In what was an important year for IPPOSI, a busy schedule of projects, events and activities was maintained throughout 2014. Our work as a task force leader in EUPATI – The European Patient Academy - culminated in the appointment of a fulltime IPPOSI employee to coordinate over 12 (IPPOSI-like) National Liaison Teams and National Platforms around Europe. In addition to the funding received from EUPATI, and the Department of Health via a grant from the Health Research Board, IPPOSI generated increased revenue in 2014 through new industry memberships.

In 2014, IPPOSI continued to play an important role in facilitating interactions between patients’ organisations, scientists, industry and State Agencies. Throughout the year IPPOSI ran a number of informative events addressing topical issues such as connected health, health technology assessment and clinical trials. The Secretary General of the Department of Health once again engaged with our members at our Annual Round Table Meeting where the subject of Health Information was heavily debated. The Outcome Report arising from this meeting was subsequently shared with the Department of Health. IPPOSI continues to monitor the issues raised, as well as the wider health information environment very closely.

Connected Health was identified in 2013 as an important subject for patients and other IPPOSI members to be made more aware of, and this need was addressed in 2014 at an IPPOSI-led conference in Dublin Castle entitled, ‘Connected Health & Me: The Patient Perspective’. The day-long conference featured a high calibre speaker line up including ‘ePatient Dave’ from the United States.

IPPOSI continues to strengthen its relationship with the National Centre for Pharmacoeconomics (NCPE), with the IPPOSI website now including a live feed of NCPE health technology decisions. In addition, Dr Roisín Adams of the NCPE continues to provide great support to IPPOSI through our HTA training day, and by taking part in our meetings and panel discussion groups.

Another highlight of 2014 was the publication of the National Rare Disease Plan for Ireland 2014-2018, and IPPOSI members continue to be represented by our Chief Executive on the Oversight Committee for implementation of the Plan. The plan published in 2014 is a proud testament to the efforts of IPPOSI and other passionate and committed players in the rare disease community who have fought tirelessly for the Plan’s development over a seven-year period.

Another good news story for IPPOSI in 2014 was the launch of the National Rare Disease Plan for Ireland 2014-2018, and IPPOSI members continue to be represented by our Chief Executive on the Oversight Committee for implementation of the Plan. The plan published in 2014 is a proud testament to the efforts of IPPOSI and other passionate and committed players in the rare disease community who have fought tirelessly for the Plan’s development over a seven-year period.

Another good news story for IPPOSI in 2014 was the launch of the www.clinicaltrials.ie website for children. The site and associated documents are part of an IPPOSI information campaign intended to advise the public (adults and children of all ages) about taking part in clinical trials. Our content partner for the sections dealing with children is the National Children’s Research Centre (NCRC) which is a charitable organisation and the largest paediatric research facility in the Republic of Ireland.

Finally, IPPOSI facilitated two consultations with members this year - one on the Universal Health Insurance White Paper, the other on HTA Guidelines published by HIQA.

In what was an important year for IPPOSI, a busy schedule of projects, events and activities was maintained throughout 2014. Our work as a task force leader in EUPATI – The European Patient Academy - culminated in the appointment of a fulltime IPPOSI employee to coordinate over 12 (IPPOSI-like) National Liaison Teams and National Platforms around Europe. In addition to the funding received from EUPATI, and the Department of Health via a grant from the Health Research Board, IPPOSI generated increased revenue in 2014 through new industry memberships.

In 2014, IPPOSI continued to play an important role in facilitating interactions between patients’ organisations, scientists, industry and State Agencies. Throughout the year IPPOSI ran a number of informative events addressing topical issues such as connected health, health technology assessment and clinical trials. The Secretary General of the Department of Health once again engaged with our members at our Annual Round Table Meeting where the subject of Health Information was heavily debated. The Outcome Report arising from this meeting was subsequently shared with the Department of Health. IPPOSI continues to monitor the issues raised, as well as the wider health information environment very closely.

Connected Health was identified in 2013 as an important subject for patients and other IPPOSI members to be made more aware of, and this need was addressed in 2014 at an IPPOSI-led conference in Dublin Castle entitled, ‘Connected Health & Me: The Patient Perspective’. The day-long conference featured a high calibre speaker line up including ‘ePatient Dave’ from the United States.

IPPOSI continues to strengthen its relationship with the National Centre for Pharmacoeconomics (NCPE), with the IPPOSI website now including a live feed of NCPE health technology decisions. In addition, Dr Roisín Adams of the NCPE continues to provide great support to IPPOSI through our HTA training day, and by taking part in our meetings and panel discussion groups.

Another highlight of 2014 was the publication of the National Rare Disease Plan for Ireland 2014-2018, and IPPOSI members continue to be represented by our Chief Executive on the Oversight Committee for implementation of the Plan. The plan published in 2014 is a proud testament to the efforts of IPPOSI and other passionate and committed players in the rare disease community who have fought tirelessly for the Plan’s development over a seven-year period.

Another good news story for IPPOSI in 2014 was the launch of the www.clinicaltrials.ie website for children. The site and associated documents are part of an IPPOSI information campaign intended to advise the public (adults and children of all ages) about taking part in clinical trials. Our content partner for the sections dealing with children is the National Children’s Research Centre (NCRC) which is a charitable organisation and the largest paediatric research facility in the Republic of Ireland.

Finally, IPPOSI facilitated two consultations with members this year - one on the Universal Health Insurance White Paper, the other on HTA Guidelines published by HIQA.
<table>
<thead>
<tr>
<th>IPPOSI Board Members 2014</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mr Godfrey Fletcher</strong></td>
</tr>
<tr>
<td>Cystic Fibrosis Registry of Ireland</td>
</tr>
<tr>
<td>Chairperson, IPPOSI</td>
</tr>
<tr>
<td><strong>Mr Philip Watt</strong></td>
</tr>
<tr>
<td>The Cystic Fibrosis Association of Ireland</td>
</tr>
<tr>
<td><strong>Mr Hugh Hardiman</strong></td>
</tr>
<tr>
<td>Bayer</td>
</tr>
<tr>
<td><strong>Mr John Church</strong></td>
</tr>
<tr>
<td>Arthritis Ireland</td>
</tr>
<tr>
<td><strong>Ms Ciara O’Rourke</strong></td>
</tr>
<tr>
<td>MSD</td>
</tr>
<tr>
<td><strong>Ms Nicola Watt</strong></td>
</tr>
<tr>
<td>Alexion</td>
</tr>
<tr>
<td><strong>Ms Avril Daly</strong></td>
</tr>
<tr>
<td>Fighting Blindness</td>
</tr>
<tr>
<td><strong>Prof Seamas Donnelly</strong></td>
</tr>
<tr>
<td>TCD</td>
</tr>
<tr>
<td><strong>Dr Tomás Carroll</strong></td>
</tr>
<tr>
<td>Alpha One</td>
</tr>
<tr>
<td><strong>Prof Brendan Buckley</strong></td>
</tr>
<tr>
<td>UCC</td>
</tr>
<tr>
<td><strong>Prof Colm O’Morain</strong></td>
</tr>
<tr>
<td>AMNCH and Trinity College Dublin</td>
</tr>
<tr>
<td><strong>Dr Amanda McCann</strong></td>
</tr>
<tr>
<td>UCD</td>
</tr>
<tr>
<td><strong>Ms Sharon Cosgrove</strong></td>
</tr>
<tr>
<td>Asthma Society</td>
</tr>
<tr>
<td><strong>Mr Martijn Akveld</strong></td>
</tr>
<tr>
<td>GSK</td>
</tr>
<tr>
<td><strong>Mr Peter Kelly</strong></td>
</tr>
<tr>
<td>Chronic Pain Association</td>
</tr>
<tr>
<td><strong>Dr Catherine Darker</strong></td>
</tr>
<tr>
<td>TCD</td>
</tr>
<tr>
<td><strong>Ms Siobhan Gaynor</strong></td>
</tr>
<tr>
<td>MMI</td>
</tr>
<tr>
<td><strong>Ms Sarah O’Callaghan</strong></td>
</tr>
<tr>
<td>AbbVie</td>
</tr>
<tr>
<td><strong>Ms Rachel Foley</strong></td>
</tr>
<tr>
<td>Irish Cancer Society</td>
</tr>
<tr>
<td><strong>Mr Fred Doherty</strong></td>
</tr>
<tr>
<td>Genzyme</td>
</tr>
</tbody>
</table>
As you know I started as CEO of IPPOSI in August 2015 and am excited to have the opportunity to represent the patient perspective as part of this wonderful organisation. I would like to pay tribute to the previous CEO and the staff of IPPOSI over the past number of years, who have remained committed and motivated to put the patient first. I promise to harness the existing expertise within our small but committed team, bringing my own experience to bear on what promises to be an exciting upcoming period for IPPOSI.

2014 marked the third year of IPPOSI's existing strategic plan. Our vision of ensuring patients in Ireland have prompt access to new and developing innovative therapies remains core to the organisation and to the work carried out in 2014. This is well demonstrated by the launch of www.clinicaltrials.ie for children with the site attracting international attention due to its unique offering in Europe for providing children with information about taking part in clinical trials.

As ever IPPOSI reacted to an evolving health environment and in June the Annual Round Table Meeting with the Secretary General was hosted on the topic of Health Information. Meanwhile In November IPPOSI and the INSIGHT Centre for Data Analytics co-hosted a Connected Health Conference in Dublin Castle arising from the conclusions reached by the IPPOSI Board in 2013 – that Connected Health was an important area to involve IPPOSI members in. It was fantastic to realise that vision with such a successful event.

EUPATI featured heavily in the IPPOSI workload in 2014, and this was facilitated by Laura Kavanagh, who has spearheaded the development of National Liaison Teams (quasi IPPOSI-like organisations) all over Europe that can implement a model of partnership and co-operation between patients, science, industry and government, as IPPOSI has done for the past several years. IPPOSI’s work with EUPATI has led to our involvement with a follow-up proposal submitted to IMI2, so hopefully the momentum that IPPOSI and EUPATI has built for patients in Europe can continue under this banner.

Here in Ireland we continue to deliver a range of training and information events, with Outcome Reports supporting these meetings as necessary. The IPPOSI website has been upgraded and a new-look monthly newsletter continues to be published thanks to the work of our Communications Manager, Ken Rogan.

IPPOSI is in a very confident position for 2015 and undergoing a period of growth and optimism for our future. We now know that IPPOSI is a unique model where patients lead discussions between all stakeholders. Queries from all over the world have been received about how we make IPPOSI work. The answer is simple - we work together with a dedicated group of stakeholders who believe patients can lead the agenda.

I would like to express my gratitude to all of you, our members for continuing to be involved and supporting IPPOSI in its mission to bring the patient perspective into decision making.

Looking forward to working with you all in the year ahead!

A message from
CEO Derick Mitchell

Above: Age-specific information about taking part in a clinical trial

Minister Leo Varadkar and IPPOSI Directors in Dublin Castle for the Connected Health conference in November
Rare diseases

IPPOSI was heavily involved in the work that culminated in the publication in July 2014 of the first National Rare Disease Plan for Ireland (2014-2018). This followed years of work by the Steering Group for Rare Diseases of which IPPOSI was an active and committed member. On what was a great and long-anticipated day for rare diseases in Ireland, a number of IPPOSI members and others in the rare disease community attended the launch event in the Royal College of Physicians on July 3rd, where the plan was published by the Minister for Health, Dr James Reilly, TD. With 48 recommendations contained in the plan, this document is the blueprint for future policy, research and service delivery for rare diseases in Ireland.

IPPOSI continued its work on the Steering Group to ensure that key provisions of the National Rare Disease Plan were included in the HSE Service Plan towards the end of 2014, including a budget for the National Rare Diseases Office.

Earlier in 2014, and around the celebration of International Rare Diseases Day (February 28th) IPPOSI attended a joint Northern Ireland / Republic of Ireland event in Queen’s Hall, Belfast where NI Minister Edwin Poots and Minister of State Alex White opened an event that saw many excellent speakers talk about their experiences of rare disease within the different healthcare systems. Speakers included Mr Philip Watt (Cystic Fibrosis Ireland and IPPOSI Board Member) and Ms Katie Murphy, a CF patient who works for CF Ireland and who is also a member of the IPPOSI working group on HTA, which was established in November 2014. One of the other speakers at this event, Dr Shane McKee (Belfast Health & Social Care Trust, Belfast City Hospital) spoke about the value of electronic care records and subsequently took part in the IPPOSI Annual Round Table Meeting with the Secretary General of the Department of Health.

The day before Rare Disease Day, IPPOSI attended a session of the Joint Oireachtas Committee on Health in Leinster House which saw a delegation of patients and patient representatives present to the committee on key issues concerning the rare disease community in Ireland. One day prior to that IPPOSI attended an event in the Mansion House hosted by Ms Avril Daly (IPPOSI Board member, Fighting Blindness CEO) in her capacity as the chairperson of the Genetic Rare Disorder Organisation.

Elsewhere in the area of rare diseases, IPPOSI continued to deliver lectures in the UCD School of Medicine’s elective module on rare diseases, which IPPOSI helped to establish in 2013. Finally, IPPOSI published a booklet written and produced by an IPPOSI member, Ms Sharon Thompson, about palliative care for children in Ireland.

Clinical Research

The major event for IPPOSI in 2014 was the launch of www.clinicaltrials.ie for children – a website that uploaded online material that IPPOSI, in partnership with the National Children’s Research Centre (NCRC) in Our Lady’s Hospital for Children, Crumlin, had written to help children of different ages (Under 8 / 8-12 / 13-18) and their parents understand and should they wish to, take part in clinical trials in Ireland.

Bringing a patient’s perspective to clinical research

The booklets are an excellent and popular resource and IPPOSI regularly receives requests from around Europe to use these materials in other countries. While www.clinicaltrials.ie was established by IPPOSI originally, it was Professor Carlos Blanco of the NCRC who saw the opportunity for speaking directly to children, and Professor Blanco spoke about his work at the launch of the website at an event held in the NCRC on May 12th. The site was launched by Dr Graham Love of the Health Research Board. Other attendees on the day included Professor Colm O’Donnell, Ms Eilish Hardiman, CEO of Our Ladies Children’s Hospital, Crumlin, and Dr Ruth Barrington.

Elsewhere IPPOSI continued its commitment to patient involvement in and understanding of clinical research by hosting two training events – the first being a lecture on the Irish Pharmaceutical Healthcare Association (IPHA) codes for marketing pharmaceuticals in Ireland. This meeting was delivered by Dr Rebecca Cramp, Scientific and Regulatory Affairs Manager with IPHA in the EU Parliament building, Dublin 2 with thirty IPPOSI members attending.

The other training event is now a staple in the IPPOSI calendar - Clinical Research for non-Clinical Researchers. Once again we are indebted to Dr Gloria Crispino (Institute of Technology Tallaght) and Ms Siobhan Gaynor (Genable) for delivering another fascinating meeting to an audience unfamiliar with the language and methodologies of clinical research.

Finally, IPPOSI brought the patient perspective to a discussion panel for the first meeting of the Irish Health Research Forum on November 4th, and IPPOSI also consulted on a Health Research Board audit in the same month. In mid-November, the IPPOSI Chief Executive chaired a session at the Irish Research Nurses Network annual conference, and IPPOSI also met with other stakeholders in the offices of McCann Fitzgerald to discuss how clinical trials activity could be enhanced in Ireland.
Universal Health Insurance Consultation & Submission

On May 20th, IPPOSI hosted a consultation session on the Universal Health Insurance White Paper in the Royal Irish Academy. Mr Eugene Lennon, Principal Officer in the Universal Health Insurance Unit within the Department of Health delivered a detailed presentation about the proposed policy and thereafter questions and comments about the policy were received from the 60+ IPPOSI members in the audience.

Immediately following this session, the IPPOSI Executive met with members of the Board to further elaborate on key points made during the session, and to decide on the structure of a submission document. The structure was as follows: Patient Voice; Access; Safeguards; Structural Issues; a Benefits Statement, and finally; Resourcing.

The submission document was compiled, sent to the IPPOSI Board Directors for further comment, and finally submitted to the Department of Health on May 28th. This document is available on the IPPOSI website.

Annual Round Table meeting with the Secretary General of the Department of Health

This year, due to the scale of member interest, the Annual Round Table meeting was relocated to a larger function room. Nearly 100 attendees heard Dr Ambrose McLoughlin speak about Health Information, the eHealth Ireland strategy and the upcoming appointment of a Chief Information Officer to the HSE. The next speaker, Mr Peter Lennon, Department of Health, spoke about the Individual Health Identifiers Bill, which was published in 2014 having been separated from the Health Information Bill.

Mr Lennon was followed by Dr Shane McKee, the Clinical Lead for Genetic Medicine in the Belfast Health & Social Care Trust, who described in detail the benefits and experience of using electronic care records in Northern Ireland. Dr McKee was followed by Professor Jane Grimson, then acting CEO of HIQA. Professor Grimson’s concern was the governance and management of research data, and this fed in to what emerged as the central issue of the meeting – the EU Data Protection Regulation.

Mr Paulo Silva of the European Commission delivered a clear picture of where this key piece of EU legislation was – at that stage in the EU Parliament undergoing amendments that could have a serious and negative impact on health research throughout Europe. The Irish perspective on data protection was provided by Mr Garrett O’Neill of the Data Protection Commissioner’s Office.

Other speakers included Mr Doug Beaton, Management Lead of the HSE Health Intelligence Team, Dr Dmitri Wall (Irish Skin Foundation) and finally Dr Graham Love of the Health Research Board. The Outcomes Report arising from this meeting was published in July 2014 and is also available on the IPPOSI website.

HIQA consultation on Guidelines for Health Technology Assessment

This session took place in EU Parliament buildings on August 27th, where Dr Conor Teljeur and Dr Michelle O’Neill, both of HIQA, laid out draft guidelines before an audience of IPPOSI members. The purpose of the guidelines are to promote the production of HTA’s that are timely, reliable, consistent and relevant to key decision makers and stakeholders in Ireland. The HIQA presentation is available on the IPPOSI website.

Health Technology Assessment

On January 24th IPPOSI hosted its annual NCPE (National Centre for Pharmacoeconomics) Health Technology Assessment training event in EU House on Dawson Street, Dublin 2. The event speakers were Professor Michael Barry, Dr Roisin Adams and Professor Cathal Walsh, all of the NCPE. While Professor Barry presented an overview of the HTA process in Ireland, including key concepts like QALY (Quality Adjusted Life Years) and ICER (Incremental Cost-Effectiveness Ratio), the most engaging element of the training remains the exercises where IPPOSI members are asked to ‘decide’ whether certain hypothetical medicines should be reimbursed or not, and on what basis. This is a highly effective exercise for applying
otherwise abstract concepts and it remains a big favourite with the IPPOSI membership.

2014 also saw IPPOSI and the NCPE partner on the publication of NCPE decisions through a dedicated section on the new IPPOSI website. The IPPOSI Chief Executive also presented at the NCPE’s two-day training module aimed at industry on March 1st, and in June IPPOSI presented at a HTAi (Health Technology Assessment International) event in Washington DC, USA. Finally, IPPOSI established a small working group on HTA in November 2014.

**Connected Health**

In November 2014 IPPOSI and the INSIGHT Centre for Data Analytics partnered to host a day-long conference in Dublin Castle on Connected Health with the aim of broadening the IPPOSI membership’s understanding of Connected Health, and bringing together patients and researchers in the area. The event was a great success and featured world class speakers on connected health, including ePatient Dave (TED Speaker), Professor George Crooks (Scottish NHS), Professor Brian Caulfield from UCD, IPPOSI’s own Professor Seamas Donnelly, and speakers from Estonia and Finland. There was also a panel discussion that was facilitated by the broadcaster Ms Áine Lawlor, which included Professor Fionnuala McAuliffe, Dr Dermot Power, and Dr Shane McKee.

The event was officially opened by the Minister for Health, Dr Leo Varadkar, TD, and he was followed by a patient with Parkinson’s, Mr Paul Carey, who spoke about his experiences and frustrations of the Irish health system. The central element of the connected health conference was a ‘Health Hack’, where partnerships of researchers and patients presented competitively to draw audience members into their facilitated discussion groups - the winner of the Health Hack was the Irish Skin Foundation.

In all, a panel of fifteen speakers, facilitators and judges all contributed to an excellent event and you can find videos of all the speakers and health hack participants on [www.ipposi.ie](http://www.ipposi.ie).
Internationally, much of IPPOSI’s work in this area is delivered via our work in EUPATI, as the section below describes. Additionally:

- In April IPPOSI spent a number of days in Italy speaking about European projects as a guest of the Italian CRO National Cancer Institute.
- In November, IPPOSI chaired a session at the World Orphan Drugs Congress in Brussels.

Locally, IPPOSI maintained a busy schedule of meetings and engagements that included 11 meetings on rare diseases, whether with the National Steering Committee, its subgroup on orphan drugs (chaired by IPPOSI), or with the Rare Disease Task Force. Elsewhere, IPPOSI:

- presented at an EFNA event in the Science Gallery, TCD (April)
- hosted an Expert Patient Training information day in the offices of Molecular Medicine Ireland (March)
- participated in the HSE’s Patient Representative Forum on Medical Card Eligibility (August)
- met with the Secretary General in the Department of Health, along with other members of the IPPOSI Board (March)
- presented to the AbbVie management team (October)
- presented to the TCD Postgraduate course in Pharmaceutical Medicine (January)
- took part in the HIQA Research Ethics Advisory Board (May)
- met with the CEO of the Health Research Board (Nov)
- consulted on the Health Information Bill – Research Ethics Approval framework

**EUPATI**

It was a very busy year for IPPOSI within EUPATI. In May we appointed Laura Kavanagh to the role of National Liaison Team coordinator and both she and the Chief Executive criss-crossed the continent to meet with patients, academics and industry representatives in the UK, Italy, Spain, Malta, Luxembourg and Switzerland. As a result of their efforts, five National Platforms launched in Europe in 2014, and two more shortly afterwards in 2015. These National Platforms are currently informal associations of individuals or groups, but it is hoped that as the conversation around patient involvement develops, IPPOSI-like organisations may emerge in several countries.

On September 16th, EUPATI hosted an event in Dublin Castle to explore patient involvement issues within the Irish medicines research and development process. A panel of experts including Dr Graham Love (HRB), Philip Watt (MRCG) and Dr Jayne Crowe (HPRA) discussed ‘Patient involvement in clinical research – the future?’ A second panel with Dr Ingrid Klingmann (EFGCP), Victoria Thomas (NICE-UK) and Dr Roisin Adam (NCPE) tackled the question of ‘How patients can best collaborate across the Health Technology Assessment process?’ Ms Áine Lawlor spoke of her experience of clinical trial participation and the importance of patient involvement for future therapies.

**Media**

Highlights of 2014 included:

- A full page of coverage in the Irish Times Health Supplement around the launch of [www.clinicaltrials.ie](http://www.clinicaltrials.ie) in May
- Coverage of IPPOSI and the RD Plan in the consumer and media around the launch of the National Rare Diseases Plan for Ireland
- Media coverage on Connected Health conference – further coverage in the Irish Times – both main body of the newspaper and in Health Supplement (full page) ahead of the conference
- GSK media healthcare awards – IPPOSI was on the judging panel for the awards
- IPPOSI again enlisted the help of broadcaster Áine Lawlor to open the AGM and EUPATI Workshop in Dublin Castle in September and we continue to foster this key relationship with a high-profile champion who is willing to speak about her experience on a clinical trial
- This year IPPOSI launched an upgraded website and a new look newsletter
- IPPOSI established and grew a presence on social media (Twitter and Facebook)
- IPPOSI now shoots ‘vox pop’ videos at key meetings, thereafter uploading the results onto our website and into our presentations. The videos are highly impactful at presentations.

**THE IRISH TIMES**

“All he wanted to do was go to somebody else’s house for dinner”

*When you hear of cancer and leukaemia, you don’t immediately think of a five-year-old boy.*
(A Company Limited by Guarantee and not having a Share Capital)

Income and Expenditure Account
for the year ended 31 December 2014

<table>
<thead>
<tr>
<th></th>
<th>Continuing operations</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2014</td>
<td>2013</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>288,825</td>
<td>226,774</td>
</tr>
<tr>
<td>Expenditure</td>
<td>(269,900)</td>
<td>(204,232)</td>
</tr>
<tr>
<td>Surplus on ordinary activities before interest</td>
<td>18,925</td>
<td>22,542</td>
</tr>
<tr>
<td>Other interest receivable and similar income</td>
<td>440</td>
<td>841</td>
</tr>
<tr>
<td>Surplus on ordinary activities before taxation</td>
<td>19,365</td>
<td>23,383</td>
</tr>
<tr>
<td>Tax on surplus on ordinary activities</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Retained surplus for the year</td>
<td>19,365</td>
<td>23,383</td>
</tr>
</tbody>
</table>

Balance sheet
as at 31 December 2014

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Notes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fixed assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tangible assets</td>
<td>8</td>
<td>2,687</td>
</tr>
<tr>
<td>Current assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debtors</td>
<td>9</td>
<td>4,605</td>
</tr>
<tr>
<td>Cash at bank and in hand</td>
<td>264,283</td>
<td>133,912</td>
</tr>
<tr>
<td></td>
<td>268,888</td>
<td>136,495</td>
</tr>
<tr>
<td>Creditors: amounts falling due within one year</td>
<td>10</td>
<td>(177,149)</td>
</tr>
<tr>
<td>Net current assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>91,739</td>
<td>72,255</td>
</tr>
<tr>
<td>Total assets less current liabilities</td>
<td>94,426</td>
<td>75,061</td>
</tr>
<tr>
<td>Net assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>94,426</td>
<td>75,061</td>
</tr>
</tbody>
</table>
PATIENTS’ ORGANISATIONS
22q11 Support Group Ireland
Action Duchenne
All Ireland Institute of Hospice & Palliative Care (AIHPC)
Alpha One
Alzheimer Society of Ireland
Angelman Syndrome Ireland
Ankylosing Spondylitis Association of Ireland
Arthritis Ireland
Asthma Society of Ireland
Ataxia Ireland
Bone Cancer Research Trust
Brain Tumour Ireland
CATTS Ireland
Children In Hospital Ireland
Chronic Pain Ireland
Coeliac Society of Ireland
Co-operation and Working Together (CAWT) Cross Border Health & Social Care
COPD Support Ireland
Cystic Fibrosis Association of Ireland
Cystic Fibrosis Registry of Ireland
Cystinosis Ireland
DEBRA Ireland
Disability Federation of Ireland
Dublin Simon Community
Duchenne Ireland
Ehlers Danlos Syndrome Awareness Ireland
Endometriosis Association of Ireland
Epilepsy & Pregnancy Register South of Ireland
Epilepsy Ireland
Fabry Ireland
Fibrolipid
Fighting Blindness
GRDO - Genetic & Rare Disorders Organisation
Heart Children Ireland
Hospice Foundation
Huntington’s Disease Association of Ireland
Huntington’s Disease Association Northern Ireland (HDANI)
IllestoMy & Internal Pouch Support Group
IMD Action Group
IMNDA - Irish Motor Neurone Disease Association
Irish Cancer Society
Irish Children’s Arthritis Network
Irish Fragile X Society
Irish Haemophilia Society
Irish Heart Foundation
Irish Hospice Foundation
Irish Kidney Association
Irish Lung Fibrosis Association
Irish ME/CFS Association
Irish ME/CFS Association
Irish MPS Society
Irish Neonatal Health Alliance
Irish Osteoporosis Society
Irish Patients Association
Irish Premature Babies
Irish Raynaud’s & Scleroderma Society
Irish Sarcoidosis Support Network (ISARC)
Irish Skin Foundation
Irish Society for Mucopolysaccharide Diseases
Irish Thoracic Society
Join Our Boys Trust
Lauralynn, Ireland’s Children’s Hospice
Marie Keating Foundation
Meningitis Research Foundation
Migraine Association of Ireland
Motor Neurone Disease Association
Move4Parkinson’s Foundation
MRCG - Medical Research Charities Group
Multiple Myeloma Ireland
Multiple Sclerosis Ireland
Muscular Dystrophy Society of Ireland
Myasthenia Gravis Association
National Paediatric Mortality Register
NCBI - National Council for the Blind Ireland
NCSRN Ireland (Irish Heart Foundation)
Neuroendocrine Tumour - NET Patient Network
Neurological Alliance of Ireland
OACS Ireland /FACS Forum Ireland
OvaCare
Parkinson’s Association of Ireland
Perinatal Ireland
Pituitary Foundation
PKU Support Group
Prader-Willi Syndrome Association Ireland
PSPA Ireland

Members
Pulmonary Hypertension Association of Raynaud’s & Scleroderma Ireland
Rehabcare
Rett Syndrome Association of Ireland
Shine Ireland
Sickle Cell & Thalassaemia Ireland (SCTI)
Sicklecell Society of Ireland
Tarlov Cyst Disease
The Saoirse Foundation
Vasculitis Ireland Awareness

INTERNATIONAL PATIENT GROUPS
European Headache Alliance
EURORDIS
Genetic Alliance UK
Men Against Cancer
NIRDP
Pain Alliance Europe
PID UK (Primary Immunodeficiency UK)
Rare Disease UK
URDDAD Foundation

UNIVERSITIES & COLLEGES
Dublin City University
Hibernia College
NUI Galway
Royal College of Surgeons Ireland
Trinity College Dublin
University College Cork
University College Dublin
University of Ulster
Waterford Institute of Technology

INDUSTRY
AbbVie
Alexion
Bayer
BioMarin
Boehringer Ingelheim Ireland Ltd
Celgene
Eli Lilly
Genzyme
GSK
ICON
Janssen Cilag
Merck Serono (Ireland) Limited
MSD
Novartis
Pfizer
Roche
Shire
RESEARCH CENTRES/DEPTs
Centre for Health Informatics, TCD
Clinical Research Centre, Beaumont Hospital
Cork Cancer Research Centre
Dublin Centre for Clinical Research
Dynamics Lab, UCD Geary Institute
Hibernia College, School of Health Sciences
HRB-TMRN - Trials Methodology Research Network NUI Galway
ICORG
INSIGHT Centre for Data Analytics, UCD
Institute for Molecular Medicine at St. James Hospital
Mater University Hospital - National Pulmonary Hypertension Unit/PHA
Molecular Medicine Ireland
Oncology Clinical Trials Cork University
RCSI Department of General Practice
RCSI Research Office
RCSI School of Pharmacy
RCSI/Perinatal Ireland
Research Foundation, Royal Victoria Eye & Ear Hospital
School of Biological Sciences, College of Sciences and Health, DIT
School of Nursing and Midwifery, TCD
School of Psychology, NUI Galway
St. James’s Hospital - Department of Immunology
TCD Centre for Health Sciences, Tallaght Hospital
TCD School of Nursing and Midwifery
Trinity Centre for Health Sciences
Trinity EngAGE Centre for Research on Ageing, TCD
UCD Applied Research in Connected Health (ARCH) research centre
UCD Conway Institute
UCD Research
UCD School of Applied Social Science
UCD School of Law
UCD School of Medicine and Medical Science
WIT - School of Health Sciences

HSE
HSE - Corporate Pharmaceutical Unit
HSE - Health Intelligence Unit
HSE - Healthcare Pricing Office
HSE - National Advocacy Unit
HSE - South Eastern Area
HSE - Southern Area, Department of Public Health

HOSPITALS
Beaumont hospital - RCSI
Belfast City Hospital
BHSCT - Belfast Health and Social Care Trust
Children’s University Hospital Temple Street
Coomeb Women & Infants University Hospital
Dublin Dental School & Hospital
Mater Hospital
Midland Regional Hospital
National Maternity Hospital
Our Lady’s Children’s Hospital, Crumlin
St. James’s Hospital
Tallaght Hospital
Temple Street Children’s University Hospital
The Adelaide and Meath Hospital

GOVERNMENT/POLICY
Department of Health
Joint Oireachtas Committee on Health and Children
Minister for Health
Seanad Éireann
Secretary General Department of Health

STATE AGENCIES
Data Protection Office
Enterprise Ireland
FORFAS
Health Information and Quality Authority
Health Research Board
HPRA
IDA
Institute of Public Health in Ireland
NTMA - National Treasury Management Agency
Science Foundation Ireland

ETHICS COMMITTEES
Athlone Institute of Technology Research Ethics committee
Ethics (Medical Research) Committee
Beaumont Hospital
European Medicines Agency Paediatric Committee
SCU/CSTAR@UL - University Hospital
Limerick Ethics Committee

ASSOCIATIONS & SOCIETIES
ICGP - Irish College General Practitioners
IMSTA Irish Medical and Surgical Trade Association
IPHA - Irish Pharmaceutical Healthcare Association
ISQSH - Irish Society for Quality and Safety in Healthcare

NATIONAL CENTRES/PROGRAMMES
National Adult Literacy Agency (NALA)
National Cancer Control Programme (NCCP)
National Cancer Registry Ireland
National Centre for Inherited Metabolic Disorders
National Centre for Inherited Metabolic Disorders, Mater Hospital
National Centre for Medical Genetics
National Centre for Pharmacoeconomics (NCPE)
National Children’s Research Centre
National Clinical Programme for Rare Diseases
National Out-of-Hospital Cardiac Arrest Register (OHCAR)

OTHER
Centogene AG
EFGCP
Eighth Day
EUPATI
EUROCAT
Genable Technologies Limited
Health & Social Care Services in Northern Ireland
INSERM, ECRIN
Minimate Limited
National Institute for Health and Care Excellence (NICE - UK)
Newcastle University
Prospectus