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.

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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 Labour 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 Watters '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.'

NOT RELEVANT

NOT RELEVANT

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.

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.

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.

NOT RELEVANT

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 photographs 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.

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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 GRO-D GRO-D resulted in a flurry of meetings in the Portsmouth area and a Society-supported decision to form a Hampshire group.

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Society Co-ordinator David Watters opened the meeting and set the group in motion as they elected GRO-D 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 GRO-D GRO-D '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 GRO-D as vice-chairman, GRO-D as treasurer and GRO-D as secretary.

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

NOT RELEVANT

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 50-150%. 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 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 haemophiliac 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 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

GRO-A

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 [illegible]mophilia. In 70% of the [illegible]ldren affected there is a k[illegible]n 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:

GRO-A

(mothers of haemophiliac children) with Maureen Fearns, Clinical Nurse Specialist in Haematology and Haemophilia, and Jean Lovie, Social Worker, Newcastle Regional Haemophilia Centre.

AGM 'AIDS' LECTURERS

Aft[illegible] the AGM Dr Charles For[illegible] 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

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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".

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VISIT TO B.T.S.

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

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