In spite of core funding cutbacks IPPOSI continued to build a very credible reputation in Ireland and the EU. Our success in the EUPATI project in 2013 has led to dedicated funding, resources and responsibility in this project. The Health Research Board provided a reduced grant in 2013 to facilitate our work and we matched that through our membership fees from our Industry members.

In 2013 IPPOSI continued to play an important role to facilitate the interaction between patients’ organisations, scientists, industry and State Agencies. Over the year IPPOSI ran a number of informative meetings targeted to address topical issues. The Secretary General at the Department of Health (DOH) kindly consented to engage with our members in what is now becoming an Annual Round Table Meeting. At this meeting the importance of patient compliance and adherence was discussed. A report with key recommendations was prepared and shared with the DOH. Connected Health featured in this meeting as a possible means of improving adherence. As a result IPPOSI have been building networks in this space for a major follow-up event in 2014.

In 2013 through our commitment to patient involvement in decision making, the National Centre for Pharmacoeconomics agreed to partner with IPPOSI to bring the patient perspective into the HTA process in Ireland. The highlight was IPPOSI presenting on patient engagement at ISPOR in November 2013. In the same period, HIQA consulted with IPPOSI members on Economic Evaluation, Budget Impact and Stakeholder Engagement.

IPPOSI members are represented by our Chief Executive on the Steering Group for Rare Diseases and lead the Orphan Drug Subgroup. Work relating to the National Plan for Rare Diseases featured throughout the course of 2013 and this plan was in the final stages of editing by the end of the year. We have been at the forefront of the move to develop a national policy for people with Rare Diseases in partnership with our colleagues in the Medical Research Charities Group and the Genetic and Rare Disorders Group. The plan was published in 2014 is a proud testament to IPPOSI’s and our partners efforts over a seven year period.

Another good news story for IPPOSI in 2013 was the further development of the clinicaltrials.ie website. The site and associated documents are part of an IPPOSI information campaign intended to advise the public about clinical trials. During the course of 2013 we developed the site to include information for children. Our content partner for those 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, 2013 saw another year of loyal support from our membership at all events, consultations and newsletter/website hits. I look forward to more enlightening discussions, partnerships and new thinking in patient engagement going forward into 2014.

Godfrey Fletcher

Chairperson’s welcome

Governance

The Board of IPPOSI consists of elected members from each of the participant sectors. Patient organisations are represented by eight seats, with science and industry members each having six seats.

The Chairperson is always a representative from a patients’ organisation.

The Board of Directors

The Board of Directors of IPPOSI met five times in 2013. The Board manages and oversees the organisation and identifies where it should focus its efforts in order to achieve goals and objectives. The Board are responsible for major decisions on spend year on year. IPPOSI Directors will continue to develop and grow the Board ensuring there is a rotation of one third of the Board every year according to our Memorandum and Articles of Association. While membership of IPPOSI is open to all those with an interest, the current Directors from each of the three sectors will also work to identify appropriate targets for membership.

Finance Committee

The Finance Committee is a subcommittee of the Board and is made up of the Chairperson, Treasurer and Secretary of the Board. The Committee interacts with the CEO on matters relating to financial management, staff remuneration and other HR issues. A full record of our financial information as of the 31st December 2013 is available in this report.
IPPOSI Board Members 2013

Mr Godfrey Fletcher  
Cystic Fibrosis Registry of Ireland  
Chairperson, IPPOSI

Ms Sinead Duffy  
Bayer

Ms Ciara O’Rourke  
MSD

Mr Philip Watt  
The Cystic Fibrosis Association of Ireland

Mr Jimmy Fearon  
DEBRA Ireland

Ms Nicola Watt  
Alexion

Ms Avril Daly  
Fighting Blindness

Prof Seamas Donnelly  
UCD

Dr Tomás Carroll  
Alpha One

Prof Brendan Buckley  
UCC

Prof Colm O’Morain  
AMNCH and Trinity College Dublin

Dr Amanda McCann  
UCD

Ms Sharon Cosgrove  
Asthma Society

Mr Martijn Akveld  
GSK

Mr Peter Kelly  
Chronic Pain Association

Dr Catherine Darker  
TCD

Ms Siobhan Gaynor  
MMI

Ms Sarah O’Callaghan  
AbbVie

Ms Rachel Foley  
Irish Cancer Society

Mr Fred Doherty  
Genzyme
A message from CEO

Eibhlín Mulroe

IPPOSI began year two of the strategic plan in 2013. Our vision of ensuring patients in Ireland have prompt access to new and developing innovative therapies was very much front and centre of the work carried out in 2013. This is well demonstrated by further development of the clinicaltrials.ie website, the work on the National Plan for Rare Diseases and the HTA training with patient representatives. However, we did move into new areas not planned for but necessary in a changing healthcare environment. Compliance and Adherence became an important topic for our members and for the Department of Health. The outcome from our Roundtable with the Secretary General on the subject led to further discussions at Board level on the need for IPPOSI to bridge the gap between our members and those involved in connected health. Some exciting partnerships and developments in this space are ongoing.

EUPATI featured heavily in our workload in 2013, in particular as Task Force Leader in Work Package 2. The responsibility rested with us to develop patient-led networks like IPPOSI in 12 member states across the EU. We organised events, meetings and many conference calls to realise our objectives. By the end of 2013 it was clear that more resources were required in IPPOSI to complete our goals in the EUPATI work plan. Thanks to the vision of the EUPATI Executive Committee, in 2014 we have a new staff member in IPPOSI, Laura Kavanagh whose role is dedicated to EUPATI. I will continue to spend a portion of my time on the project working closely with Laura and the Work Package-2 team. Ken Rogan who joined us in 2014 on a part-time basis, will as Communications Manager look after the needs of our IPPOSI membership.

IPPOSI is in a very confident position for 2014 and undergoing a period of growth and optimism for our future place. We are realising more and more that IPPOSI is a unique model in that patients lead discussions between all stakeholders. We have had queries from people all over the world in the last 12 months 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 being involved and supporting IPPOSI in its mission to bring the patient perspective into decision making.

Looking forward to the year ahead!

Eibhlín Mulroe
IPPOSI maintained its strong position as the key provider of the patients’ voice of consensus in 2013. As the activities below demonstrate, in line with the Strategic Plan 2012-2015, our focus on patient concerns in the context of policy and legislation in medicines development continue to provide a unique platform for our members and for the government to progress healthcare in Ireland in an inclusive way.

Looking to 2014 and beyond, IPPOSI aims to cement this position further, while growing its international reputation and model. We will also seek to expand IPPOSI’s focus into emerging areas of relevance, such as Connected Health, while building on the work we have done in Health Technology Assessments to further improve patient access to new treatments.

Rare diseases

The Rare Disorder Without Borders conference took place in Dublin City Hall on 28th February 2013 to mark Rare Disease Day, the internationally recognised day for rare diseases. It was an all-Ireland conference coordinated by the Rare Disease Task Force in Ireland which brings together the Genetic and Rare Disorders Organisation (GRDO), IPPOSI and the Medical Research Charity Group (MRCG) in partnership with the Northern Ireland Rare Disease Partnership NIRDP and Rare Disease UK.

In line with the theme ‘Rare Disorders Without Borders’, the conference promoted collaborative and innovative ways of working between Ireland and the UK, north and south, east and west and across the EU in the field of rare diseases. The conference also took place in Dublin to coincide with the Irish Presidency of the Council of the EU, fitting given the 2013 deadline for the development of national plans for rare diseases in the EU.

Speakers at the event included Minister of State Alex White, TD; Mr Edwin Poots MLA Minister of the Department of Health, Social Services and Public Safety; Professor Eileen Treacy of the HSE, and now the Clinical Lead for Rare Diseases in Ireland; Fiona McLaughlin of the Northern Ireland Rare Disease Partnership; Alastair Kent, chair of Rare Disease UK, and Director of Genetic Alliance UK among many other speakers from patient organisations and the wider healthcare sector. More than 200 delegates attended the event and we are very grateful to the Lord Mayor’s office for allowing us the use of such a distinguished venue.

The conference was quickly followed up on the IPPOSI website with a series of patient / carer interviews edited together to give viewers a sense of what it’s like to have a rare disease in Ireland. These videos are still regularly viewed by site visitors.

Three weeks later, the Rare Disease Task Force, of which IPPOSI was an active member, produced the Easy Guide to Rare Diseases, a 48-page document that included an overview of rare diseases in Ireland, fifteen profiles of people living with different rare diseases in Ireland, and a section about the National Plan for Rare Diseases. IPPOSI sat on the Steering Group for Rare Diseases and led the Orphan

Bringing a patient’s perspective to clinical research

Drug subgroup. Work relating to the National Plan featured throughout the course of this role.

In April, one of the patients to feature in both the Easy Guide, and the IPPOSI Patient Videos, Jamie O’Brien, appeared on TV3’s morning programme, Ireland AM, with IPPOSI CEO Eibhlin Mulroe to talk about his condition and the challenges of having a rare disease in Ireland. In June, IPPOSI partnered with MRCG to produce a report on the publication of the Health Information and Human Tissue Bills called: ‘An update on forthcoming legislation’.

Finally, 2013 saw the Rare Disease module in UCD go into its second year. Overall IPPOSI did a great deal of work in the area of rare diseases in 2013.

Clinical Research

In November, IPPOSI hosted a half-day event in the EU Parliament Offices on Molesworth Street titled: Clinical Research for Non-Clinical Researchers. The event covered terminology, ethics, methodological and statistical considerations in clinical research, and children in research. The event was attended by sixty or more members who enjoyed the contributions of the speakers, including: Siobhan Gaynor of Molecular Medicine Ireland; Dr Gloria Crispino from ITT Dublin; and Sinead Nally from the National Children’s Research Centre based in Our Lady’s Children’s Hospital Crumlin. Each of the speakers’ presentations are still available on the IPPOSI website.

In September, Professor Carlos Blanco of the National Children’s Research Centre, Our Lady’s Children’s Hospital, Crumlin, spoke about the importance of communicating directly with children when it comes to clinical trials. Indeed, Professor Blanco’s passion in this particular area led to a redevelopment of the www.clinicaltrials.ie material for adults with a younger set of audiences in mind – under 8’s; 8-12’s; and 13-18’s. These leaflets were developed by IPPOSI and the National Children’s Research Centre and the website was redesigned to accommodate the age-specific categorisation of the patient leaflets. In all this included three new leaflets and a full site redevelopment including input from NALA and others to ensure development of the most appropriate and most useful materials possible.

Also in September, IPPOSI contributed informally during a brief for patients by the Irish Pharmaceutical Healthcare Association on the disclosure of clinical trial data. Finally, in June, IPPOSI presented on patient involvement in Clinical Research at the Eli Lilly UK Medical Forum in London.
Influencing policy that impacts research and access to innovative therapies

Annual Roundtable meeting with the Secretary General of the Department of Health

In June IPPOSI hosted the Annual Roundtable meeting with Dr Ambrose McLoughlin from the Department of Health on the theme of Compliance and Adherence. The board of IPPOSI identified patient compliance and adherence as an important issue to highlight in 2013. According to the European Patients Forum, policy makers, health managers and healthcare professionals often underestimate the opportunity to improve health outcomes and rationalise health expenditure through monitoring what happens after a medicine has been prescribed.

The issuing of a prescription is the first step towards safe and high-quality pharmacotherapy, however it is estimated that 20% to 30% of patients do not adhere to medication regimens that are curative or relieve symptoms, and 30% to 40% fail to follow regimens designed to prevent health problems. When long-term medication is prescribed, 50% of patients fail to adhere to the prescribed regimen.

This meeting discussed the patient experience behind these figures and debated the issue in the context of the overall provision of treatments. Other issues discussed included the background psychology of non-compliance, the economical and health risk of prescribing therapies that are taken sub-therapeutically or not at all, the payers perspective (HSE), health literacy and how future technologies might address some of these issues.

The meeting was well attended by IPPOSI members and featured speakers such as Dr Roisin Adams of the NCPE; Dr Colm Galligan, Medical Director of MSD; Professor Seamas Donnelly, Consultant Respiratory Physician and many others drawn from patient organisations and clinical environments.

The Outcomes Report arising from the Compliance and Adherence meeting was published in late September with the assistance of Minister for State Alex White. The findings of the Outcome Report acknowledged that the issue was a complex, multi-dimensional one with no one-stop shop solution, and that adherence doesn’t just mean medicine, but also diet and lifestyle interventions. The report also recommended the establishment of a specific working group to address the issue. The Outcome Report is available on the IPPOSI website.

Also in June, IPPOSI presented to the Irish Medicines Board about the work and objectives of IPPOSI. In May 2013, IPPOSI gave a presentation to the Annual General Meeting of the European Patients’ Forum in Dublin, and also to the Federation of European Academies of Medicine, at the FEAM Spring Conference.

In September, IPPOSI presented to its membership at our Annual General Meeting, which was attended by Minister of State for Health, Mr Alex White, TD.

Health Technology Assessment

The National Centre for Pharmacoeconomics agreed to partner with IPPOSI to bring the patient perspective into the HTA process in Ireland. The highlight was IPPOSI presenting on patient engagement at ISPOR in November 2013.

- In July 2013, IPPOSI published a glossary of terms to help members understand the jargon and vocabulary of HTA. This glossary was informed in part by literature from HTAi, the International HTA body.
- In October, IPPOSI hosted a meeting for members where the Irish Pharmaceutical Healthcare Association was invited to update members around the marketing codes for prescription medicines and devices in this country.

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IPPOSI Roundtable Meeting
A Focus on Patient Compliance and Adherence in 2013
An IPPOSI Roundtable Meeting for Patients’ Organisations, Science and Industry members
Other highlights

- In May, IPPOSI hosted an information meeting for members about organisational governance, which was provided by Boardmatch Ireland. Mr Liam O’Dwyer gave a presentation titled: Everything you need to know to become a Board member but were too afraid to ask.

- In September, IPPOSI hosted an information day in the Mansion House that included the launch of the Outcomes Report arising from the Annual Roundtable Meeting, a discussion about the use of social networking sites in relation to diabetes care, with thanks to Dr Vincent McDarby, Clinical Psychologist TCD. The next speaker at the September event was Ms Claire O’Riordan of the National Adult Literacy Agency, and she addressed the issue of ‘Health Literacy and Patient Wellness’.

- In October IPPOSI held a meeting in EU House, Dawson Street, called ‘Healthcare landscape in Ireland’. The event was delivered in conjunction with Prospectus and it covered topics including the National Reform Programme; Health Funding Levels; UHI and Money Follows the Patient; Health Structures; Hospital Groups; and Primary Care development. Vincent Barton facilitated the event which targeted the Patient Leadership in IPPOSI.

- In December, IPPOSI welcomed three officers from HIQA to address the issue of public consultation guidelines for members. Eibhlín Mulroe is a member of the Science Advisory Group for Health Technology Assessment at HIQA, and when the Draft Updated Guidelines for Economic Evaluation and Budget Impact Analysis were presented to this group Eibhlín sought HIQA’s assistance in informing IPPOSI members on the guidelines. The three speakers from HIQA were, Dr Máirín Ryan, Director of Health Technology Assessment, HIQA and Lecturer in Pharmacoeconomics in the Dept. of Pharmacology and Therapeutics, Trinity College Dublin; Mr Patrick Moran, Information Scientist, HIQA; Dr Conor Teljeur, Mathematician/Statistician, HIQA.
Increase awareness and understanding of IPPOSI work

The majority of IPPOSI’s work in this area was done through EUPATI but also by presenting at global meetings for example in 2013;

- ISPOR Patient Roundtable (16th Annual European Congress)
- DIA global meetings and Federation of European Academies of Medicine, FEAM Spring Conference.

At home, IPPOSI presented at:
- GSK’s Healthcare speaker series; and
- The Enterprise Ireland ‘Industry input on 5 year connected health technology centre funding workshop’; and finally at
- The National Health Service Executive Medical Forum Meeting in the Royal College of Physicians

IPPOSI also increases awareness and understanding of its work through EUPATI, where efforts are being made to duplicate the IPPOSI model in other EU member states.

EUPATI

In March, a EUPATI National Liaison Team Workshop took place in Barcelona. The aim of this event was to gather National Liaison Team (NLT) representatives or potential NLT representatives so that they could be updated on the EUPATI development, exchange experiences, gain further knowledge about the goal of the EUPATI National Platforms and how they function.

IPPOSI, as a consortium partner, was represented by CEO Eibhlín Mulroe, Taskforce Leader for Work Package Two (WP2) and members of the Irish NLT; Sinead Duffy of Bayer, Peter Kelly of Chronic Pain Ireland and Siobhan Gaynor of Molecular Medicine Ireland. National Liaison Teams are the temporary task forces of one representative of each stakeholder group (patients, industry, academia) which will work out the country-specific approach of how best to implement the "EUPATI National Platform" (ENP) in their respective country. The ENPs will help EUPATI to meet its objectives on a national basis, to raise pan-European programme awareness, disseminate information in national media, and identify future topics of national interest.

Media

In a public-facing capacity, the highlights of 2013 include:

- Appearing on TV3’s Ireland AM programme with Jamie O’Brien in the aftermath of the Rare Diseases Without Borders event
- Facilitating the appearance of patient perspective media articles on the value of clinical trials
- Uploading patient focused videos to the IPPOSI website
- Working with the Rare Disease Taskforce on Rare Disease Day and the work of the National Steering Group
- Pharmaceutical Managers of Ireland (PMI) video – a series of recorded video interviews were distributed internationally through the networks of PMI which explained the origins and objectives of IPPOSI.
Irish Platform for Patients' Organisations, Science and Industry Limited  
(A Company Limited by Guarantee and not having a Share Capital)

Income and Expenditure Account  
for the year ended 31 December 2013

<table>
<thead>
<tr>
<th>Notes</th>
<th>Continuing operations</th>
<th>2013</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>€</td>
<td>€</td>
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<tr>
<td>Income</td>
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<td>226,774</td>
<td>116,815</td>
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<td>Expenditure</td>
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<td>(177,682)</td>
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<tr>
<td>Surplus/(deficit) on ordinary activities before interest</td>
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<td>20,035</td>
<td>(60,857)</td>
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<tr>
<td>Other interest receivable and similar income</td>
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<td>841</td>
<td>131</td>
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<tr>
<td>Surplus/(deficit) on ordinary activities before taxation</td>
<td></td>
<td>20,876</td>
<td>(60,736)</td>
</tr>
<tr>
<td>Tax on surplus/(deficit) on ordinary activities</td>
<td></td>
<td>-</td>
<td>-</td>
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<tr>
<td>Retained surplus/(deficit) for the year</td>
<td></td>
<td>20,876</td>
<td>(60,736)</td>
</tr>
</tbody>
</table>

A separate Statement of Total Recognised Gains and Losses is not required as there are no gains or losses other than those reflected in the profit and loss account.

Balance sheet  
as at 31 December 2013

<table>
<thead>
<tr>
<th>Notes</th>
<th>2013</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fixed assets</td>
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<tr>
<td>Tangible assets</td>
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<td>Current assets</td>
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<td>Debtors</td>
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<td>Cash at bank and in hand</td>
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<td>133,912</td>
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<td></td>
<td></td>
<td>136,495</td>
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<td>Creditors: amounts falling due within one year</td>
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<td>(64,240)</td>
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<tr>
<td>Net current assets</td>
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<td>72,255</td>
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<td>Total assets less current liabilities</td>
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<tr>
<td>Net assets</td>
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<td>72,554</td>
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<tr>
<td>Reserves</td>
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<tr>
<td>Revenue reserves account</td>
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<td>72,554</td>
</tr>
<tr>
<td>Members' funds</td>
<td>11</td>
<td>72,554</td>
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</table>
PATIENTS' ORGANISATIONS

22q11 Support Group Ireland
Alpha One
Alzheimer's Society of Ireland
Ankylosing Spondylitis Association of Ireland (ASAI)
Arthritis Ireland Asthma Society Ataxia Society Ireland
Bee For Battens, The Saoirse Foundation
Bone Cancer Research Trust
Brainwave The Irish Epilepsy Association
CATTS Ireland
Children In Hospital
Chronic Pain Ireland
Cystic Fibrosis Association of Ireland
Cystic Fibrosis Registry of Ireland (CFRI)
Cystinois Foundation of Ireland
DEBRA Ireland
DERCUM DISEASE
Disability Federation of Ireland
Duchenne Ireland
Ehlers Danlos Syndrome
Eurordis
Fabry Ireland
Fighting Blindness
Genetic & Rare Disorders Organisation (GRDO)
Hospice Foundation
Huntington's Disease Association of Ireland
Ileostomy & Internal Pouch Support Group
IMD Action Group
Irish Cancer Society
Irish Fragile X Society
Irish Haemophilia Society
Irish Heart Foundation
Irish Hospice Foundation
Irish Kidney Association
Irish Lung Fibrosis Association
Irish Lupus Society
Irish ME/CFS Association
Irish Motor Neurone Disease Association (IMNDA)
Irish Osteoporosis Society
Irish Patients Association
Irish Premature Babies
Irish Raynaud’s & Scleroderma Society
Irish Sarcoïdosis Support Network (ISARC)
Irish Skin Foundation
Irish Society for Mucopolysaccharide Diseases MPS
Irish Thoracic Society
Marie Keating Foundation
ME/CFS Assoc.
Men Against Cancer
Meningitis Ireland
Migraine Association of Ireland
Move4Parkinson’s Foundation Ltd
MPS Society MRCG
Multiple System Atrophy (MSA)
Multiple Sclerosis Ireland
Muscular Dystrophy Society of Ireland Ltd
Myasthenia Gravis Association
National Adult Literacy Agency (NALA)
OvaCare
Pain Alliance Europe
Parent of child with the Rare Condition 'Krabbes'
Parkinson’s Association of Ireland
Patient with Rare Condition - Pompe Disease
Pituitary Foundation
PSPA Ireland - PSP Patient Support Group
Raynaud’s & Scleroderma Ireland
RehabCare
Rett Syndrome Association of Ireland
SADS (Sudden Adult Death Syndrome)
Sarcoïdosis
Tarlov Cyst Disease
The Mater Foundation
Tommy Hoey Trust - Cavan
TPN

SCIENCE

AIT Research Ethics committee
AMNCH - Adelaide & Meath Hospital - National Children’s Hosp.
Beaumont Hospital
Beaumont Hospital - Clinical Research Centre
Belfast City Hospital
Biobank Ireland Trust
Children’s University & Mater Hospitals
Children’s University Hospital - Temple Street
CSTAR
Department of Public Health, HSE - Southern Area
Dr Steeven’s Hospital
Dublin Centre for Clinical Research
Dublin Dental School & Hospital
EMA Paediatric Committee
Epilepsy & Pregnancy Register South of Ireland
Ethics (Medical Research) Committee Beaumont Hosp.
ICORG
Institute for Molecular Medicine at St. James Hospital
Irish College of General Practitioners
Irish Heart Foundation
Irish Medicines Board
Mater Dei Institute of Education, A College of Dublin City University
Mater Hospital
Mater University Hospital - National Pulmonary Hypertension Unit/PHA
Members

Hypertension Unit/PHA
Mater University Hospital / UCD
Midland Regional Hospital
Molecular Medicine Ireland
National Centre for Medical Genetics
National Centre for Pharmaeconomics - St, James
National Children’s Research Centre
NCRI
NUI Galway
OHCAR - the National Out-of-Hospital Cardiac Arrest Register
Oncology Clinical Trials Cork University
RCSI Regional Immunology Service The Belfast Trust
Royal Victoria Eye & Ear Hospital
School of Health Sciences
SFI
St. James Hospital
St. Vincent’s Hospital - UCD Clinical Research Centre
St. Vincent’s University Hospital
TCD
TCD - School of Nursing & Midwifery
Tril - Technology Research for Independent Living
UCD
UCD Conway Institute
UCD Research
UCD School of Law
UCD School of Medicine and Medical Science

INDUSTRY MEMBERS

AbbVie
Alexion
Bayer
BioMarin
Celgene
Genzyme
GSK
Janssen Cilag
MSD
Novartis Ireland Ltd.
Pfizer
Shire Pharmaceuticals Ltd