

Irish Haemophilia Society

Annual Report 2007



**“A Landmark Day for the
Irish Haemophilia Society”**

Irish Haemophilia Society

Cumann Haemifile na hEireann

We represent People and Families with
Haemophilia,
von Willebrands Disease,
Rare Bleeding Disorders

Programmes

Education
Publications
Counselling
Family Support
Advocacy
Conferences

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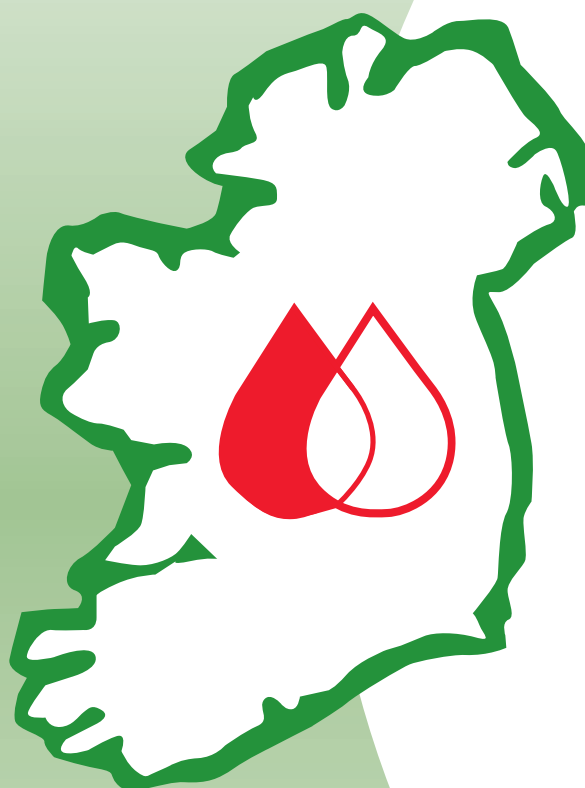
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A Message from the Chairman.....



Michael Davenport, Chairman

2007 was a very busy but terrific year for our Society. The highlights of the year for me were: the AGM in Killarney, the Official Opening of our Headquarters by President McAleese and the Members Conference in Mullingar. Although various staff and committee were involved with many issues throughout the year, these events stand out because they gathered so many of us together as a group of people with mutual problems that are being addressed in a positive way.

The Annual General Meeting was a tremendous success with a record attendance and great participation in the parallel programmes for adults, teenagers and children. The Spring-Summer 2007 newsletter carried a full report with lots of photos of smiling faces. We were all pleased as punch to have President McAleese arrive at our new Headquarters in June to officially open the new offices. We managed to squeeze in as many members and former committee members as we could, as the occasion was so unique. Margaret and the team had everything gleaming, food and beverages laid on and activity timed to the last second. President McAleese generously took time to meet as many people as possible before and after her address. The President included in her remarks the following words which I believe sum up our mission in having our own premises:-

"There is a plan to have here a memorial to the ninety-one people who have already passed away and it is right to remember them in such a way but today we honour them with another kind of memorial in these headquarters, for it is in and through the work carried out here that a much better future will be crafted for our citizens with haemophilia and related bleeding disorders"

[Extract from President McAleese's speech at Official Opening of our new H.Q.]



President Mary McAleese during her speech at the official opening of our new H.Q.



Nathan & Jamie O'Hagan Doyle



Fun & Games at our Members Weekend - October 2007

Our second Members Conference in Mullingar was again a great success. This was fully attended with participation by all.

As well as interesting speakers on haemophilia issues we had a very good debate between a young person with haemophilia and an older person with haemophilia on whether haemophilia is a disability or not?

We also had an outdoor sports day for the first time that I can remember. It was great to see young and not so young having a ball in the various races but disappointing to hear that a prominent member was caught cheating in the egg and spoon race.

Our representation on external bodies is vital to ensuring the continuation and improvement of

treatments and services for people with Haemophilia and Von Willebrands Disease. These bodies are; The National Haemophilia Council (NHC), The Haemophilia Product Selection Monitoring and Advisory Board (HPSMAB), The Consultative Council on Hepatitis C, and The European Haemophilia Consortium (EHC). I would like to acknowledge the commitment and co-operation of all the board members who work with us on these bodies.

The NHC focussed on a number of issues during 2007. Among these was the proposal for a Patient Involvement Programme to be piloted in the National Centre and later rolled out to other treatment centres. It's objective is to ensure that services provided are relevant and timely. It will focus on patients experiences and expectations at various points of contact with the services such as inpatient service, outpatient service, out of hours, home treatment etc. A panel of patients will be formed and periodically reviewed with criteria such as convenience, accessibility, the provision of information etc., and how they relate to the aforementioned services. Watch out for further information as you may have the opportunity to become involved in a very useful project.

National Treatment Guidelines are being prepared for publication and distribution to all hospitals to ensure that should anyone with haemophilia, who finds themselves in a hospital that is not a designated centre, will receive appropriate treatment. The Guidelines will be in ring binder form so that treatment updates can be added without reprinting the whole document.



Our excellent debaters Daryl Butler & Gerard O'Reilly



Kidlink Group with their certificates for the Haemophilia Quiz



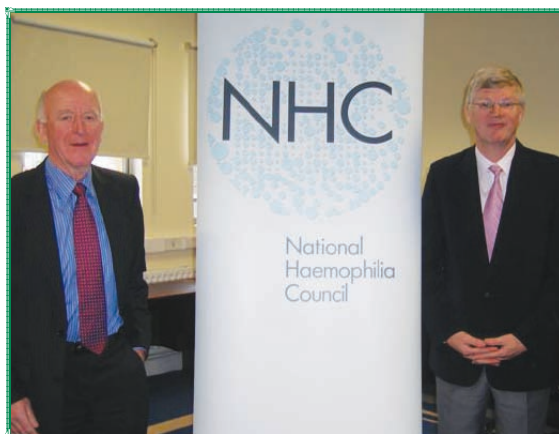
Sports Day - Father's Race

The NHC is continually working on developing services in Cork University Hospital and in Our Lady's Hospital in Crumlin. Audits have identified deficiencies in both centres with Cork University Hospital being particularly in need of development for many years now.

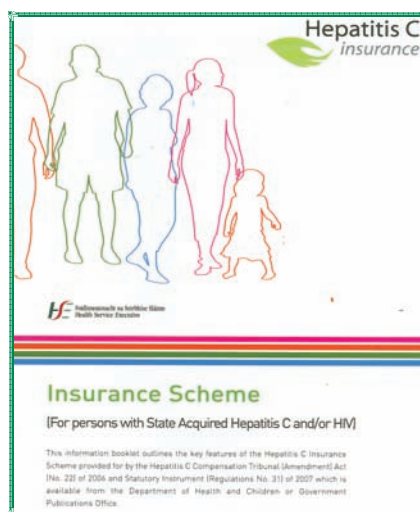
However, efforts are currently being made to address these deficiencies by H.S.E. members of the NHC. Both Cork and Crumlin require a Consultant led service and hopefully this will occur in the near future. An Information Day organised by Administrator of the NHC, Gareth Presch was held in Dr. Steeven's Hospital in October. It had a very interesting programme of speakers but attendance could have been better.

Although the Statutory Instrument establishing the Haemophilia Product Selection Monitoring Advisory Board (HPSMAB) has yet to be signed since the group commenced operating in 2001, it continues to operate very effectively in tendering for and monitoring factor concentrates. The new Benefix pack was rolled out in 2007 and was well received at presentations around the country. In conjunction with the NCHCD it was ensured that everyone who uses FIX was informed and instructed in advance of receiving it.

The HPSMAB also keeps an eye on international developments with attendance and reports from conferences such as the ISTH Conference in Geneva which Brian O'Mahony attended. The group also monitors reports and developments in areas such as vCJD.



Professor John Bonnar, Chairperson NHC with Dr. Nick Goddard from the U.K.



Insurance Scheme Booklet

The European Haemophilia Consortium is proactive in areas such as EU legislation which may have an effect on the supply of treatment products. It also runs member organisation training programmes in which we have taken part. As you may already be aware, we are hosting the EHC's Annual International Conference in September in Dublin Castle. Speakers, sponsorship, trade stands etc. have already been organised and the event is advertised on our and the EHC's websites. Over 250 delegates are expected from all parts of Europe and we hope it will be a very successful event. Sadly the EHC's chairman for the past three years, Dr. Hubert Hartl recently passed away at a very young age. Our sympathies go to his wife and children.

Margaret Dunne continues to be our representative on the Consultative Council for Hepatitis C chaired by Dr. Elizabeth Kenny of Cork University Hospital Hepatology Department. As Margaret reported in our Winter Magazine the Council oversaw a report, launched by the Minister for Health and Children, Mary Harney, called 'The National Hepatitis C Database'.

It was produced by the Health Protection Surveillance Centre and will help the medical profession track the progression of Hepatitis C and help Health Care providers plan future services. The Consultative Council also held a very successful Information Day in Dublin Castle last March.



Michael Walsh (left) Fundraiser of the Year 2007



Michael Davenport making a presentation to Pat Devlin

After many frustrating years, countless meetings between affected groups, negotiations with Department of Health Officials, rows in the Dail and Information Meetings for our members, the Insurance Scheme for those state infected with Hepatitis C and/or HIV was finally launched in September. This finally gives us an opportunity to have life assurance, in particular, and to provide for our families should the worst occur. Many of our members have put by compensation awards in lieu of insurance but this need no longer be the case. Unfortunately there have been unforeseen difficulties in the operation of the Scheme and efforts are being made to resolve these but if you have not yet considered life assurance, do so shortly as certain benefits are lost after the first year of the Scheme.

The office can supply you with any details you need to join the Scheme.

Once again this year, our fundraisers did not let us down. The Flora Ladies (and Gents?) Mini Marathon is now Ireland's largest single day charity event. The marathon winner's name, coincidentally, was Marie Davenport. The only relationship we have is that she completed the course in 33 minutes, which is the same time it takes me to put on my shoes! There were four other Davenports in the race also but we took a little longer to go around.

Michael Walsh organised a fun run in Waterford and raised €1,700. Well done and thanks Michael!

Throughout the year we also received individual donations and a number of people continue to support the Planned Giving Scheme, which helps to anticipate income for the Society.

Once again I must thank the Committee for their outstanding commitment to the running of the Society. Traci Dowling, Ger O'Reilly and Pat Downey joined us this year and have hit the ground running. After many years of loyal service to the Society, in which he has seen many changes and developments, Pat Devlin is retiring from the Committee and on behalf of all the members I would like to say a big 'THANK YOU' to Pat and wish him and Tess all the best for the future.

This is Brian O'Mahony's second year as CEO and it has to be said, he has us all exhausted! He has too much energy but fortunately he has channelled most of it into very worthwhile development programmes for the Society. The Strategic Plan is on track, staff education is continuing apace and a number of policies have been put in place for the future. I would like to sincerely thank Brian for his commitment to the position of CEO.

Margaret Dunne, Nina Storey, Debbie Greene, Anne Duffy and Patricia O'Connor have excelled themselves again this year. I would like to thank them for their assistance to me and their commitment to the Society throughout the year.

Michael Davenport
Chairman

Honorary Secretary's Report.....



Kevin Birkett, Secretary

At the 18th Annual General Meeting of the Irish Haemophilia Society, which was held in the Gleneagle Hotel, Killarney on Saturday 3rd March, 2007 the Incoming Governing Body of the Society were elected as follows;

Kevin Birkett

Michael Butler

Michael Davenport

Pat Devlin

Traci Dowling

Declan Noone

Ger O'Reilly

In the period since the last AGM, eleven full executive meetings were held. At the first executive meeting following the AGM the following officers were elected:

Chairman: Michael Davenport

Vice-Chairman: Traci Dowling

Hon. Secretary: Kevin Birkett

Hon. Treasurer: Ger O'Reilly

Also at the first executive meeting it was decided to co-opt two new members on to the executive. Subsequently Pat Downey and Barbara Guilfoyle joined the executive.

In June the executive and staff held a day-long review of our strategic plan to monitor progress and ensure that its objectives remain relevant.

Meetings organised by the Society

As usual the Society organised a number of meetings throughout the year.

Our biggest meeting of the year was the 18th Annual General Meeting and Conference of the Irish Haemophilia Society, which took place over the weekend of the 2nd-4th March in the Gleneagle Hotel, Killarney. It was a fantastic success attracting 99 adult delegates, 37 children and young adults for the kidlink programme, and 20 younger children and babies for the crèche. The programme for the weekend was packed with informative debates and lectures but as usual the kids had all the fun.

Another hugely important event was our second 'Members Weekend', which was held on the weekend of the 19th-21st October in the Bloomfield House Hotel, Mullingar. The weekend was a great success with 121 members of all ages taking the opportunity to get to know each other better.

Unlike the AGM weekend the 'Members Weekend' is much less formal with the emphasis on fun. This year's highlights included fun physiotherapy workshops, our very own Olympics and a never to be forgotten quiz night.

The Society would like to extend its thanks to all those who helped organise these events particularly Alison Daly and her team for all the work they do for our young adults and older children; and also the girls in the crèche, Carmel, Claire, and Deirdre for providing a stimulating programme for our younger members.

Perhaps the most significant event organised by the Society this year was the official opening of our new headquarters by our Patron, President Mary McAleese in June. As the President remarked it was a 'landmark day for members and supporters of the Irish Haemophilia Society.'



Children's Samba Performance at AGM Gala Dinner 2007

The new office not only provides the Society with a modern state-of-the-art facility from which to organise its day to day activities it also provides a venue to hold education sessions for different groups of members on a regular basis.

The first meeting to be held in the office was an Information and Education day for Carriers and Women with Bleeding Disorders. Held on the 23rd June the event covered a number of areas of concern to this group and finished with a 'Make-Up Demonstration & Pampering' session. A similar day was held in September at the Heritage Hotel, Portlaoise.

The office was also used in October for a meeting updating members on current HIV/Hepatitis C treatments.

A number of other meetings arranged by the Society took place during the year. In November a weekend was arranged for those who have been through the legal process while a number of information meetings were arranged in Dublin, Cork and Limerick for those contemplating availing of the

Insurance Scheme. Individual appointments were also arranged for members to meet with experts.

This year Wyeth secured the marketing and distribution rights to Benefix. In conjunction with Wyeth the Society arranged three meetings in Mullingar, Cork and Sligo to help members familiarise themselves with the new kits and also to answer any concerns they may have regarding the change over.

Regional visits are an important part of the Society's work, this year Michael Davenport, Brian O'Mahony, Anne Duffy, Margaret Dunne and Gareth Presch - Administrator NHC - undertook a series of regional visits in the second half of January and the first half of February.

Visits to Cork, Limerick, Galway, Waterford, Monaghan and Letterkenny allowed them to meet and discuss issues with our members throughout the country.

These visits also allowed them to meet with clinical teams at treatment centres.

Conferences and other events

During the course of the year board and staff members of the I.H.S. represented the Society at a number of conferences and other events.

The Annual Hepatitis C Information Day organised by the Consultative Council on Hepatitis C was held in Dublin Castle on March 31st. The event was a great success with some 350 people in attendance many of whom were members of the Society. Among the topics discussed were the National Hepatitis C Database, the Insurance Scheme, Liver Transplantation and Current Hepatitis C Treatment.

In May, Brian, Margaret, Debbie and I travelled to Parma, Italy to attend the European Haemophilia Consortium (EHC) conference and pre-conference workshops. This was an opportunity to keep in touch with developments with the European Union and beyond. The Society was also able to promote EHC Conference 2008 which will be held in Dublin Castle on the 12th-14th September. Finally Brian was elected to the steering committee of the Consortium.

In November the National Haemophilia Council held an open-day which was attended by a number of members and staff from the I.H.S.

The open-day gave members of the Society the opportunity to question Professor Bonnar, Chairman of the Council, and others about the future of haemophilia care in this country, especially services outside of Dublin, and paediatric services.



President Mary McAleese greeting some of our members



Ajdin Hacimic, President of H.S.B.H. being presented with a commemorative plaque from our Chairman, Michael Davenport

Twinning

The highly successful twinning programme between the I.H.S. and the Haemophilia Society of Bosnia-Herzegovina has now ended. To mark this and to acknowledge the bonds of friendship that have grown between our two societies a Twinning Reception was held during the first evening of this year's 'Members Weekend.' During the course of the reception Ajdin Hacimic, President of the H.S.B.H., gave a presentation recalling some of the twinning activities that have taken place during the programme while Brian O'Mahony spoke about the growth of the H.S.B.H. and outlined some of the programme's achievements.

During the course of the year I went to Sarajevo to attend a Physiotherapy Workshop organised by the Bosnian Society and co-funded by the I.H.S. and the World Federation of Haemophilia. The event was attended by medical professionals and patients from Bosnia, Croatia, Macedonia and Serbia. During the course of the weekend Kevin and Ajdin Hacimic, President of the H.S.B.H. were presented with the 'Twin of the Year'

Award by Catherine Hudon from the W.F.H. The official presentation will take place later this year during the W.F.H. Congress in Istanbul. Ajdin attended our members weekend.

While the official twinning programme has ended the Society continues to support the work of the H.S.B.H.

Web-site / Publications

You can keep up with all the latest news by logging on to our website.

The new web address of the Society is www.haemophilia.ie, which is the same name as our revamped newsletter.

In the summer of 2007 Debbie Greene undertook the task of renaming and revamping the Society's newsletter. The result was the much more colourful haemophilia.ie which was launched in December last. The Society would like to thank all those concerned with the revamp especially Debbie for hours of work on the magazine and John O'Mahony for his professional advice.

The Society also launched its first DVD this year Entitled 'Haemophilia through the Generations' it tells the story of forty years of treatment in Ireland through the eyes of five people. The premier of the DVD was during the official opening of the office and it is now available to all our members through the office. The Society would like to thank Shay Farrelly, Margaret Dunne and Brian O'Mahony for all their work during the production of the DVD and a very special thank you for all those who allowed their stories to be told.

2006 ORGANIZATION TWIN AWARD

HAEMOPHILIA SOCIETY OF BOSNIA & HERZEGOVINA
IRISH HAEMOPHILIA SOCIETY



With the ongoing support of their Irish twin, Bosnia and Herzegovina made significant headway in 2006 through their diversified fundraising initiatives, improved volunteer recruitment, and diligent lobbying of the Ministry of Health for an increased supply of factor, and for the official recognition of their national Hemophilia Treatment Centre. They also organized their first hemophilia symposium, which drew over 100 participants from 5 countries and major media coverage, sent delegates to the Irish Conference on Hepatitis C, and established preliminary contacts with the Bosnian Serbian Republic.





THE WFH TWINNING PROGRAM:

Twinning links hemophilia organizations and treatment centres in developing and developed countries.

The WFH helps twins arrange trainings, exchanges, workshops, patient education and other activities to improve hemophilia treatment and care.



**WORLD FEDERATION OF
HEMOPHILIA**
FEDERATION MONDIALE DE HEMOPHILIE
FEDERAZIONE MONDIALE DI EMOFILIA
Treatment for All

WFH 2006 Organisation Twin Award - Ireland & Bosnia Herzegovina

The current Society Staff are:



Brian O'Mahony,
Chief Executive Officer



Margaret Dunne,
Administrator



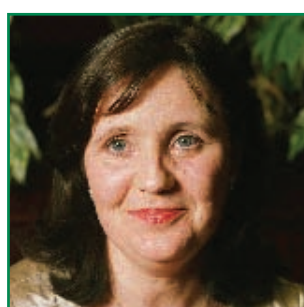
Anne Duffy,
Counsellor/Family Support



Nina Storey,
Administrative Assistant



Debbie Greene,
Administrative Assistant



Patricia O'Connor,
Administrative Assistant



Alison Daly,
Youth Group/Kidlink Co-ordinator

Society Representation

The Society is represented on a number of external committees as follows:

National Haemophilia Council & Haemophilia Product Selection Monitory & Advisory Board:	Michael Davenport Brian O'Mahony
Haemophilia HIV Trust:	Margaret Dunne Brian O'Mahony
Disability Federation of Ireland:	Margaret Dunne
World Federation of Haemophilia:	Brian O'Mahony
European Haemophilia Consortium:	Brian O'Mahony
Inherited Diseases Organisation:	Pat Devlin
Hepatitis C Consultative Council:	Margaret Dunne

**Kevin Birkett
Honorary Secretary**



President McAleese arriving into our new H.Q.



President McAleese in our new Board Room



Dr. Bruce Evatt, Justice Roderick Murphy,
President Mary McAleese & Professor John Bonnar



Hilary O'Sullivan, Sheila O'Shea, President Mary McAleese,
Brian O'Mahony, Niamh Birkett & Conor Birkett

We're home and we

Remarks by President Mary McAleese Irish Haemophilia Society's new Headquar

This is a landmark day for members and supporters of the Society. It is a great delight to have been asked to share it with you. I thank Clive for asking me to perform the official opening and in doing so, I wish to welcome you to these fine new headquarters.

They open in perfect time for next year's celebration of 40 years of the Society for sufferers, carriers and their families as well as others with haemophilia. These past four decades with, on the one hand huge improvements in the condition and on the other, the appalling story of HIV and AIDS.

This Society has been an advocate, champion, guide, friend and supporter for 40 years. Today, thanks to your efforts and those of the medical profession, the vast majority of people are now treating themselves at home. That fact alone gives people enhanced independence. Today, children with haemophilia can be treated prophylactically as possible, blending in more easily with the lifestyles of their peers.

The state-of-the-art National Centre for Hereditary Coagulation Disorders, a centre of improved services and also improved communications, is now actively involved in decision-making. Today, across many sectors, with expertise flowing only one way, there is a growing recognition that the insight of all the constituencies involved is a crucial resource. The practice that work best. The Society has an important role to play in the Minister for Health on haemophilia policy through the work of the very distinguished Professor John Bonnar. The Society also provides medications for haemophilia through the Haemophilia Programme, so ably chaired by National Haemophilia Society.

So, nationally, this Society has already created a stunning legacy. In the World Federation of Haemophilia this Society's involvement is a testament. I know this day is more than tinged with sadness at so much that has been lost. They should have lived. There is a plan to have here a memorial to those already passed away and it is right to remember them in this way. Another kind of memorial in these headquarters, for it is in this place that a much better future will be crafted for our citizens with haemophilia.

To Michael and Brian O'Mahony, congratulations on these new headquarters. To all of us who benefit from the Society's work in seen and unseen ways, and the members of the Executive for the dedication they have shown in working so effectively with the statutory agencies to ensure the best care with haemophilia. May that partnership continue.

I wish you all every success in your work.

and we're here to stay..

McAleese at the official opening of the Headquarters, Thursday 14th June 2007

supporters of the Irish Haemophilia Society and it is a real
you. I thank Chairman, Michael Davenport and the Society
g and in doing so I salute the huge team effort that brought
new headquarters into being.

celebration of forty years service by the Society to haemophilia
as others with bleeding disorders. It has been a rollercoaster
and huge improvements in treatment and management of the
viral of HIV and Hepatitis C infection as a result of treatment.

on, guide, friend and support throughout these very heady
use of the medical, pharmaceutical and research professions,
g themselves at home with safe and effective factor concen-
independence, enhanced safety and control over their lives.
treated prophylactically allowing them to lead as normal a life
lifestyles of their friends than in any previous generation.

editary Coagulation Disorders is another excellent example
communications between patients and professionals with both
across many sectors that were previously simply medicalised
is a growing recognition that the wisdom, experience and
a crucial resource in designing and sustaining the models of
important role in shaping haemophilia policy and in advising
y through the National Haemophilia Council, chaired by the
The Society also has a direct involvement in the selection of
Haemophilia Product Selection and Monitoring Advisory Board
l Haemophilia Director, Dr. Barry White.

ed a stunning legacy of achievement and as a leading player
his Society's international contribution is second to none.
ness at so much grief and loss, so many lives robbed of years
have here a memorial to the ninety-one people who have
ember them in such a way but today we honour them with
ers, for it is in and through the work carried out here that a
citizens with haemophilia and related bleeding disorders.

tions on these wonderful new headquarters and, on behalf of
in seen and unseen ways, I warmly thank Michael and Brian
edication they have shown over the past number of years in
encies to ensure the very best service possible for all those
at partnership flourish in the years ahead.

ccess in your new offices. Thank you.



I.H.S. Board with President Mary McAleese



President McAleese officially opening our new offices



President Mary McAleese being presented with a bouquet of flowers by Luz Maria Heaney & Conor Birkett



I.H.S. staff with President Mary McAleese

The year in review from our Chief Executive.....



Brian O'Mahony,
Chief Executive

New Headquarters

2007 was a momentous and highly significant year for the Irish Haemophilia Society. Without doubt the single most significant event of the year was the Official Opening of our new Head Quarters by President McAleese. During the course of the past 39 years the Irish Haemophilia Society has operated, initially from people's homes, then from a small shared office, and then a succession of rented premises which by definition did not offer any sense of permanence or ownership for the members of the organisation. It has long been our aspiration to be able to purchase a permanent Head Quarters for the Society and this became a reality when we purchased the offices in Cathedral Court, New Street South in Dublin.

The logistics of moving office and cataloguing all of the files, publications and other items which had to be moved was quite daunting. The logistics of moving to the new location went very smoothly thanks to a lot of advanced planning, and we were absolutely delighted when President McAleese agreed to officially open our new offices. Some 70 members were in attendance and following the official opening President McAleese took the

opportunity to meet with all of those in attendance on the day.

The remarks made by President McAleese on the opening of the office were both moving and entirely appropriate. I share the view of many of those who were present on that day that the Presidents Speech was the single most effective piece of oratory we had heard on haemophilia in Ireland in the course of the last 39 years. In her delivery which was informal and not from a script, the President managed somehow to encapsulate the experience of people with haemophilia and the journey - often turbulent and sometimes tragic - which this community has had to undergo in the course of the last 39 years, and more particularly in the course of the last 20 years.

During the course of 2008 we will be looking at the possibility of having a permanent monument in the new Head Quarters to all those with haemophilia who have died in the past, but it is perhaps appropriate to reflect on the fact that the most fitting monument is a strong, active and effective organisation finally operating from a permanent Head Quarters which can be a focus for all of the support and services which are required by our growing and more diverse membership.

The office gives us the possibility to hold in-house meetings in a more comfortable, appropriate and cost effective environment. During the course of 2007 we had meetings for carriers and for members with Hepatitis C and HIV. A number of Information Meetings were also held on the new Insurance Scheme

and the availability of a board room /meeting room and individual offices meant that members could also avail of individual consultation with experts on insurance. Prior to 2007 all of these meetings would have had to be held in hotels or other venues. The new Head Quarters are therefore not only cost effective in saving us the costs of booking rooms in hotels, but it became clear during the year that members feel more comfortable coming to the office and feel more at home here in a supportive and confidential environment.

Meetings, Conferences and Communication

The Annual General Meeting & Conference and Members Weekend were again enormously successful during the course of 2007. Over 150 members participated in the Annual General Meeting including some 54 children and young adults. The Members Weekend was a concept we began in 2006 which was again held in October 2007, and was even more successful. It is fair to say that this weekend conference has now become part of the calendar. It is also a significantly different event than the AGM and Conference in that many of the speakers at the Members Weekend come from the membership and from the board. It is an indication of a growing maturity of the organisation, and the ability of members to reflect on the reality of living with haemophilia, that members now feel happy and comfortable in speaking about their experiences and putting their experiences in context with those of others. It was interesting and salutary to witness the debate at the Members Weekend on the topic of



The I.H.S. Creche, Members Weekend-October 2007



Family Sports Day, Members Weekend - October 2007



Physiotherapy for kids



I.H.S. Youth Group and Leaders

"Is haemophilia a disability?" It was also greatly encouraging to see that the majority opinion in the audience following the debate was that haemophilia is not a disability. Events such as the Members Weekend are hugely important in assisting people with haemophilia and their families in dealing with the condition in a positive manner in a way which minimises the impact of the condition on their lives. It is also an opportunity for the coming together of the different generations of people with haemophilia. We are now living in a time when the children, teenagers and young adults have had access to prophylactic therapy for haemophilia for a number of years. They are therefore growing up without the joint damage or other sequelae which were a routine part of living with haemophilia in the past.

Availability of prophylactic therapy has meant that, not only is their haemophilia clinically less severe,

but their perception of haemophilia is different. Children with severe haemophilia are now growing up in a situation where their haemophilia is moderate because of the availability of prophylactic therapy. It is difficult for them or their parents to comprehend in many cases the full benefit of the therapy because they have not had to suffer through years of untreated bleeding episodes or treatment with suboptimal therapy. We wish to ensure that children and young adults with haemophilia continue to take therapy in an optimum manner and we wish to assist them in contextualising their haemophilia in relation to the improvements made in therapy. We are also aware that there is a new generation of doctors and nurses who are treating the children and young adults and who have not seen and hopefully will not see the devastation of joints wrought by untreated bleeding in the past. However, there is a necessity for them to be familiar with the ramifications of untreated haemophilia in

order to appreciate the benefits of current and early therapy. To satisfy both of these requirements we produced a DVD during the year entitled "Haemophilia through the Generations". The different realities and improvements in therapy are explained through the personal stories of several people with haemophilia and parents. Their stories cover the period from the 1960's to the present day and they are powerful testament not only to the improvement in therapy but to the resilience of the human spirit. The DVD has been widely disseminated among the members of the Society and to the Health Care Workers in the Treatment Centres, and we are also utilising it as part of our Education Programme for nurses and any external groups to whom we are asked to give talks or presentations on haemophilia. Our thanks go to Society member Shay Farrelly who directed the DVD for the organisation and did such an exemplary job, that he has now

been drafted in to direct a DVD for the 40th Anniversary of the Irish Haemophilia Society in 2008. Communication from the Society was further enhanced by a comprehensive restyling of our regular quarterly newsletter.

Representation on External Bodies

The Society has been actively and effectively represented on external and statutory bodies during the course of the year. Through our representation on the National Haemophilia Council we worked to clarify the requirements for the comprehensive Haemophilia Treatment Centres which were identified in the course of the audit of the centres in 2006. These included the requirement for an In-Patient Unit for St. James's Hospital for haemophilia and hepatology, the requirement for an additional consultant and much improved infrastructure for Cork University Hospital haematology service, and a requirement for a lead consultant to be appointed for the haemophilia service at Our Lady's Children Hospital in Crumlin along with additional posts for a psychologist and physiotherapist. Progress was made and some of these appointments were made during the course of 2007 and we will continue to work to ensure that the additional appointments and infrastructure requirements are prioritised for 2008.

Agreement was also reached through the auspices of the Council on patient participation in audits of the Haemophilia Treatment Centres, and new audits will take place during the course of 2008. These audits will be carried out by a team of 3 external auditors comprising of a doctor and a nurse from abroad and a patient representative from abroad nominated by the Irish Haemophilia Society.

We were also involved in the organisation and planning of the National Haemophilia Council Information Day which took place in November and featured an excellent overview of Orthopaedic Surgery in haemophilia.

The Haemophilia Product Selection & Monitoring Advisory Board again met on several occasions during the year, although no major tenders were required to be completed during the year. The board monitored the demand and use of products during the year on a National basis, oversaw the introduction of a collection service for sharps containers from the home delivery company, and in addition the Society worked in co-operation with the National Centre for Hereditary Coagulation Disorders to ensure adequate and complete information was given to patients with Factor IX deficiency when the new formulation and home treatment packs for recombinant Factor IX were introduced in late 2007. Through our representation on the Hepatitis C Consultative Council the Society were involved in the publication of the first comprehensive review of persons with Hepatitis C who were infected through blood or blood products in the state.

This Database, which was published by the Health Protection Surveillance Centre, will be updated on an annual basis and I am confident that it will prove to be an invaluable resource in following the natural history of Hepatitis C infection in our members along with the other groups, and in giving us information on the outcomes of treatment, therapeutic options, complications, and in assisting us in planning our future services. Information on 107 people with haemophilia and von Willebrands disease was included in the database report. The findings showed a significantly higher incidence of

liver disease in persons with haemophilia and related bleeding disorders at 16% as compared to 9% for all participants. During the course of the year the Society also strongly supported the application by St. James's Hospital for the purchase and installation of a Fibro Scan machine for St. James's Hospital which could be used to monitor the Hepatitis C status of many of our members on an ongoing basis, therefore diminishing the requirement for regular liver biopsy's. We also advocated successfully during the year for implementation of a better admissions policy for members with Hepatitis C and/or HIV when required. The purpose built In-Patient Unit in St. James's Hospital for haemophilia and hepatology is now at the design stage and we will continue to advocate the immediate building of this facility once the design stage is completed.

The long awaited Insurance Scheme for persons affected by HIV and/or Hepatitis C commenced in September. The Society representatives on the Insurance steering group put an enormous amount of work into the drafting of the regulations (completed in January) and in defining parameters for the Scheme. Information meetings were held in Dublin, Cork and Sligo and members are being afforded every assistance possible from the Society to help them to understand and participate in the Insurance Scheme. By the end of 2007, some 35 members had signed up for Life Insurance.

Assistance to Developing Countries and WFH

The Irish Haemophilia Society has always maintained a strong interest in assisting people with haemophilia in developing and emerging countries. We have been doing this over the past number of years by virtue of our involvement in the Twinning Programme with the

WFH, and by our involvement in the Global Alliance for Progress Programme. Our Twinning Programme with the Haemophilia Society of Bosnia & Herzegovina (HSBH) was officially closed at the end of 2007. This was an extremely successful Twinning Programme over the course of the 4 years and was recognised as such by the WFH in 2006 when the Twinning Programme was awarded the "Twin of the Year Award".

During the course of our work with HSBH the amount of factor concentrates used for routine treatment in Bosnia has tripled, the organisation has held its first National and International Conference on haemophilia and related bleeding disorders, and they organised a major Physiotherapy Symposium for Bosnia and the surrounding countries in 2007 with our assistance and participation. At the end of 2007 they were moving for the first time ever to a Head Quarters for the organisation. Up to that point they had operated from the home of their President in a situation reminiscent of the Irish Haemophilia Society prior to the mid 1980's. The Twinning Programme with Bosnia is now officially completed but we will continue to work with them and assist them over the course of the coming year as they set about working from their new office and hopefully hiring their first part time member of staff.

The Society has also been a significant donor to the WFH's GAP Programme, as part of a 3 year commitment we gave in 2006. This programme promotes the development of sustainable haemophilia care programmes by ensuring that all aspects of haemophilia care including medical treatment, infrastructure, development of the patient organisation, development of adequate options for factor replacement therapy and government support and commitment are in place. To date the programme has been operational in 12 countries and official haemophilia treatment programmes have been set up by signed agreement with the government in 8 of these countries. By the end of 2007, 8526 persons with haemophilia and von Willebrands Disease has been diagnosed and registered, and were obtaining for the first time, access to treatment through the auspices of the GAP programme. In addition during the course of 2007 we were successful in being selected as the conference venue for the European Haemophilia Consortium Conference which will take place in Dublin in September 2008. This will be the first International Conference on haemophilia to take place in Ireland since the World Federation of Haemophilia Congress in 1996. This will provide an opportunity to again increase the profile of haemophilia nationally during the course of our 40th Anniversary year.

Strategic Plan

The Society's Strategic Plan for the period 2006 - 2009 continues to be our focus for activities during the year. Steady progress has been made during the course of 2007. The Strategic Plan sets out 4 broad goals for the organisation, and these then are sub divided into 24 objectives and 100 strategies. At the end of 2006, 38 strategies were either ongoing or had been completed. By the end of 2007, 70 of the 100 strategies are ongoing or have been completed. Nine strategies have been dropped and 4 are under review. Among the ongoing strategies which we implemented in 2006, and which continue to be successful in 2007 were, ascertaining the requirements of members by phone contact with members on a regular basis, evaluation forms at the completion of all Society programmes and activities, and an ongoing staff education programme. We also initiated specific meetings with carriers and for members who had completed the legal process. Policies were finalised on child protection, travel and expenses, use of internet and email and on corporate funding. External experts were sourced and consulted in relation to Insurance and actuarial matters for the assistance of members. Discussions were held with the Irish Department of Foreign Affairs in relation to the possible integration of some haemophilia activities in developing and emerging countries



Twin of the Year Presentation at our Members Weekend
October 2007



Kidlink Arts & Crafts - October 2007

via the Irish Development Aid Budget. The availability of the new office has also lead to an increase in the uptake of counselling and advice services, and we are now providing not only counselling but specific and individual advice in areas including Insurance, Benefits in conjunction with the HSE and Health Services. Strategies dropped included strategies which were superfluous thanks to the success of other activities. We dropped the strategy to hold an Annual Think Tank and to set up Focus Groups for Members as the information required from these activities is being adequately gathered from the phone survey of members and from the open forums at our conferences and annual meetings. The Strategic Plan has been a very beneficial tool in assisting us to focus our activities and services for the benefit of all members. We expect the current plan to be fully implemented and completed in the course of 2009 and during the course of 2009 we will be developing a further Strategic Plan.

We also dropped, for the present, the concept of having a representative from the Society available adjacent to treatment centres during clinics. A service was available in St. James's during the course of 2006 and early 2007 but this was not availed of. The area of future co-operation with the Children's Chernobyl Project in relation to helping to improving haemophilia care in Belarus is one which is under review at the moment, and will be re-examined in 2009.

Financial Matters

Financially the year was dominated by the purchase of the Head Quarters. The H.Q. was purchased at the end of 2006 at a cost of €2,130,000. At the time of purchasing the building we had taken out a mortgage of €1.1 million to be repaid over a 15 year period. We had also been relying on applications for Capital Grants which we made to the HSE and to the fund linked to the National Centre.

In the course of 2007 we were successful in obtaining the maximum Capital Grant which we had requested from the HSE in the amount of €600,000 and we received a grant of €100,000 in Capital Funding from the National Centre fund. We are very grateful to the HSE and to the National Centre fund for these Capital Grants. The provision of these grants allowed us to pay €400,000 off the mortgage and we also elected to continue the repayments in the amount which we had been paying for the mortgage of €1.1million. That means that in effect, we are also paying off the mortgage more rapidly. During the course of the year therefore our mortgage of €1.1 million has been reduced to €638,145 and by the end of 2007 a reduction of €461,371. If we can maintain the mortgage payments at this rate we should have completed paying for the building in a period of 8 years.



Members playing draughts at our Sports Day - October 2007



Kidlink Samba Performance - AGM 2007



Our young adults at workshop - AGM 2007



Members attending workshop - October Weekend 2007

Income for the year excluding the Capital Grants was €717,080. Our expenditure for the year was €725,362. A major source of income was again the annual grant from the HSE and the HSE Northern Area. A detailed budget and analysis of the requirements for the year was submitted to the HSE for 2007 and a grant of €495,000 was allocated. This together with the grant from the HSE Northern Area brought the total grant up to €620,000. Fundraising constituted an extremely low proportion of our income for the year, €8,624, just over 1% of the total income.

The staff and board do not have the time to focus on fundraising and we are reliant on members to fundraise for the organisation. This is an area which will require more thought in coming years. Administration expenses were lower in 2007 than in 2006 while activity expenses were higher. We also had Head Quarters costs of €85,484 which were primarily for the installation of partitions, walls, air conditioning and other essential services in the new Head Quarters. These will not be repeat costs.

At the end of the year our balance sheet shows a healthy situation. There are reserve funds of €548,820 which, if you exclude the €122,928 in the current account, leaves an actual reserve of just over €425,892 or approximately 7 months operating capital. It is necessary to keep approximately €100,000 in the current account as the operational requirement of the Society is about €60,000 per month and there can often be a delay in receiving grants during the year, which can leave us in a poor cash flow position. The reserve funds are invested currently in a guaranteed bond with Hibernian and in a deposit account with a reasonably good yield.

Our investments during the course of the year have again been very prudent and we have managed to avoid the turmoil which has hit the Irish and other stock markets by our non exposure to direct equities. The value of fixed assets and buildings is €1,310,470 which on the face of it looks as if the building has greatly decreased in value since we purchased it. Nothing could be further from the truth, the major discrepancy here is the fact that the Capital Grants of €700,000 are being deducted from the current fixed asset value of the building, therefore the real value of our asset is over €2,000,000. It is also standard accounting practice to depreciate the value of a building by 2% per annum. Despite the fact that the Irish property market seems to have peaked and values are falling in residential sector during the later part of 2007, it is clear that there is a disconnect between accounting practice where the value of a building is depreciated on an annual basis and the reality where you expect the value of a building to go up over the long term.

Our financial position at the end of 2007 is therefore very healthy. We have 2 months operating capital in our current account, approximately 6 months operating capital in our reserve fund, and a Head Quarters valued in excess of €2,000,000 with an outstanding loan against that value of €638,000. When we purchased the Head Quarters at the end of 2006 we took out what was essentially a 50% mortgage which was very prudent at the time. Thanks to the Capital Grants and to our ability to maintain the mortgage payments at the higher level during the course of 2007 we now have a mortgage which is equivalent to only 30% of the value of the Head Quarters.

Board and Staff

It has been a pleasure to work with the board and with the Society staff team during the course of the year. Members should appreciate the extent of the commitment which is given by the board members who meet on average 11 times per annum in addition to taking part in conference calls and other activities.

An additional significant time commitment has been given during the year from the Chairman Michael Davenport, the Treasurer Gerard O'Reilly and the Honorary Secretary Kevin Birkett. The time and commitment given by the board members of the Irish Haemophilia Society to the organisation greatly exceeds that of board members in the majority of haemophilia organisations globally.

I also wish to thank the staff team of Margaret Dunne, Anne Duffy, Debbie Greene, Nina Storey and Patricia O'Connor for their hard work, dedication and enthusiasm during the year.

Truly 2007 was a landmark year. In achieving our Strategic Objectives we are providing optimum support and services for all of our members to help them to deal with the impact of haemophilia in their lives and to help them to move forward and to continue to work for a future where the quality of life for people with haemophilia and related bleeding disorders keeps improving. For the first time we are able to do this work from a permanent Head Quarters for the Society.

Brian O'Mahony
Chief Executive

Financial Reports.....

Independent Auditor's Report to the members of the Irish Haemophilia Society

We have examined the financial statements from which the summary has been taken.

Respective Responsibilities of Directors and Auditors

The Directors are responsible for preparing the Director's report and financial statements in accordance with applicable Irish Law and accounting standards generally accepted in Ireland. Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and auditing standards issued by the Auditing Practices Board applicable in Ireland. This report and its opinion has been prepared only for the company's members as a body in accordance with Section 193 of the Companies Act, 1990 and for no other purposes.

Basis of Opinion

A full scope audit was undertaken of the financial statements in accordance with auditing standards issued by the Auditing Practices Board.

Opinion

In our opinion the financial statements give a true and fair view of the state of the company's affairs at December 31st 2007, and of its net income and cashflows for the year then ended, and have been properly prepared in accordance with the Companies Act 1963 to 2001.

Statement by the Board of Directors

The summarised financial statements are not the statutory accounts but a summary of information relating to the Statement of Financial Activities and the Balance Sheet.

Auditors

The full financial statements from which the summary is derived have been independently audited and have an unqualified audit report. The full financial statements were approved on 1st March 2008.

Copies of the Report and Financial Statements can be obtained from the Irish Haemophilia Society, Cathedral Court, New Street, Dublin 8.










Michael Davenport

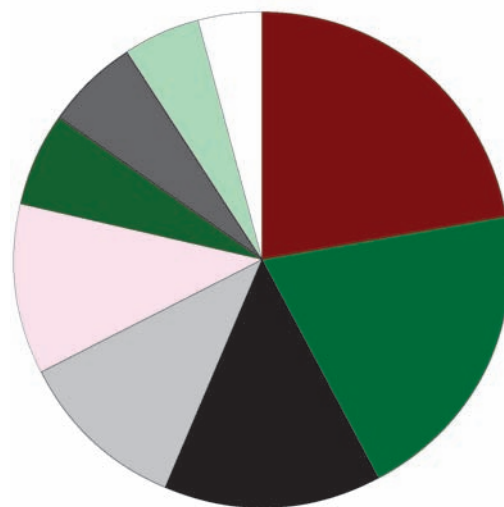
Chairman

Auditors
Howlin & O'Rourke,
Accountants,
2 Seapoint Building,
Clontarf,
Dublin 3.

Registered Office
Irish Haemophilia Society Ltd.,
First Floor,
Cathedral Court,
New Street,
Dublin 8.
Company Number: 142834
Reg Charity Number: CHY9214

How we spent our money.....

Establishment/Headquarters		22%
AGM & Meetings		20%
Members Conference & Meetings		14%
Counselling & Support		11%
Publications & Website		11%
External Representation		6%
Financial Support to Members		6%
Administration & Finance		5%
International Development Assistance		4%



Income & Expenditure Account

For the year ended 31st December 2007

	2007 €	2006 €
Income		
Health Service Executive - Northern Area	125,000	125,000
Health Service Executive	495,000	492,000
NCHCD Educational Fund	30,000	-
Memberships	4,650	5,540
Donations - Members	30,297	19,581
Donations - Other	7,000	4,161
Fundraising	8,624	12,810
H.H.T.Trust	9,220	-
Investment Income	7,289	22,283
	<hr/>	<hr/>
	717,080	681,375
Expenditure as per schedule	(725,362)	(652,194)
	<hr/>	<hr/>
	(8,282)	29,181
Reveral of previous overprovision for legal fees re Lindsay Tribunal	-	451,408
	<hr/>	<hr/>
Surplus /(deficit) for period	(8,282) =====	480,589 =====

Schedule Of Expenditure**For The Year Ended 31st December 2007**

	2007		2006	
	€	€	€	€
Administration Expenses:				
Wages, State Insurances and Pension Costs	198,608		201,674	
Employer's PRSI Contribution	17,270		18,700	
Office Expenses & Stationery	12,726		8,085	
Telephone & Fax	10,787		13,328	
Travelling Expenses	10,616		12,530	
Overseas Travel Expenses	9,689		20,933	
Advertising Expenses	-		2,088	
Archive Storage Fees	4,356		4,755	
Relocation Expenses	4,549		-	
Sundry Expenses	7,986		3,483	
Cork Office Expenses	<u>-</u>	276,587	<u>3,102</u>	288,678
Financial Expenses:				
Bank Charges & Loan Interest	44,546		1,592	
Professional Fees	80,184		54,555	
Audit & Accountancy Fees	<u>5,445</u>	130,175	<u>5,445</u>	61,592
Activities:				
Help to members	10,225		15,955	
Family Activities	6,219		10,924	
H.H.T.Trust	10,000		10,220	
Subscriptions	1,948		1,519	
Fund Raising Expenses	1,356		975	
A.G.M. & Meeting Expenses	39,404		37,677	
Postage, Publications & Photocopying	31,650		35,126	
Educational Grants	18,000		14,500	
Safety/Supply Activities	3,352		4,653	
Counselling & Support Meetings	6,488		22,180	
Twinning	1,931		9,932	
Website	2,905		2,304	
WFH GAP Program	18,832		(271)	
Sponsorship/Training	1,621		-	
Member's Conference	<u>22,803</u>	176,734	<u>-</u>	165,694
Establishment Expenses:				
Service Charge & Insurance	3,997		43,617	
HQ Costs	85,484		-	
Repairs & Maintenance	-		15,257	
Computer Services	3,419		11,223	
Light & Heat	<u>4,611</u>	97,511	<u>2,471</u>	72,568
Other Costs:				
Depreciation- Fixtures, Fittings & Equipment	18,073		23,380	
Depreciation- Land & Buildings	<u>26,282</u>	44,355	<u>40,282</u>	63,662
Total Expenditure		725,362		652,194
		=====		=====

Balance Sheet as at 31st December 2007

		2007		2006	
		€	€	€	€
Fixed Assets					
Buildings	Note 5	1,247,515		1,973,797	
Office Equipment & Fittings	Note 5	62,955		52,911	
			1,310,470		2,026,708
Current Assets					
Hibernian Spectrum Bond		150,000		150,000	
Anglo Irish Bank		-		61,644	
EBS Investment Account		-		634	
First Active Deposit Accounts		255,461		-	
Allied Irish Bank - Current Account		122,928		86,426	
Allied Irish Bank - Planned Giving Current Account		16,001		8,081	
Allied Irish Bank - Deposit Account		3,912		3,854	
EBS Deposit Account		-		1,861	
Sundry Debtors & Prepayments	Note 6	-		941	
Cash on Hand		518		414	
		548,820		313,855	
Current Liabilities					
Sundry Creditors & Accruals	Note 7	(64,211)		(75,831)	
		(64,211)		(75,831)	
Net Current Assets/(Liabilities)		484,609		238,024	
Long Term Liabilities					
Long Term Property Loan	Note 8	(638,145)		(1,099,516)	
Net Assets/(Liabilities)		1,156,934		1,165,216	
Represented By:					
Accumulated Funds					
Balance 1st January 2007		1,165,216		684,627	
Surplus / (Deficit) for the year		(8,282)		480,589	
Balance 31st December 2007		1,156,934		1,165,216	

Tangible fixed assets	Land and buildings €	Fixtures, fittings and equipment €	Fixtures, fittings and equipment €	Total €
Cost or valuation				
At 01/01/07	2,014,079	62,248	72,243	2,148,570
Additions	-	28,117	-	28,117
Capital Grants	(700,000)	-	-	(700,000)
At 31/12/07	1,314,079	90,365	72,243	1,476,687
Depreciation				
At 01/01/07	40,282	9,337	72,243	121,862
Charge for the year	26,282	18,073	-	44,355
At 31/12/07	66,564	27,410	72,243	166,217
Net book values				
At 31/12/07	1,247,515	62,955	-	1,310,470
	=====	=====	=====	=====
At 31/12/06	1,973,797	52,911	-	2,026,708
	=====	=====	=====	=====



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