



NATIONAL HAEMOPHILIA

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INCORPORATED!

Happy New Year!

1987 is off to a good start for the HFA with the news that we are now an **incorporated** body. The name change to Haemophilia Foundation of Australia is now final too.

Compensation

The Working Party has completed its task, presenting its final recommendations to N.A.C.AIDS in December. It was pleasing to see that there was no discussion regarding whether a form of Compensation or Benefits would be recommended, just which option. N.A.C.AIDS finally recommended the "best" of these which allows for an income adjustment benefit, impairment benefit and death benefit. The final decision is now in the hands of the Government.

Educator

We are pleased to have Wendy Naylor join us for six months as our educator. Wendy is preparing four kits for the use of our members, their families and health carers. She introduces herself to you in this newsletter.

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NATIONAL HAEMOPHILIA is an official publication of the Haemophilia Foundation of Australia (formerly the Australian Federation of Haemophilia). It provides education and information for persons with haemophilia (and other related bleeding disorders), their families and health carers.

Haemophilia Foundation of Australia

Contents

This month we bring you some comments regarding the visits made to British Health Centres last year. Next month we will follow with further notes about the British Haemophilia Society.

The National A.I.D.S. Conference in Sydney October/November 1986 had a panel presentation on haemophilia. The members of the panel presenting material were Dr. K. McGrath, Dr. P. Gatenby, Alison Bellamy and myself. We bring you the presentations by Dr. K. McGrath and myself in this newsletter.

Space precludes us including the second talk from the Haemophilia Conference in May by Gerard Volk. It will be in the next issue!

Jenny Ross.

EDUCATOR



INTRODUCTION:

I'm Wendy Naylor, and I will be working with the H.F.A. for the next six months as Educator. My experience has been entirely in education: I have taught English and French to Australian and French students, and to migrants. My interest in writing has been long-term, and I value the opportunity to apply both writing and educative skills to such a worthwhile project.

In my first week at the H.F.A. I have benefited from the friendly and efficient working environment. The pace is lively to say the least!

During the week I have been doing a good deal of background and essential reading. I talked at length with Jenny about haemophilia, the H.F.A. and the implications of the A.I.D.S. virus. I also viewed videos on these topics. At the Alfred Hospital I visited the Haemophilia Treatment Centre and spoke with Alison Street and Natalie Clarkson. Other meetings have been arranged for next week.

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We have established an Advisory Committee which will meet on a monthly basis to assess the content and progress of the writing. The members: Jenny Ross, Terry Carbis (HFA), Ellen Prendergast (HFA), Tass Mousaferiadis (Health Promotions Unit, Health Department) and Judith Jones (Social Biology Resources Centre). The committee will be of great value as a forum for ideas and suggestions. Each month I will also write a report on my progress and activities.

I look forward to a rewarding, if hectic, six months and aim to produce material which will be interesting in content, exciting in presentation, but above all, useful.

A Special Request:

If the material I produce is to be useful, I need your help.

While I will be talking with many people who have expertise in health issues and haemophilia, the only people who can really advise me about specific needs and attitudes are those with haemophilia themselves.

I have prepared a questionnaire on the issues of general health, blood products and the effects of discovering seropositivity for HIV (this section of course for those to whom this applies). The opportunity to talk with some people in Victoria about these issues will be valuable, but a response from all States would give the material a more realistic focus.

To request a questionnaire, please call the HFA on (03) 819 1366, or write to:
Ms. W. Naylor,
H.F.A.,
76 Lynch Street,
HAWTHORN. 3122.

The questionnaire can be returned anonymously. Of course, the sooner it is returned the better. It will take only a short time to complete, but your responses will be much appreciated.

WENDY NAYLOR.

BRITISH VISIT

Visits to British Haemophilia Treatment Centres

Despite the saturation of information received from the Milan and Paris Conferences, the visits to centres in Britain were far more useful. This was not just because everything there was relevant to haemophilia and people, but also because it was a wonderful change to really share experiences and knowledge with people as committed to the haemophilia cause as ourselves.

Two overwhelming impressions especially remain. Firstly the intense involvement with the work or people by health professionals and Societies. An incredible warmth emanated from individuals and the centres. Work is not a job, but more of total dedication by most of the staff. Secondly there was a very strong bond between Treatment Centre and Haemophilia Society everywhere I went. On every occasion the centre spoke very highly of their Society members and the support given by them eg. sending flowers to staff on death of A.I.D.S. patients. The

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compliments were mutual with Society members speaking in glowing terms of their treatment centre and staff. There is a great deal of interaction between Society and Centre, with both working closely together in their "common cause".

It was not surprising that Society members were so proud of their Centres as two of those I visited are recognised as the two leading centres in Britain. So keeping things in perspective we must acknowledge that there is not the same high level of care everywhere in the country (even elsewhere in London).

Here is an outline of how the centres I visited function.

Haemophilia Centre. Royal Free Hospital, Hampstead, London

This centre is quite unique in that it has magnificent facilities in its own wing of the hospital. Dr. Katherine Dormandy started this centre, using a caravan parked in the grounds of the original hospital. During rebuilding the family of a haemophilia patient donated £100,000, enabling the centre to be incorporated in the new hospital in 1978. Approximately 700+ patients are attached to the unit which also acts as a reference centre for other treating hospitals in the area and other regions in London and East Anglia. Primarily a Haemophilia Centre, this unit also provides for other bleeding disorders and haematological services.

Dr. Peter Kernoff (Co-Director) invited me to attend their weekly staff meeting. Having counted sixteen people around the table I enquired if they all had a haemophilia role. Yes, all were either full or part time on staff, or in a handful of cases, working very closely with the team and patients. A quick appraisal of the staff included two consultants, haematology registrar, one part time doctor, two sisters, two staff nurses, two full time and one part time secretary, part time social worker (3 days), and physiotherapist shared with rheumatology. Close liaison with hospital school, occupational therapist, district co-ordinating sister (for haemophilia), orthopaedic surgeon and paediatrician.

Services include:

- 24 hour service with doctor on duty.
- Sister available to 9 p.m.
- Direct to centre no casualty. Walk in service during the day.
- Ring in for home care supplies.
- Regular reviews - Mild Haemophilia A & B - Annual.
 - Severe " " - six monthly.
 - A.R.C. " " - three monthly.

A six monthly review looks at all bleeding patterns (computerized) and joints at risk, during the thorough physical examination. The part time doctor works with the social worker in the counselling area and family interviews/therapy sessions are conducted annually. Special attention is paid to A.I.D.S. issues, safety re disposal, safe sex etc. "Negative" people are given the same messages as "positive" ones.

Records are all stored at the centre. HIV antibody test results are in a separate file.

The Haematology Unit is funded by the National Health Service, 80% of

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which is used to purchase the blood products for treatment. This cost must be born by all hospitals treating haemophilia in Britain.

The social worker is a key member of this team seeing her role as three pronged, working/liaison with staff, with families, and on behalf of the unit in relationship to the Haemophilia Society and the Region. She works with individuals and groups, but is particularly developing the family therapy programme.

Cardiff Haemophilia Centre. University of Wales Hospital

Visiting Cardiff on the invitation of Prof. Arthur Bloom and his wife Jane (with whom I've been in contact since meeting them at the last Haemophilia Conference in Melbourne) I had been given the impression by others that this was a great research centre, but not a "real treatment centre".

I disagree. Spending two and a half days with the Blooms, the hospital staff and the Society, I found a very warm, close knit group of people providing excellent care. Physically the staff were "operating" from a single room in very overcramped conditions, but the day I was there Arthur received news that new space had been granted - giving them four rooms.

There are 300 patients registered, 150 receiving regular care. All are reviewed six monthly.

Staff. Apart from Prof. Bloom there is a part time doctor, the registrar, one full and one part time sister and a part time social worker (who is trying to be upgraded to full time to cope with the workload). With boys using prophylaxis there is less call for orthopaedic work and no physiotherapist attached to the unit.

On A.I.D.S. issues. Patients are tested as they come in for treatment. The sister there said this is general throughout Great Britain. "People with haemophilia know all about themselves medically - this is just one more fact". They have had three deaths, 25% of those tested are antibody positive, with no illness among the children. There had been problems with almost all the "positive" children at school, necessitating doctor and nurse visiting each one.

Prof. Bloom also heads a large research team and my third evening in Cardiff saw Jane entertaining over fifty people for dinner. A delightful group of people - all obviously think as much of their director as he thinks of them.

Haemophilia Treatment Centre, Queen Victoria Infirmary, Newcastle-on-Tyne

You have probably all heard Sister Maureen Fearn and Dr. Peter Jones speak, read their written material, and possibly met them personally too. A very articulate, high profile pair with a great depth of experience in haemophilia care.

They certainly head up a professional team including two doctors, three sisters, social worker, physiotherapist and office staff. The comprehensive care outlined by Maureen in her talk in May is co-ordinated by her, and runs smoothly and efficiently. Consultation with each other is an important key.

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The team was particularly taken up with A.I.D.S. problems when I was there, being quite shattered by the deaths they had had, each patient being like a friend. They support each other and receive great support from the patients and society members.

As in Wales, patients are tested for HIV antibody as they come to treat - many mild/moderate people still untested.

Some of the difficulties revolved around children wanting their results/information regarding A.I.D.S. while their parents would not allow it. Another problem was seeing patients removed to another section of the hospital for nursing when ill with ARC or A.I.D.S.

Jean Lovie is the third strong member of this excellent team. Apart from her role as social worker for haemophilia problems, she is also involved in regular A.I.D.S. counselling, and she works very closely with the local Haemophilia Society Group. In fact she supports the local group to an extent that they are encouraged to support each other at times rather than using the Treatment Centre. This is necessary to help people dissipate the anger that is inevitably directed towards health carers and hospital in the A.I.D.S. situation.

While not members of the Society Group's committee the staff attend meetings when asked or as necessary. Staff and society worked together last year to restructure the committee and train them in telephone counselling resulting in a much stronger, closer knit committee. Newly diagnosed are always referred to the Society with the staff ready to "take them back" if the burden becomes too much. Interaction between Society and centre are very strong, and able to bear criticism at times from both directions.

Jean runs groups too, apart from individual counselling. A mother's group has been viable for 10 years and the latest group established for families who have lost members with A.I.D.S. is giving great support to the families involved and helps others with A.R.C. problems too.

Being able to spend time discussing problems and issues with Maureen and Jean was extremely beneficial. They too (like staff from the other centres) appeared interested in hearing about the Australian scene. They also appreciated an opportunity to "bend the ear" of someone who was not involved personally with their patients - but who understood their problems and feelings.

Jenny Ross

NATIONAL A.I.D.S. CONFERENCE

Dr. K. McGrath, who chaired the panel at the Haemophilia session of the 2nd National A.I.D.S. Conference presented an Australia-wide update of figures, and current problems. These were researched through personal contact with all states and consultation with the other panel members.

The following tables represent the most pertinent of Dr. McGrath's overheads on which her talk was based.

HIV INFECTION IN HAEMOPHILIA : AUSTRALIAN EXPERIENCES

ALL COAGULATION DISORDERS

STATE	NO TESTED	NO POSITIVE	%	PROP ⁿ TESTED
VIC ADULTS CHILDREN	126 93	45 42	36% 45%	all having blood product in last 5 years all severe & moderate
NSW ADULTS CHILDREN	170 30	78 8	46% 27%	virtually all
QLD ADULTS CHILDREN	53 35	17 9	32% 25%	not all
S.A./N.T.	69	6	8%	all severe & moderate disease
W.A.	201	11	7%	all
TAS	16*	7*	43%*	all severe
ACT	12*	6*	50%	not all
	805	229	28%	

* MAINLY SEVERELY AFFECTED PATIENTS TESTED

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MAJOR PROBLEMS CONFRONTING PATIENTS

1. Access to experienced and appropriately trained medical and paramedical staff, for haemophilia and A.I.D.S. care, removed from STD clinics.
2. Prospects for finding spouses and sexual partners.
3. Prospects for parenthood.
4. Impact of AIDS on marital relationships in long term.
5. Stress on other family members.
6. Financial security if AIDS prevents the earning of an adequate family income.
7. Punitive legislation.
8. Fear of discrimination.
9. Access to safe blood products.

MAJOR PROBLEMS FOR HEALTH CARE WORKERS

1. Centralised care facilities with appropriate support staff.
 - Comprehensive Care Centres.
2. Protection from infection.
 - Full information re patient HIV status.
3. Education and guidelines for medical and paramedical staff unaccustomed to haemophilia and A.I.D.S.
Guidelines for appropriate access to rehabilitation, physical therapy and other facilities.
4. Information concerning natural history and treatment of HIV infection in haemophilia. Does it differ to that of other risk groups?
 - Is the risk of A.I.D.S. the same?
 - Did clotting factor concentrates all contain live virus?

NEED FOR CO-ORDINATED CARE - URGENT

1. Statistics.
2. Experience in management.
3. Education of medical and paramedical staff.
4. Trials of new drugs.
5. Surveillance of blood products.
6. Surveillance of disease progress.
7. Surveillance of transmission.
8. Patient access to counselling and information.
9. Access to special equipment.
10. Treatment of A.I.D.S. in haemophilia in STD facilities is not acceptable to patients.

Dr. K. McGrath

N.A.C.AIDS CONFERENCE CONTINUED

Paper presented by J. Ross

Overview of Needs Within Haemophilia Community Throughout Australia

It would certainly be quite reprehensible for us to wish to have a larger group of people suffering from haemophilia in Australia!

However, greater numbers would certainly make it easier for support groups to be formed and to function effectively. One of the great difficulties in the haemophilia community has been finding enough people to maintain such a body (who are themselves not drained emotionally and physically from coping with haemophilia in their own family). Even in Victoria and New South Wales where State Societies have been functioning for over 30 years it is often extremely difficult to fill committee places.

The present situation in Australia sees Haemophilia Societies operating in Victoria, N.S.W., S.A., Qld., and a fledgling group in W.A. Small local groups also operate in the A.C.T. and Newcastle. The Australian Federation of Haemophilia (presently undergoing a name change to the Haemophilia Foundation of Australia) was established in 1979. It consists of a council made up of delegates representing member State Societies. In general the Australian Federation of Haemophilia takes direction from the States in its management of Federal matters. Now however the Federal body also offers its assistance and support to the Societies too, especially the newer, smaller groups.

The descent of A.I.D.S. on our small community really was a disaster! However it has resulted in a rapid development of the Federal body in order to cope with the desperate needs of the haemophilia group.

Initially there was no one available to manage the now well known counselling issues of families struggling to cope with eg. the sexual area, family planning, concerns about blood products, nervousness about affectionate contacts with family, and the fear of discrimination in schools and workplace, the media having made us a highly identifiable group with everyone feeling extremely vulnerable. Alison Bellamy will develop some of these issues, particularly the special plight of our teenage group and young couples wishing to have a family.

When A.I.D.S. descended in 1984 Alison was the only haemophilia social worker in Australia available to assist. Many people were forced to turn to an individual they knew such as myself for help and support, but many more had (and some still have) no one and nowhere to go. We are extremely grateful for the intervention of the

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Federal Government into this desperate situation. Our needs were expressed in four easily identified areas.

- 1) Setting up proper comprehensive care for people with haemophilia in every state. It is extraordinarily difficult to provide care regarding A.I.D.S. problems where the actual treatment leaves much to be desired!
- 2) Accurate information/ education for members on A.I.D.S. issues specifically.
- 3) Counselling assistance in every State.
- 4) The need to guarantee financial security for families at risk.

With Government assistance the Australian Federation of Haemophilia has already made progress in these four areas. I'd like to touch briefly on what has been done in each before expanding on our plans and needs for the future.

1) Education/Information

We have informed and educated members through a regular newsletter and mailings of N.A.C.AIDS productions. This has enabled people to sift the fact from the fiction - made so complicated by the media.

We have established personal contact with the majority of doctors treating haemophilia in Australia, and have kept them, together with our own Medical Advisory Panel, supplied with the latest A.I.D.S. information from the Task Force and overseas.

2) Counselling

The Federation, assisting the State bodies in their lobbying, has assisted in establishing the start of a counselling network throughout Australia for haemophilia families. Much time has been spent trying to convince treating doctors in some cases, and state Health Departments in others, of the desperate need for a full or part-time social worker.

In this support area the Australia Federation of Haemophilia has also assisted Western Australia set up its own Haemophilia Society where some families had never met another person with haemophilia! The initial meeting was quite overwhelming.

3) Comprehensive Care

The higher profile given to the Australian Federation of Haemophilia through A.I.D.S. has assisted us in our work towards improving comprehensive care throughout the country. A new Haemophilia Treatment Centre in Melbourne has been established, and another is presently being set up in Brisbane.

4) Financial Security

The need to provide financial security for families at risk through some form of compensation or benefits scheme has been before N.A.C.AIDS for some time. Progress has been made in this area by the N.A.C.AIDS Compensation Working Party.

Now Let Us Look To The Future

Education/Information

Three important projects are planned.

We are changing the emphasis of our A.I.D.S. News Bulletin to a newsletter with information on both haemophilia and A.I.D.S. - "National Haemophilia". For us information about haemophilia includes information about A.I.D.S. The two are intertwined.

While members were desperate for accurate details initially we feel that a continual bombardment of undiluted A.I.D.S. information becomes depressing, and some members have expressed tiredness with it. In order to stop this A.I.D.S. education becoming counter-productive it makes sense to present it more naturally in its proper context. We are pleased to find the Federal Department of Health through the A.I.D.S. Liaison Unit imaginative enough to see the need for this change of emphasis, having agreed to continue funding our newsletter in this form.

A major Federation production "Haemophilia and A.I.D.S. in Australia" is now being printed and is about to be mailed to members. This book that covers all aspects of A.I.D.S. and how it relates to haemophilia is in loose leaf form so it can be readily updated.

We are looking towards the appointment of a part time educator through the National Education Programme. This educator will further improve the A.I.D.S. education message in the newsletter, and develop kits to be used by state groups and Health Carers on Safe Sex, Use of Blood Products, Positive Steps to Good Health in regard to Haemophilia and a Haemophilia Schools Kit.

Counselling

November 7th sees an exciting event for us when Alison Bellamy leads a workshop in Melbourne for the social workers now working in haemophilia in Australia.

However not everyone in this country has access to counselling yet. Tasmanian families, while few in number, have special needs, and more effort is needed to set up a structure of support for them and provide proper counselling services there. In fact it is most disheartening to face the Tasmanian Health Department's unrelenting attitude towards the minute amount of funding it would take to cost share (together with the Federal Department of Health) a Social Worker for only 2-3 days per week for our group. This person would not only be available for family counselling and help, but could act as a co-ordinator or pivot for liaison between the patients, their hospitals, the Haemophilia Society of Victoria, and Australian Federation of Haemophilia, answering many of the needs of this small, scattered group.

Negotiations in Western Australia for a Social Worker resulted in the Society there being advised and encouraged to apply for funding on this year's budget. However we are

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still anxiously waiting on the result of this, as the latest rumour (of this week) is that the Society's budget has been cut so dramatically that there will not be funding for this social worker.

State Societies Support Groups

The Haemophilia Society of Western Australia will continue to need direct support from the Federation in order to become firmly established.

Tasmania does not have enough families to sustain their own group, but links between the families there with the Haemophilia Society of Victoria and the Australian Federation of Haemophilia must be strengthened.

In general all groups must support each other. At the present time eg. the N.S.W. Haemophilia Society is having problems filling its committee as the members there are staying away. They appear to have gone underground from fear as a direct result of the N.S.W. A.I.D.S. legislation.

Comprehensive Care

At the present time there are only two real Haemophilia Treatment Centres in Australia, one in Sydney and the other in Melbourne.

The Federal Body, working with the State Societies must work harder towards establishing true comprehensive care in all states. Again there are particular problems in Tasmania. Isolated, part-time care of haemophilia makes coping with A.I.D.S. an impossible task!

Financial Security

The Compensation Working Party will place its recommendations before N.A.C.AIDS at its December meeting regarding a proposed Compensation or Benefits Scheme for families of those who acquire A.I.D.S. medically. This includes the Haemophilia Group. We look to an equitable solution to this matter.

In summing up - the strengthening of the Haemophilia support networks through the advent of A.I.D.S. has brought us a long way, and assisted our members and health carers greatly. However there is still much to be done in the areas outlined, and that must be done by very few.

Jenny Ross
Nov. 1986

P.S. Since this paper was presented we are pleased that:

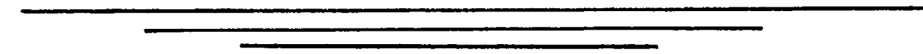
- 1) The A.I.D.S. and Haemophilia material has been mailed.
- 2) Our part time Educator has been appointed.
- 3) The Social Worker's workshop was held on 7/11/86.
- 4) Recommendations for Compensation/Benefit Scheme for families of those who acquired A.I.D.S. medically has been placed before N.A.C.AIDS.

N.A.C.AIDS Conference (Cont.)

Session Summary

MAJOR REQUIREMENTS FOR HAEMOPHILIA GROUP

1. COMPREHENSIVE MEDICAL CARE
 1 or 2 coordinating centres per State currently available in Victoria and for adults in N.S.W.
2. NATIONAL ACCURATE STATISTICS
 Haemophilia
 HIV Infection
 Clinical HIV Disease
3. PREPACKAGED EDUCATIONAL PROGRAMS AVAILABLE FOR INDIVIDUAL AND GROUP USE
 Audiovisual or printed
 Targetted to specific problem areas for different age groups including patients, spouses, parents, family members, school and work colleagues.
4. COUNSELLING FACILITIES IN TASMANIA & WESTERN AUSTRALIA
5. EDUCATIONAL PROGRAMS FOR MEDICAL STAFF WITH ONLY OCCASIONAL EXPOSURE HIV POSITIVE PATIENTS
6. PROVISION FOR FINANCIAL SECURITY
7. STUDY OF VIRUS TRANSMISSION BY SEMEN:
 Sperm VS Seminal Fluid
8. LEGISLATION TO ENSURE IMMEDIATE CARE GIVERS HAVE ACCESS TO PATIENT ANTIBODY RESULTS



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GRO-C

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