and more difficult to get permission for their fund-raising exercises which have produced excellent returns in the past.

According to group secretary Pauline Sanderson 'we have to be on our toes to get permission'.

The group stages flag days in Gosforth, Darlington, Durham, Washington and Sunderland, and whereas average income is £100 for each day the Darlington collection last August was a particularly good one—with over £200 in the can!

N.E. OUT ON THE STREETS

North Eastern group has been doing quite well with street collections.

They collected £260 operating from Sainsburys in Leeds and £160 from Marks & Spencer in Leeds.

Plans are drawn up for a collection at the Arndale Centre in Bradford for September and at Lewis' in Leeds the following month.

A Lot of Bottle

Collecting money for the Society through an empty whisky bottle installed in an Arbroath restaurant proved a smash hit as £100 was revealed when the bottle was ceremoniously broken open to disgorge its £p to £5 note contents.

COLOUR TV AS TOMBOLA PRIZE

At the end of July North West group will be taking part in an annual summer show at Adlington, and manning a tombola stand.

'It's an annual exercise for us,' says group chairman Norma Guy, 'and we run the annual raffle for a colour television.'

'We make about £150 profit from the raffle alone.'

CHANGE OF PROBLEM

Most regions face the same difficulties of the distances involved when trying to organise social and fund-raising events.

'We are obviously delighted that the Seminars have been held in Bournemouth for the last three years and this has meant local members could attend some important lectures, literally on their doorsteps,' says Southern group secretary Liz Burrows. 'But our fund-raising tends to narrow down to a few events and a hard core of familiar faces.'

The group will be repeating their successful fund-raising event at the Fordingbridge Agricultural Show on July 20, when they will be running a tombola stall. 'We've raised money at this show for five or

six years,' says Liz. 'We did try various raffles and games at one stage, but found tombola pays the best.'

The group takes advantage of the holiday season when Jean Payne takes her teddy bears and lucky straws to Bournemouth gardens for three days.

The local council provides a permanent site and allocates its use for charities' fund-raising efforts. Jean has raised a tremendous amount of money from her teddy bears over the last few years, and works long hours planning, stocking and running the stall. 'However,' she says, 'what takes the greatest effort is counting and carrying all the loose change to the bank!'

STEAM ENGINES AND MARATHONS

East Kent group, with some notable exceptions, is not renowned for its fund-raising activities, focussing as it does more on social and informative events with the emphasis on sharing in fellowship with each other all the problems and concern associated with the disorder.

The notable exceptions include the Steam Rally at Sellindge, near Ashford, where Mary Clark, Elizabeth Newman and Peter Knight, apart from raising funds, help to make the general public more aware of haemophilia.

For the past two years Peter Knight has pulled on a Society T-shirt and pounded out the

famous Canterbury marathon course, regarded as one of the toughest because of the undulating country it covers.

Last year Peter raised £225, and if he can be persuaded to run again the next marathon is planned for the autumn.

FACILITIES HAVE IMPROVED

'There seems little demand for any help from local haemophiliacs and their families,' says Northampton & District group secretary, Martin Shaw.

'It's unlike the early days,' he adds. 'Treatment facilities have improved so much.'

The group sent new delegates to the weekend seminar at Bournemouth and they're trying to persuade some youngsters to tackle the North Wales adventure holiday.

YOUTH SECTION?

Tayside group is investigating the possibility of starting up a youth section.

POINTS OF VIEW

Dear Sir

In his letter Dr. Winter expresses his disagreement with opinions of one of the workshop groups at a residential seminar organised by the Haemophilia Society in Bournemouth, March 1983. In particular, he challenges the group's conclusion that 'genetic counselling should not be carried out by the medical profession, because the medical profession is too biased towards prevention of genetic disorder' and that 'telling people probabilities with which their children might be affected is only a small part of counselling'. Since I was the leader of the group I would like to comment on these group's opinions.

I agree with Dr. Winter that 'it is time to get away from the time-honoured rivalry between medical and non-medical professionals'. However, in genetic counselling, it is not the rivalry that is the issue but some much deeper social psychological and ethical problems.

1. One of the basic assumptions of genetic counselling is that the counsellor should be neutral in the sense that he or she should not direct the counsellee towards any course of action. It is up to the counsellee to make up his or her mind on the basis of provided information. However, the role of a medical professional has traditionally developed, not along the lines of neutrality, telling people facts, but along *advice giving*, directing people towards, or away from, a particular course of action in order that they should get better. Thus, the doctor gives the patient advice as to a regime of pills, as to what to eat, and so on. The doctor knows that it is his job to give advice to the patient and the patient knows that in order to get better he must follow the advice of the doctor. How then can both the doctor, and the patient and carrier, suddenly switch into a realm of neutrality that contradicts everything they have been used to? As Porter (1977) points out, 'neutrality is unusual in medical practice, and it is a difficult attitude for many physicians to adopt and may be even confusing to some clients who expect to be guided by the physician'. The counsellor may *think*, of course, that he or she only communicates facts. He may choose words very carefully, structure his argument or even present the counsellee with a 'neutral booklet'. However, words and sentences of a communication form

only a part of the message we transmit to each other. We all know too well that silences may be more effective than words, that the way we say things and the emphasis we put on words all determine what is actually understood.

In a recent study concerned with the consumers' view of genetic counselling in haemophilia, carried out in Scotland and Canada (Markova, Forbes and Inwood, 1984), it was found that only a few counsellees thought that a counsellor would prove to be neutral and give information only. Understandably, many of these counsellors conflated the roles of counsellor and doctor.

2. Dr. Winter quotes from a recent Working Party report of the Clinical Genetics Society that says that good intentions cannot be substitutes for factual accuracy of risk estimation. Although no doubt it is important that counsellees understand probabilities and their own risks, a number of researchers (e.g. Pearn, 1973) have demonstrated that interpretation of statistical probability is highly subjective. What is a high risk for one person, may be a low risk for another. In an optimistic state of mind, a risk of 25% may mean to a person a small risk, while in a pessimistic state of mind he might consider it a very high risk. In addition, telling someone that the probability of having an affected child is, say, 50%, may be very confusing. Discussing the same problems with respect to Huntington's chorea, Wexler (1979) points out that in real life a 50-50 risk always means for a particular individual a 100% certainty that he will either develop or not develop the condition. However, such a certainty changes, depending on the mental state of that particular individual, from moment to moment, day to day, month to month. Finally, information can be provided in different ways. The counsellor may say either 'there is a 50 per cent chance that you will have an affected child' or 'there is a 50 per cent chance that you will have a healthy child'. Which of these formulations is more factual? Are these formulations the same facts for the consumer?

3. The Working Party report of the Clinical Genetics Society claims that the aim of genetic counselling is to reduce stress, fear, and anxiety. Such aims, of course, are very important. In order to achieve such aims, counsellors should be trained in communication and counselling

skills. Unfortunately, medical curricula rarely provide courses for the teaching of such skills. There simply is no time for such issues at medical schools. Some doctors like everybody else may not need special training in empathy and communication. Others need it badly. The counsellee may or may not be lucky. Specially trained counsellors, perhaps non-medically qualified, understand that it is their job to reduce stress, fear, and anxiety. It is not a question of rivalry, medical against non-medical, it is simply the question of the fact that each of us is trained for something different. Non-medical genetic counselling, of course, has to be backed up by skilled clinical and laboratory diagnosis, accurate genetic interpretations and precise risk estimation, but the latter must also be backed up by skilled communication and human understanding.

In conclusion, the opinions expressed by the workshop group 'Genetic counselling—its benefits' were very much in line with the findings of the above-mentioned international study on consumers' views carried out in Scotland and London, Ontario.

Finally, each of us is at some risk of carrying a genetic disorder. With the advances in biochemistry and technology it is likely that more

defective genes will be discovered, and thus prospective genetic counselling and screening to determine carrier status will become more common. A number of medical, ethical, social and psychological problems concerning genetic counselling remain unanswered, and it is time that medical and non-medical professionals attempted to solve them jointly.

Yours faithfully,

Ivana Markova
Professor of Psychology

REFERENCES

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Porter, I.H. (1977). 'Evolution of Genetic Counselling in America'. In H.A. Lubs and F. de la Cruz (eds), *Genetic Counselling*, New York: Raven Press.
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LITERATURE FROM STOCK

By Dr Peter Jones:-

Living With Haemophilia - 2nd Edition - Including p&p to Society members: £9.40 (Normally retails at £16)

Aids and the Blood - £1.50 plus 50p p&p.

Haemophilia Home Therapy - £8 per copy including p&p.

NOTE: The Series 'Introduction to Haemophilia', Notes for... has been replaced by a brand new 'Introduction to Haemophilia', although Notes for Parents remains in print. To obtain a copy of this new publication please send an A5 sae to 16 Trinity Street along with your request.

QUICK + QUICK + SLOW = £600

Dancers in the North West have raised over £600 this year. A Valentine dance raised £300 at Crewe, and in March a similar sum was contributed from the Manaco ballroom at Leigh.

DISCO OF APPRECIATION

To show their appreciation for all the support they received during the year Bristol and South West group will be holding a disco in November—for free!

'We like to show our appreciation to all the families and friends who give so generously, so we try to lay on a free function each year,' explains chairman Bill Payne.

'Our local Stapleton Community Centre are very supportive, and let us have their hall—and they donate prizes for our raffle.'

The group has held wine and cheese parties, cabarets, and even the national draw in previous years.

NEW GROUP IN HAMPSHIRE

Hampshire has a new Haemophilia group, following a well-attended meeting at Oak Park Community School, Havant on Tuesday evening May 7.

An original Solent group in Southampton had virtually faded from the scene a few years ago, but vigorous prompting by Jenny Berry resulted in a flurry of meetings in the Portsmouth area and a Society-supported decision to form a Hampshire group.

APRIL IS THE BEST TIME FOR JUMBLE

April is the best time of year for jumble sales. This is the advice of Norfolk and Norwich group chairman Michael Rainsford. 'It's the time of year when people are spring-cleaning and all sorts of odd items get turned out.

The spring-cleaning syndrome clearly proved correct for the group when they staged their annual Jumble Sale at North Walsham Church hall in April, and raised £115.

GOOD NEWS AND BAD NEWS

When Dr. Peter Jones, Director of the Newcastle Centre spoke to Northern group at the Royal Victoria Infirmary on May 7 he reviewed his recent trip to Atlanta.

Over 100 people were at the meeting, which, according to Northern group secretary Pauline Sanderson 'contained good news, and bad news, although Dr. Jones was relatively optimistic'.

DR. O'BRIEN IN PENRITH

'The Bleeding Disorders of the Royal Family' was the talk topic for Northern group's Penrith meeting in April.

Held at the Tourist Information Centre in Penrith, the talk, given by Dr. Hugh O'Brien Consultant Haematologist at the Cumberland Infirmary, Carlisle was well attended.

Society Co-ordinator David Watters opened the meeting and set the group in motion as they elected Roger Simmons as their chairman. He has been a member of the Society for about 25 years, through relative involvement, and his election as chairman marked the culmination of quite a day for his family, as they had started 'home treatment' for their six-year-old son that morning.

'The formation of a group like this is so important,' said Roger Simmons. 'It's like the Samaritans, it's so important to have somebody to talk to, especially if that person has had first hand experience of your problem.'

And this vital ingredient was emphatically underlined as a lively and interesting discussion ensued following the election of Val Collier as vice-chairman, Jack Forrest as treasurer and Nickey Redmond as secretary.

A further spur to discussion was the presence of Dr. Anthony Aronstam, director of the



Far right of this picture is Tony Aronstam, and on his right is the new group Chairman Roger Simmons, then comes treasurer Jack Forrest, secretary Nickey Redmond and Jenny Berry.

Lord Mayor Treloar Haemophilia Centre at Alton, who spoke about the responsibility of such groups to bring their experiences together and guide everybody to understand that they were not alone in the world with their problems.

He also declared the importance of establishing a good rapport with the local Centre (of which there are 4 in Hampshire). 'It is the quality of input you make which will govern the sort of service you get,' he said. 'If you go to a Centre with a chip on your shoulder, you'll upset people and that is not an ideal atmosphere to start with.'

RELATIONSHIPS

In the discussions which followed it became clear that the committee will have plenty to talk about at their meetings, embracing (a) relationships with Centre directors; (b) what does Hampshire want from its Centres (c) procedures for treatment (abolishing

unnecessary waiting time!); (d) learning all there is to know about the disorder; (e) access for patients to all relevant medical information.

'THINK HAMPSHIRE'

What also became clear to the new group, which included people present who had travelled a considerable distance from far-flung corners of the county, was that they must 'think Hampshire' and not just 'Portsmouth'.

It is hoped to organise general meetings at various locations around the county.

As the meeting drew to a close the thinking of those present was running along the lines that consideration will have to be given to forming sub-groups to concentrate on setting up excellent relationships with each Centre aimed at ensuring that haemophilia families receive the standard of treatment to match their expectations.

VALUABLE LESSON!

Part proceeds of a local amateur dramatic group's presentation of the hilarious comedy 'Educating Rita' contributed a welcome donation to the Haemophilia Society. Chairman of the Northern group Lorna Reynolds is closely connected with the drama group, hence their donation from a special performance at the Royalty Theatre, Sunderland in May.

MEETING IN PUB CHEERS

'Let's hold a meeting in a pub,' was the inspired suggestion from Sister Celia Shilling to the Norfolk and Norwich group.

And that's just what they did on Tuesday May 21 at The Arlington in Norwich.

'It was an excellent idea which we all went along with,' says group chairman Michael Rainsford. 'Haemophiliacs are inclined to be withdrawn, and so meeting in more convivial and informal surroundings seemed a good idea.'

And so it turned out to be as

over 20 people attended, including Dr. Leslie and his wife.

There is no truth in the rumour that the date and venue for the next 'pub' meeting has been delayed until heads are a little clearer!

Selling teddy-bears at the famous Thriplow Daffodil Weekend has proved an annual bonus for Cambridge who were there again this year flogging furry friends to all, comers on April 14.

HAEMOPHILIA— WHAT IS IT?

Haemophilia is a life long disorder in which a part of one of the proteins required to ensure the blood clots is inactive or missing. In haemophilia A, classical haemophilia, the missing protein is known as Factor VIII, and in Christmas Disease as Factor IX.

One in 10,000 males suffers from haemophilia A in this country and approximately 4,500 people from haemophilia A or a similar bleeding disorder.

Bleeding disorders affect mainly males but some, like von Willebrand's Disease, affect women also. Possibly you associate haemophilia with the Royal families of Europe. Queen Victoria was a carrier of haemophilia and Prince Alexis, the last male heir to the Russian throne, a sufferer.

Contrary to what you may think, our children with haemophilia bleed no faster than anyone else. In appearance, our boys are like their friends but when they do bleed the bleeding persists until treatment is given.

Small cuts and grazes are usually of no consequence and require only washing and the application of a plaster until healed.

ACTIVITY LEVEL

In the general population, the normal range of Factor VIII or Factor IX activity can be measured as between 50-200%. Mildly affected haemophiliacs have an activity level of between 6-50%.

They do not bleed spontaneously and usually do not require injections to replace some of the missing Factor, other than in the event of a major accident or with surgery.

Moderately affected haemophiliacs have an activity level between 1% and 6%. They can bleed spontaneously but usually receive treatment again in a similar way to mildly affected persons.

In severe haemophilia, there is a Factor VIII or IX activity level of under 1%. The bleeding is internal and usually into joints and muscles. The bleeding episodes can be spontaneous or occur as a consequence

of an accident. In the non-affected person, ruptures in a small vessel are repaired by the body's own clotting system.

In haemophilia, bleeding can persist and if left can cause swelling and sometimes a temporary loss of movement in a joint or muscle, which can be painful.

DAMAGE

If allowed to develop, these bleeds may damage permanently the joints or muscles. Joint bleeds can finally cause a form of arthritis, known as haemophilic arthropathy. Bleeding can be stopped by the giving of an injection into a vein. Spontaneous bleeds can develop regardless if the boys are active or resting. As parents, we see many occasions when our boys knock themselves and no bleeds develop.

At other times, bleeds develop for no apparent reason. With treatment, surgery also is feasible.

Toddlers unsteady on their feet are especially prone to head injuries. However, the life expectancy of haemophilic sufferers is about that of the general population, it is now very rare for someone to die from a haemophilic bleed.

BEFORE INJECTIONS

A considerable number of the older haemophiliacs have damaged joints as they grew up in the days before injections of Factor VIII or IX were available. The children with haemophilia growing up now are relatively free of joint damage, thanks to the recent medical advances.

In the past 20 years, we have progressed from using fresh



In this picture: At the back (left) Margaret Kelly and Jennifer Holmes. Seated is Ruth Gibson with Robert and Jean.

blood to frozen plasma. In the early 1960s Dr. Judith Pool and her colleagues in California discovered cryoprecipitate, available in the United Kingdom since 1966.

Now Factor VIII and IX are produced in highly concentrated forms. At present, much of the Factor VIII is imported from the United States. Some concentrated Factor VIII and IX is produced in this country at our Blood Product Laboratory at Elstree and it is hoped that we shall be self-sufficient in the coming years.

The concentrated preparation means that our sons' factor VIII or Factor IX activity levels can be raised to within normal to stop a bleed.

The blood products are made from human blood. As parents we look forward to a time when synthetically produced Factor VIII or Factor IX will be available. All blood products cannot be guaranteed free of the viruses associated with hepatitis and other disorders such as AIDS.

However, the minimal risks

associated with this treatment are in our opinion outweighed by the advantages of using these products which ensure our children do not grow up crippled.

The golden rule is early treatment, the sooner a bleed is treated, the sooner it stops. Our boys can tell us they are bleeding long before we can see a swollen joint. They can feel a sensation associated with bleeding. In babies and young children, the veins are small and can be difficult to find.

AT ANY TIME

The children are required to attend a Haemophilia Centre at a specific hospital. There are over 100 Haemophilia Centres in this country. Visits to the hospital can occur at anytime of the day or night.

It can be a great relief to be offered the facility of Home Therapy. We, as parents, are taught how to inject our children. This usually happens

WHAT IS HAEMOPHILIA?

once the boys are settled into school, but this varies from Centre to Centre. No more visits to a hospital on a cold wintery night when the roads are icy! The treatment is all ready in a cupboard.

From time to time, a Headmaster will ring and then it is off to school to give the treatment there. There is no escaping lessons. Many boys, by the time they are 12 years old, choose to inject themselves.

Once trained by the hospital how to give the injections, picnics can be planned with some security that they will take place. Bleeds often start at the most awkward times and places!

It can be quite devastating to discover one's child has haemophilia. In 70% of the children affected there is a known family history. In the remaining 30% the haemophilia has not been apparent.

In the latter case, the first signs of haemophilia are usually large bruises once the child becomes mobile. If the haemophilia is confirmed, there are feelings of panic, and 'why has this happened to us?'

We have all felt a sadness that the disorder has occurred and have had to gradually learn how to recognise bleeds and how to secure treatment.

We were told straightaway that our boys would be able to

do most of the things other boys do. It is very reassuring as a parent with an affected baby to meet a teenager with haemophilia who looks and talks just like any other teenager! We have learnt from other parents, our hospital Haemophilia Centre, the Haemophilia Society and from older haemophiliacs themselves.

Haemophilia is a family affair. Hospital visits can disrupt family life. We have to be careful to leave time for all our children. They all need some of our time and it is not an advantage to a haemophiliac child if he is constantly the centre of attraction.

UNTHINKING REMARKS

For us as parents, particularly hurtful are the unthinking remarks made by passers by when they see the bruises on our children's arms and legs. We have all been accused of child battering at some time.

We make haemophilia a family affair because the sisters of haemophiliacs may be carriers of the disorder. The sons of haemophiliacs are not affected by the disorder, but their daughters are obligatory carriers with a 50/50 chance of having affected children.

We encourage our daughters to learn about their brothers' treatment in case they should have haemophiliac children in the future. During pregnancy, the foetus can be tested and a termination contemplated if

severe haemophilia is confirmed.

We are hoping that the present advances in genetic engineering will make the eradication of haemophilia possible in the future. For the present, the choice whether to have affected children has been ours and ours alone. The hospital Haemophilia Centres are there to give the facts. The final choice is ours.

DISCOURAGED

You will probably be surprised by all our boys are encouraged to do. Body contact sports are discouraged, such as judo, karate, boxing and rugby. Many other sports, such as rowing, swimming, gymnastics and cycling help build up their muscles. Strong muscles help ward off bleeds.

We are frequently asked if we restrict their activities. It is easy to overprotect or over care. We have learnt that the boys will bleed whether their activities are restricted or not. They have to learn to live with their haemophilia.

We have gradually become more confident and able to permit our sons to attempt what other children do, except when recovering from a bleed. They seem to gradually learn what they can and cannot do. We concentrate less on what they cannot do but rather on what they *can* do the positives to build their confidence in

themselves. All parents do this for their children if they can.

Nearly all forms of employment are now open to those with haemophilia, with the exception of the Armed forces and police. Some older haemophiliacs with joint damage can find climbing, heavy lifting and walking distances a problem. It is a case of looking at each person and what he can do.

One of the hardest things for our sons at present is the general ignorance about their haemophilia. Many are keen to work, and are able to inject themselves in a lunch hour if a bleed occurs but employers are still wary of them and unwilling often to take time to find out what their condition entails.

One pleasant exception was one employer who said, 'If you are able to take responsibility for injecting yourself, you will do here'. Not all see it this way.

We hope that we have reassured you about haemophilia and that you will spread the word that haemophilia isn't now something to be afraid of. It isn't any more.

Written by:
Jennifer Holmes, Margaret Kelly, Ruth Gibson, Kathleen Newton, Pauline Sanderson (mothers of haemophiliac children) with Maureen Fearn, Clinical Nurse Specialist in Haematology and Haemophilia, and Jean Lovie, Social Worker, Newcastle Regional Haemophilia Centre.

AGM 'AIDS' LECTURERS

After the AGM Dr Charles Forbes, Director of Glasgow Haemophilia Centre, chairman-designate of the UK Haemophilia Centre Directors' Organisation and chairman of that body's AIDS Committee, and

Dr. Richard Tedder, senior lecturer and consultant virologist at the Middlesex Hospital, gave a talk on "Acquired Immunodeficiency Syndrome".

Questions and answers followed.



Dr. Charles Forbes



Dr. Richard Tedder

POPULAR TRIP TO THE VALLEY

Northern group anticipate their usual coach load of families for their July outing to Lightwater Valley, Ripon, a venue rapidly becoming the group's favourite.

'The Valley is a wonderful place to go,' says group secretary Pauline Sanderson. 'There are lots of animals and amusements for the children.' 'We can pick fruit and enjoy a quiet (!) picnic.'

It's good fun and very good value, and we try to go at least once a year.'

INCREASED ANNUAL SUBS

We are happy to note that more people than ever before have paid their subscription this year—even though it's now £5 rather than the old £1.

Even more people have made Covenant's with the Society and pay their subscription (plus a donation, usually) direct from their bank account to ours—thereby saving a great deal of their time—and ours—and enabling us to reclaim the tax from the Inland Revenue and add to our income.

WHERE EXCITEMENT IS THE NORMAL ROUTINE

There are a few places left for the brave and intrepid who would like an exciting adventure holiday in North Wales in August.

Carol Holliday has organised another great week at the old refurbished manor house on Anglesay from August 10-17.

'We want the children to feel as normal as anybody else, and from past experience they really have a wonderful time.'

'The holidays have been getting more and more popular in the three years we've been running them, and I think it is true to say that of those who have been that the more adventurous the sport the more fun they've had.'

There's canoeing, mountain climbing, sailing, pony trekking, archery and lots of other adventures to be had.

In 1981, the first year, 10 children joined the fun. The following year the number rose to 22, and in 1983 there were 37. This was just a little too big, so we kept it at 30 last year, because this number means we don't have to call in extra adult support,' explained Carol.

There is excellent nursing staff available. Local Bangor hospital sends a girl over and another comes up from St. Thomas' in London.

So get in touch with Carol at 54 Bastion Gardens, Prestatyn, Clwyd LL19 7LU (07456 7212). She'll tell you how much the week costs (and there is a subsidy).

FAMILY DISCO

Colchester group held a family disco at Leavenheath Village Hall in May. Catering was arranged by Clacton member Joan Bleeze, and over 90 people attended.

£2,000 CHEQUE



The Society recently received a generous £2,000 donation from Legal & General Group Ltd. In this picture, taken by Lewis Photos Ltd, John SKAE, general manager (Group Resources) of Legal & General is seen presenting the cheque to our Chairman, the Rev. Alan Tanner.

NO SUBSTITUTE FOR PERSONAL CONTACT — says North West's Chairman Norma Guy

'We believe that personal contact has no substitute in a regional group,' says North West chairman Norma Guy. 'A group will never be active just sitting in committee rooms.'

'You have to get out and meet and talk to members, and if you do, you will find more people becoming interested and active.'

North West's fund-raising turnover is on the £6,500 mark each year, and so much of these funds comes from outlying areas where members 'do their own thing' organising events and sending regular fat cheques as a direct result of their labours.

'But we don't go visiting members to raise funds,' explains Norma. 'It is a policy to try and visit some members each week.'

'I suppose it's a welfare service in a way, but our members realise we are not a committee of faceless people who sit drinking tea once a month in somebody's house.'

'Far from it. We meet to discuss business, real business, and thrash things out to their conclusion even if it means staying up until the early hours. We don't let things hang over meeting to meeting.'

The North West is a large territory, but distance is no object for the volunteers.

'It's very important that people are visited,' says Norma. 'It may sound a bit corny to say that we hold out a hand. But we do.'

People don't have to take it, but at least they know that somebody cares, that they talk of the same problems and they know where to turn in need.'

And proof of the validity of the North West Policy must surely lie in the volume of funds that come rolling in, cash that says the haemophilia population of the North West appreciates the active policy of its group.

£110 HIGH NOTES

A special evening of choir recital at St Johns, Higham, near Rochester, raised £110 for the East Kent group in May.

Mobility Allowance and Attendance Allowance

As has already been reported, we have assisted a large number of members to obtain mobility and attendance allowances. We urge more people to apply especially if:-

In the case of Mobility Allowance, there are a large number of bleeds into lower limb joints and resultant joint damage. However, even if joint damage has not yet occurred we would suggest that you apply since the relevant regulation speaks of the **likelihood** of such damage—and repeated bleeding episodes into, say ankles or knees, is a strong indicator of that likelihood being fulfilled.

In the case of Attendance Allowance, you have a child at a normal school and as a condition of that you have to be on call at all times during the day. Otherwise, your application is unlikely to succeed nowadays **unless** you require frequent attention in connection with bodily functions—and that means **precisely** what it says and **does not mean** 'occasional attention' or 'attention when there is a bleed'.

Have a word with the Co-ordinator if you want further advice or guidance.

VICTOR WILKINSON

It is with very great sadness that we have to report the death of Victor Wilkinson of the Norfolk and Norwich group. Mr Wilkinson was a former Chairman and latterly vice Chairman of the group but also well known and held in high regard by members of the Society throughout the country for the vital role he played in the Council of the Society and at annual general meetings.

The condolences of the Society have been expressed to his widow and representatives of the group attended his memorial service on behalf of the whole Society.

Contact your Local Group

Members may not be aware that there are local groups of the Society around the country. The names and addresses of the contact people are listed below and they will welcome any approach from you:

Marion Gregory
17 Hazelton Road
Marlbrook
Bromsgrove
Worc B61 0JG

Bill Payne
8 Reedline Close
Beech Hill
Stapleton
Bristol BS16 1UG

Christine Brooks
Old Close, Hockerill School
Dunmow Road
Bishops Stortford
Herts CM23 5HX

Douglas Steward
Willow House, Lower Street
Stratford St Mary
Colchester, Essex

Mary Clark
12 The Larches
Higham
Rochester
Kent ME3 7NQ

Jean Daghorn
10 Clos de Maitland
Rue de Presbytere
St Clement
Jersey

Ben Lewis
335 Butterwick Drive
Beaumont Leys
Leicester LE4 0UH

Alan Weir
147 Wellmeadow Road
Catford
London SE6 1HP

Sue Cook
Craypool Cottage
Craypool Lane
Scothern
Lincs LN2 2UU

Julian Lander
10 Gypsy Grove
Liverpool L18 3LH

Michael Rainsford
43 Cromer Road
North Walsham
Norfolk NR28 0HA

Martin Shaw
23 High Street
Great Houghton
Northampton
NN4 0AF

Irene Clinton
22 Rydal Avenue
Bradford
West Yorkshire BD9 4LS

Pauline Sanderson
5 Newstead Court
Glebe, Washington
Tyne & Wear NE38 7PE

Bill Johnstone
3 Pinehill Park
Bangor
Co. Down BT19 2SB

Carol Holliday
54 Bastion Gardens
Prestatyn
Clwyd LL19 7LU

Norma Guy
78 Park Road
Bolton
Lancs BL1 4RC

Barbara Weir
The Old Stables
Market Square
Lechlade
Glos

Andy Cowe
106 Houstoun Gardens
Millburn Park
Uphall
West Lothian EH52 5SH

Mrs L. Judge
52 Toll Bar Road
Sheffield S12 2QZ

Elizabeth Burrows
12 Tennyson Road
Wimbourne
Dorset BH21 1NT

Robin Baker
'Rekabs'
47 Seaforth Avenue
Southend on Sea
Essex SS2 4ER

Barclay Bissett
18 Whinfield Road
Montrose DD10 8SL

BUSMAN'S HOLIDAY



Over in the UK with the Queensland Parliamentary Delegation, Dr. Ian Wilkey of the Queensland State Health Department took a busman's holiday to attend the AIDS lecture given by Dr's Forbes and Tedder.

Dr. Wilkey was over in the UK as a technical adviser to the Australian delegation, and explained that he had heard that the lecture was being given: "so I took the opportunity to keep fully up-to-date on AIDS treatment developments and research".

LEWISHAM OFFICERS VOTED BACK

At their April AGM Lewisham group put all last year's officers firmly in their place—and elected them all again.

Chairman is Alan Weir, secretary Heather Hodgkinson and treasurer Ian Copping. The committee includes those three plus Jean Copping, Jean Weir, Barbara Robinson, Harry Minter, Fred Hetherington, John Grindley, Elizabeth Blackwell—and a new member Wendy Fulford, Fred Hetherington's daughter.

TRACKING FOR PROFIT

North West group supporters enjoyed a night at the races in June, by courtesy of The Griffin at Newton-le-Willows who staged a special video racing evening.

Race prizes were bottles of whisky, all donated, which made it a very profitable night for the group.

STALLING IN NORWICH

Every year Norfolk and Norwich group gets the chance to man a stall on Norwich market—thanks to Society member Adrian Campling who works for the City council.

The market organisers make the stall available to charities on various dates and the Norfolk group is looking forward to September when their next 'stall' is scheduled.

They managed to raise £200 at the last event which was well supported by well-wishers who supplied a lot of new and 'nearly-new' items for sale.

TAYSIDE 'STATUS QUO'

At Tayside's AGM in May, held at Carnoustie, all honorary officers, and the Committee were re-elected.

Chairman is Mary Edward, secretary Barclay Bissett (Jnr.) and treasurer David Edward. The committee comprises Ann Malloch, Dorothy Hynd, Barclay Bissett (snr.), John McAughy, Pat McAughy and Christine Macrae.

BIKERS BOOST FUNDS

Local radio amateurs willing to give up their time and put their equipment and vehicles at the disposal of North West group will make a special charity cycle race possible on September 15.

'Eighty to one hundred cyclists take part,' explains group chairman Norma Guy, 'it's a 25-mile race from Aspull around the Wigan area and the police let us run it because we can keep tight control by radio.'

They expect to raise £1000.

VISIT TO B.T.S.

A conducted tour of the blood transfusion service centre in Dundee is planned by the Tayside group for September.

ADOPTION AN ALTERNATIVE FOR HAEMOPHILIACS AND THEIR FAMILIES

After considering all the options available when planning to have a family, my wife and I decided to try and adopt a baby, fully realising that this might prove to be a long and difficult task.

That was back in June, 1977. We then made the necessary enquiries and shortly afterwards wrote a letter to a well known charitable society which also ran an adoption service.

In our letter, we enquired about the possibilities of adoption and received a standard reply stating that the society's adoption list was closed.

Despite this setback and with considerable encouragement from our Vicar, we persisted, and eventually the adoption society concerned decided to consider us as potential adoptive parents. They then went ahead with their vetting procedure.

This involved regular visits by social workers, during which time we maintained that, for us, adoption represented the most socially responsible way in which to have a family.

PESSIMISTIC VIEW

All went reasonably well and despite a frequently pessimistic view about the eventual outcome being expressed by a more senior social worker, our application was heard by a committee and, thankfully, approved. This meant that our names were then added to the adoption society's list of potential adoptive parents.

The procedure to this point had taken us about nine months.

We next had to wait until the adoption society could 'match' a suitable baby to our family, and so after about eight months we were delighted to have been presented with a baby boy.

Happy though we obviously were at the time, this was to herald the onset of a whole series of complications as the biological father of the baby decided to contest the adoption of his son.

From our own personal point of view, matters went increas-

ingly badly during 1979 until in November of that year, the case was taken to the High Court where it was heard over a period of some ten days. Fortunately, the adoption society agreed to pay all legal costs for us, as they were still legally responsible for the baby at that stage.

During the Court hearing, the question of haemophilia was raised by Counsel representing the biological father, and it was implied that haemophiliacs might not make satisfactory fathers because of the physical limitations brought about by their medical condition.

At this juncture, we were very kindly assisted by Dr. Barrie Murphy (my Consultant Haematologist) who gave evidence to the Court on our behalf.

A little later, my wife and I were called to do likewise. When the case ended, we were greatly relieved to find that our (by now) little toddler was to stay with us. We were then able to go ahead with the normal procedure of seeking an Adoption Order to verify this.

FURTHER PROBLEMS

All went well, yet despite our tremendous happiness at the time, further problems were developing for the future as doubts had been cast in the mind of our senior social worker—these resulting from what she had heard about haemophilia during the Court case.

Despite the problems involved with the adoption of our first baby, we next went ahead with plans to try and adopt a second one. We were told to wait until our little boy was eighteen months old (to

comply with an adoption ruling).

This meant waiting some four months at the end of which time we were then given clearance to go ahead with our second application. Disappointingly (and particularly in view of the way we had overcome the many difficulties arising out of our earlier experiences), the vetting procedure for our second child went badly. Moreover, when the application was formally heard in Committee, we were shattered to learn that it had been turned down. The senior social worker strongly advised us not to lodge any appeal and became aggressively personal when we questioned the outcome of the decision (at the same time indicating that she was quite definitely prejudiced about haemophilia and its consequences).

SHATTERING

Nonetheless, we did appeal.

At this time, our Centre Director, was absolutely marvellous in helping us recover from what was a shattering blow. He listened to our story with great concern, sympathy and interest and then advised us to contact the Reverend Alan Tanner, Chairman of The Haemophilia Society, who was also most supportive. Our Vicar also helped during this period.

Just what went on and what was said at this time we shall never know. All that we can say is that the appeal proved to be successful (the only time this had ever happened, we were later told). By now, it was the end of October, 1980, and we were back in business again.

All was going well though we did hear that the adoption society with whom we were linked was considering a termination of the adoption side of their work.

Consequently, we wrote to that society in January 1981 and received a high level assurance that a baby would be placed with us by June. Yet in March of that same year, we were to officially learn that the society was completely giving up adoption work. Again, this was a terrible blow but we persisted, and after making many representations, were placed on the list of another adoption society.

TURNING POINT

In retrospect, this proved to be a real turning point, and although we had to submit ourselves to a further six month period of vetting, there were to be no further problems. Hence, by May 1983 we were delighted to be presented with our second baby, a little girl.

For us, therefore, the procedures related to adoption presented many difficulties, but we never wavered in our determination to succeed. We were very fortunate in that we had many supportive friends and the best possible counsellor and adviser in Dr. Murphy, who was always so kind and sympathetic to us as individuals.

Perhaps more than anything our experience underlines the need for society as a whole to be made fully aware of what haemophilia involves today, as well as the fact that one should never give up despite what one might be told to the contrary.

N.B. The contributor of this article is a haemophiliac. Regrettably, for reasons of confidentiality arising out of the Court case described in the article, he is unable to give his name and address. However, both he and his wife are more than happy to help and advise any other families who may find themselves in a similar position. For those who may need advice with regard to these matters, contact can be obtained through David Watters, Co-ordinator, The Haemophilia Society.

HOW OTHERS OPERATE

Recently, Colchester group, through their former secretary Pat Bridges manned a stand at a special 'Charities Day' held at Sudbury Town Hall where the local council made facilities available so that charities could project themselves to the public.

'It was an excellent idea,' said Pat 'and I found it particularly interesting to talk to other

charities and compare notes on how we run our organisations.'

'I was also very interested in a local toy library run by mothers of handicapped children, from a council clinic.'

The Mayor of Sudbury visited the stand and Michael and Sue Amos-Blake called in to lend their support to the centre.

IS THIS FUN FAIR?

We don't know whether to recommend attendance at North West's annual Haemophilia weekend from August 23-25.

There are distinct possibilities that you might be hit amidsthips by custard pies or wet sponges, thrown into the stocks or dragged into the Wigan canal. This annual jamboree of jollification will be staged at the Griffin in Newton-le-Willows, with all proceeds going to AIDS research.

Just look at their programme: 48-hour disco; Pool Championship; card school; tug-o-war over the Wigan canal, organised by the professional Shamrock T-O-W team; a charity soccer match; pop-quiz; yard-of-ale drinking competition; a non-stop 'bring and buy' stall, and a Miss Wet T-shirt competition.

But that is not all

To raise money for haemophilia Gaz Augusta is going to have his head shaved, another man has offered his car to the 'breakers' (anybody paying 50p

can smash the car to smithereens).

Suitable miscreants (all paid up society members?) will be placed in the stocks and pelted with wet sponges, and a gentleman has volunteered to sit for 12 hours in a bath of custard (Sic!) where you can throw custard pies at him to your heart's content.

For the more sedate—there is a tombola!

Sponsorship has come from Finefare, Kerr's Minerals, Tetley, Arthur Rogers (accountants) and the St. Helen's Star,

CAMBRIDGE IN THE MARKET

Stalls at the local Cambridge market two or three times a year, with most of the 'goodies' given 'free' is one of Cambridge group's fund-raising exercises.

They also run a card stall on the second floor of Joshua Taylor's department store which is made available to charities each year for Christmas sales.

'We didn't do too well with the cards last autumn,' according to group secretary Christine Brooks, 'We're looking for a new supplier, because we found our cards were not so attractive or price competitive as other charities.' Any suggestions?

a local newspaper.

On Bank Holiday Monday 'August 26' Olive Derbyshire will be raising funds for the society with a morning 'Bring-and-Buy-Sale' to be held at her caravan at Crook-o-Lune, Lancaster.

KEN LEADBETTER ONE OF THOSE SPECIAL PEOPLE

We are very sad to have to report the death of Ken Leadbetter. Ken was one of those very special people who worked tirelessly raising funds for the Society, although there was no haemophilia in his own family.

He was an hotelier in Jersey "and was raising funds for haemophilia before our group was formed," says Beryl Picot, wife of the group chairman.

Ken and his wife Joan were long-time friends of the Picot's "and it was this friendship which prompted his wonderful efforts," explained Beryl.

"He was a tower of strength to us in Jersey, and worked non-stop on fund-raising for us. "We will miss him greatly," she added.

The Jersey group and the Society extend their deepest sympathy to Ken's, widow Joan and the Leadbetter family.

ORGAN PLAYED ITS PART ON MERSEYSIDE

A day of very poor weather didn't dampen the enthusiasm of Merseyside group when they were out on the streets for a flag day in March. There were around 50 people helping with boxes around the city, but takings were fractionally down on previous days.

'We grossed over £900, but expected to do £1,000,' said chairman and treasurer Julian Lander. 'But it poured like hell.'

But the group had one good thing going for them — a magnificent organ loaned to them by John Webster of Webster's Fine Furnishers. It was the centrepiece of the collection based on Clayton Square and attracted hundreds.

John Webster very kindly loaned the organ without charge, for which everybody

is extremely grateful. 'We've been trying to get a date for another display with the organ in the Merseyside Festival of Gardens during the season,' said Julian Lander 'and if all goes well we should be there on Sunday August 25 as part of the Merseyside Development Corporation Exhibition.'

ANTIQUE IDEA

South Wales group has come up with a fund-raiser that could be adopted around the country. They've jumped on the bandwagon of antiques fairs.

No they don't sell off their older Society members, just organise 'fairs' in local halls charging stall-holders a fee and pocketing the entrance fee from the public, and profit from refreshments.

'We hire the halls,' explains Diane Lewis one of the group's committee. 'We charge the stall holders £10 and take the money at the door.'

'It needs a few of us on duty on the day, but we net something between £150-£200 each time.'

They staged a fair in June, their third in as many years. It was held at a hall in St. Fagan's, —a picturesque village near Cardiff, and was apparently as successful for the dealers as it was for the group.

Highfields Centre, Cardiff, was the venue for South Wales group's dance and supper on June 1.

FRIDAY EVENING COLLECTIONS

Special collections staged in Marks & Spencer store doorways are a very important source of funds for the Southern group.

Marks & Spencer are so good to charities in this way, according to group secretary Liz Burrows.

'They let us collect through tins and boxes at two of their stores in Bournemouth and

Boscombe.'

'We don't have to get council permission because the collections are made on private premises.'

'And the only proviso that Marks make is that our collection days must not clash with any other charity's flag day.'

'So we hold our collections on Friday evenings, and very good they are too,' says Liz.

£450,000 FOR RESEARCH

Since the Society was formed in 1950 well over £450,000 has been collected by members and given to research.

ANNUAL SEMINAR



These pictures were taken at the Annual Seminar, held again at Heathlands Hotel, Bournemouth in March.

In the picture (smaller group) are left to right Olive Redding, Richard Haynes, Fran Foy, Molly Briggs and Pat McCaughey.

In the other picture, left to right: Michael Blake-Amos, George Kirman, Keith Colthorpe, Jenny Berry and Dr. Kuttner.

SCOTLAND'S D.I.Y. ESSENTIAL

Scotland presents tremendous difficulties for those trying to organise group meetings. 'We can only meet three times a year,' explains Sheila Cowe, the group's secretary. 'And vast distances involved don't help in organising fund-raising events so we tend 'to do our own thing' and individuals run events themselves.'

And very successful they've been at it in the past year. Kenneth and Brenda Holmes raised about £460 from a coffee-morning at their Edinburgh home. That must have been some coffee!

In Dumfriesshire a family ran a joint venture with spina-bifida and netted £600; while in Falkirk two young lads—Neil and Stuart Robertson—washed cars, ran errands and collected jumble on their way to raising £50.

'The Golden Wonder crisps appeal was good for us too,' says Sheila. 'We got £130 from Golden Wonder by collecting 13,000 empty crisp packets.'

The packets came from everywhere. Individuals, local schools, even hospitals sent in bundles of empty packets. It was a wonderful response.

'But after flattening, counting and bundling 13,000 packets—it'll be a long time before I eat crisps again!'

NATURE TRAIL

East Kent group went on a nature ramble in May on a Canterbury nature reserve where former Centre Director Prof. Ingram is a warden.

This is an annual outing which covers 'reasonable terrain' and walkers can view wild orchids in profusion.

CAMBRIDGE ON 'THE SPOT'

Cambridge group found themselves on the spot when they organised their annual fund-raising swim last year.

Two primary schools in their area undertake sponsored swims for the Society, but one of them was going through a bout of chicken-pox at the time for the swim.

So they held two swims.

The Cambridge group hires a school swimming pool and aided by pupils and teachers from Thriplow and Foxton primary schools, plus some members of the Society they manage to raise something like £300 each year.

Foxton school got the 'spots' last year, so two swims were staged because the children didn't want to miss out on 'doing their bit'.

This year's swim is in July.

'180'

A special knock-out darts competition raised over £200 for the Northampton & District group. They've been closely involved with the tournament for several years, and it's always proved a good money-maker.

CARNIVAL BENEFICIARIES

Northampton & District group anticipate a welcome addition to funds as the result of being nominated as the main beneficiary of a carnival in their area in September.

Hopefully an Anglia TV personality will open the event, and the group will have a stand at the Carnival headquarters.

SOCIETY REPRESENTATIVES

For some years now we have been concerned that a number of local groups have not been able to sustain the necessary interest to continue in existence. Equally, in some of the remoter, and even not so remote, parts of the country there are small pockets of enthusiastic Society members who have a lot to give but not enough manpower to become a formally constituted group.

Late in 1984 your Council agreed to a new structure whereby, subject to the satisfaction of the Executive Committee, individuals in local areas could be appointed as Society Representatives without all the detailed work involved in being a fully-fledged local group.

We have already appointed two Society Representatives: Wilfred Gough represents the Society in Cornwall and he can be contacted at: Bonython, Grampound, Truro, Cornwall.

Bob Martin, former chairman of the Sussex group—now disbanded—remains an active Society member by being our Representative in Sussex. He can be contacted at: Jamieson Farm Cottage, Albourne, Hassocks, Sussex.

Members who want to become more involved in either of those areas should contact their Society Representative.

DONATIONS FROM LOCAL GROUPS

Since January 1 1985, the following donations have been received from local groups of the Society:-

	£
CAMBRIDGE & DISTRICT	1,000
JERSEY	1,000
MERSEYSIDE & DISTRICT	886
NORTHERN BRANCH	2,000
NORTH EAST DISTRICT	1,000
NORTH WEST DISTRICT	1,000
NORTHAMPTON	1,000
OXFORD	600
OXFORD	500
SOUTH WALES	500
TAYSIDE	750