Ensures patients in Ireland have prompt access to new and developing innovative therapies
Chairperson, Margaret Webb

As Chairperson of IPPOSI, I am pleased to report that 2011 was yet another successful year for our organisation.

IPPOSI delivered on the 2011 strategic goals identified by the Board. Our work in the areas of clinical research, rare diseases, access to new treatments and biobanking has had a positive impact on the sector in Ireland. IPPOSI is increasingly considered by decision makers as the principal point of contact for consulting with key stakeholders in these key policy areas.

IPPOSI envisages that the changing healthcare environment and reduced healthcare budgets will continue to influence the activities and discussions in 2012 and 2013. We plan to play a pivotal role in bridging the gap between patients, science and industry and the decision makers in the Department of Health. The Health Information Bill is an important step for all those engaged in health information and in particular for patient registries. IPPOSI has widely disseminated the IPPOSI/MRCG 2011 document entitled; ‘National Strategy for Patient Registries – Considerations for Government’. Further steps will be taken to promote the recommendations in that report in 2012/13.

Eibhlín Mulroe, CEO of IPPOSI is continuing her work as Sub-committee Chair on the Department of Health’s Rare Diseases Steering Group and this will reach completion in 2013. Next year will also mark the point at which all EU member states will be compelled by a council recommendation to produce a national plan for rare diseases.

Finally I would like to thank the staff of IPPOSI for their hard work and commitment during the year. I would like to express my appreciation to my colleagues on the board for their contribution to our work and to the shared goal of improving Irish patient’s access to new treatments and therapies.
IPPOSI Board Members 2011

**IPPOSI Chairperson**
Ms Margaret Webb
Raynaud’s and Scleroderma Ireland

Mr Godfrey Fletcher
Cystic Fibrosis Registry of Ireland

Mr Philip Watt
The Cystic Fibrosis Association of Ireland

Mr Jimmy Fearon
Debra Ireland

Ms Gina Plunkett
Irish Chronic Pain Association

Ms Sinead Duffy
Bayer

Dr Stephen McDonough
GSK

Dr Amanda McCann
UCD

Ms Ciara O’Rourke
MSD Ireland (Human Health)

Dr Velichk Valcheva
Sanofi

Mr John McCormack
Irish Cancer Society

Dr Ruth Barrington
Molecular Medicine Ireland

Prof Colm O’Morain
AMNCH and Trinity College Dublin

Prof Brendan Buckley
Irish Medicines Board

Dr Tomás Carroll
Alpha One

Dr Fergus O’Ferrall
Trinity College Dublin

Mr Fred Doherty
Genzyme

Mr Philip Watt
Irish Medicines Board

Prof Seamas Donnelly
UCD

Ms Avril Daly
Fighting Blindness

Ms Nicola Watt
Alexion
GOVERNANCE

The Board of IPPOSI consists of elected members from each of the participant sectors. Patient organisations are represented by eight members, 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 four times in 2011. The Board manages and oversees the organisation and 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 will continue to develop and grow the Board and membership of IPPOSI to increase the representation and mandate of the group. While membership is open to all those with an interest in this area, the current members 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 2011 is available in this report.

Think-Tanks
IPPOSI think-tanks evolved in 2011. The Clinical Research Think-Tank members were invited to work with MRCG in developing a national strategic plan for patient registries in Ireland. The Rare Disease Think- Tank Group joined forces with MRCG and GRDO to create the Rare Disease Task Force chaired by Mr John McCormack who is also a Director of IPPOSI. In 2011 the Emerging Healthcare Environment Think-Tank focused on educating stakeholders on health technology assessments and access to medicines and hosted its first information day. The think-tanks met over the course of the year to plan events and actions in the context of rare diseases, access to medicines and clinical research.
TOWARDS 2015
CEO Eibhlín Mulroe

In recent months IPPOSI has completed a strategic planning process which will assist in planning the organisation’s activity for the coming years.

In more difficult economic times there is greater responsibility to ensure that an organisation such as IPPOSI is targeting resources on those areas which are strategically important to the organisation's mission. With this objective in mind, IPPOSI has recently completed a strategic planning process which was carried out in full consultation with Directors and Members. The Board of IPPOSI and membership met in 2012 to begin the strategic review. It became clear that the unique partnership has provided a perspective that is valued by key stakeholders in the health care environment. Stakeholders are open to partnering further in the future as IPPOSI has developed influence, provided access to key decision makers and facilitated consensus. Resources are limited and there is a need to ensure focus on where there can be an impact and not duplicate effort. In the coming years, IPPOSI Members agreed to work on creating more awareness of what they stand for and how they contribute.

The Board of IPPOSI, in consultation with a management consultant began the strategic planning exercise in early 2012. The Board completed a questionnaire exercise followed by workshops outlining the key areas of priority for IPPOSI going forward. This work was then revisited by the wider membership and the final strategic priorities, objectives and actions were presented by the CEO to the Board in May 2012. The strategic plan restates IPPOSI’s vision of **ensuring patients in Ireland have prompt access to new and developing innovative therapies** and defines the organisation’s mission as **expediting the development of and patient access to innovative therapies through a unique partnership of patient groups, science and industry.**
## STRATEGIC PLAN 2012 - 2015

### STRATEGIC PRIORITIES

<table>
<thead>
<tr>
<th>Bring a patient’s perspective to clinical research in Ireland</th>
<th>Actively influence policy that impacts on research and access to innovative therapies</th>
<th>Increase awareness and understanding of the work done by IPPOSI</th>
<th>Source funding to ensure IPPOSI’s sustainability</th>
</tr>
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</table>

### STRATEGIC OBJECTIVES

| • Develop a society where there is increased understanding and support for clinical research | • Participate in the development of a national strategy on rare diseases | • Engage members (existing and prospective) and develop an active membership base | • Maintain current funding and grow new sources of funding in Ireland and Europe |
| • Bring a patient perspective to the development of clinical research infrastructure | • Participate in the development of a national strategy and framework for biobanking and patient registries | • Establish IPPOSI as an expert group with the media outlets | • Develop a funding strategy to source future funding |
| • Facilitate stakeholders to develop a national strategy for biobanking and patient registries | • Bring increased transparency to the decision making process around access to innovative therapies | • Increase members understanding of the challenges around the development of and access to innovative therapies | |
I wish I did not have to have needles and I wish I could get better someday, I do not want to get sick.
Sustainable funding
In 2009, IPPOSI secured a three-year grant from the HRB which matches the funds received by industry members. A patient-led organisation must have a balanced funding stream which reflects the partnership ethos of the organisation. IPPOSI has developed a strong reputation as a patient-led organisation working on policy surrounding access to orphan drugs, access to medicines, HTA training, public attitudes to clinical research and patient registries. Membership from industry remained the same in 2011, a positive signal in difficult times.

Clinical Research
In 2009 through an IPPOSI Clinical Research Think-Tank Group initiative and with the assistance of sponsorship from our industry partners, IPPOSI commissioned market research into public attitudes to clinical research. The research outcome report was launched at the IPPOSI-facilitated "National Strategic Forum for Clinical Research" in Farmleigh, November 2009. The IPPOSI Clinical Research Think Tank decided in 2010 to suggest ways in which this report could be utilised to further support the driving forward of the clinical research agenda in Ireland. The think-tank met with the Minister for Health in 2010 to discuss developing a web portal in partnership with key government stakeholders to provide an information resource to patients and the public on Clinical Research. In 2011, IPPOSI continued to seek funding for a public information portal through industry. Industry members agreed to fund a public/patient information leaflet on clinical research which will be circulated to clinical research facilities and hospitals throughout Ireland in 2012. The FP7 funded EU project; Patient Partners agreed to support this initiative by providing the text for the document which is an outcome from the last three years of their work on developing tools to educate the public.
IPPOSI also partnered with the Medical Research Charities Group (MRCG) in 2011 to facilitate a high level round table on Patient Registries. The roundtable meeting was well attended with representative from key patient organisations, science and industry members, Department of Health officials, Health Research Board experts and staffs from the Data Protection Commission were present. In 2012, IPPOSI will work to disseminate the valuable findings in the outcome report to key decision makers.

- In 2011 IPPOSI submitted on the FORFAS, Research Prioritisation Stakeholder Engagement Document.

- IPPOSI submitted in collaboration with ICRIN on the EU Consultation on the review of the Clinical Trials Directive 2001/20/EC.

- IPPOSI responded to the consultation on FP7 Patient Partner Ethical Principals of Partnership in Clinical Research.

- IPPOSI facilitated a consultation with its members on the HRB framework for biobanking developed by the Health Research Board.

Rare Diseases

IPPOSI has been successful in building on partnerships with key patient groups and other actors involved in rare diseases in Ireland and Europe. Since 2008, IPPOSI has partnered with the Genetic and Rare Disorders Group (GRDO) and the Medical Research Charities Group (MRCG) to effectively drive the rare disease policy agenda. IPPOSI reports and materials have been drawn upon by a variety of stakeholders to enhance understanding of rare diseases and the challenges they present to the key stakeholders. Although not a patient group IPPOSI receives quite a number of requests from rare disease patients looking for reliable information and IPPOSI has endeavoured to assist in this regard by providing information and by linking individuals with groups and entities that can help. IPPOSI launched a patient video channel in 2010 and promoted this channel in 2011. IPPOSI was a co-organisers of the Europlan conference scheduled for December 2010 but due to weather conditions took place in January 2011.

The outcome report from this conference was disseminated and used in 2011 by IPPOSI to stimulate the development for a National Strategy for Rare Diseases.
The report was particularly useful in the work of the CEO with the Department of Health Steering Group on Rare Diseases. In April 2011, the CEO of IPPOSI was appointed by the Minister of Health to the Department’s steering group. The CEO chairs a subgroup on that committee on orphan drug policy in Ireland. Considerable time has been given to the Steering Group by the CEO, most notably in presenting a paper *Orphan Drugs and New Technologies Policy in Ireland Today and Recommendations for the Future*. The Steering Group organised a major consultation exercise in 2012 and IPPOSI was one of the key organisers of the consultation.

IPPOSI also partnered with UCD Medical School in 2011 to develop a 20-week rare disease module for medical students where patients and scientists lecture students on a variety of rare diseases. The module began in January 2012.

**BBMRI Stakeholder Forum**

The preparatory phase of the BBMRI (Biobanking and Biomolecular Resources Research Infrastructure) Stakeholder Forum came to its end in January 2011. IPPOSI CEO administered the final reporting commitments.

**EUPATI**

In 2011, IPPOSI became a partner in an exciting consortium proposal for the third call of the Innovative Medicines Initiative. The European Patient Academy in Therapeutic Innovation (EUPATI) is led by the European Patient’s Forum and includes other European patient and academic umbrella groups, academics and industry. The expression of interest was approved in the last quarter of 2011. IPPOSI will secure €114,000 over five years and contribute to Workpackage 2 and lead a taskforce in WP2.
Partnerships in 2011

- IPPOSI has developed a working arrangement with the Irish Medicines Board (IMB) and in the summer of 2011 invited Dr. Pat O’Mahony, IMB to speak to the IPPOSI membership about their plans to engage with patient groups through IPPOSI. Eibhlín Mulroe, IPPOSI CEO has also been appointed to the Consultative Forum on Legal Classification of Medicinal Products.

- IPPOSI CEO Eibhlin Mulroe was appointed to the HSE’s Patient Forum set up by Dr Barry White, HSE Director of Clinical Care.

- IPPOSI CEO Eibhlin Mulroe was appointed to the HIQA Advisory Board on Research Ethics in 2011 and this will form part of the work plan in 2012.

- In 2011, IPPOSI and HIQA partnered with GSK to provide accessible training on Health Technology Assessments (HTA) to patient groups, industry and clinicians/researchers. The report from this meeting will be presented to key opinion leaders in 2012 and it is hoped that the partnership will continue.

- The CEO of IPPOSI was appointed to the HIQA Advisory Board on HTA providing a patient perspective.

- IPPOSI CEO was appointed to the GSK Healthcare Media Award Judging Panel in 2011 and subsequently spoke at the ceremony to the gathered healthcare media. Topics covered included: Patient perspectives on access to clinical trials, rare diseases and access to medicines.

- IPPOSI CEO appointed to UCD SSRA Poster Adjudication Panel.
Awareness of IPPOSI’s work

In 2011, IPPOSI carefully managed its budget and a proposal was made to the Board to employ a Communications Officer to assist in disseminating the work of IPPOSI and to provide valuable information on key initiatives to a wider audience.

The CEO will continue to be involved in presenting on key initiatives to industry-specific audiences, patient groups, academics, clinical research students and EU audiences at home and abroad.

IPPOSI has increased its brand awareness in Europe as a result of the success of the consortium partnership in the IMI EUPATI consortium, the benefits of IPPOSI’s involvement in this project will evolve in 2012 and 2013.

In 2011 the IPPOSI Patient Video Channel was promoted as an education tool to the Royal College of Surgeons in Ireland, UCD Medical School teaching staff and to the Irish Research Nurses Network. Requests for inclusion in the IPPOSI e-communication mailing lists continued to steadily increase as did the readership of IPPOSI newsletters and e-alerts. IPPOSI has received sizeable feedback on the value and quality of these communications and how they have enabled organisations to inform and enhance their own activity.
**ACCOUNTS**

**Irish Platform for Patients' Organisations, Science and Industry Limited**  
(A Company Limited by Guarantee and not having a Share Capital)

**Balance sheet**  
**as at 31 December 2011**

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>€</th>
<th>2010</th>
<th>€</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fixed assets</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tangible assets</td>
<td>8</td>
<td>-</td>
<td>69</td>
<td></td>
</tr>
<tr>
<td><strong>Current assets</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debtors</td>
<td>9</td>
<td>90</td>
<td>5,584</td>
<td></td>
</tr>
<tr>
<td>Cash at bank and in hand</td>
<td>136,676</td>
<td>117,863</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>136,766</td>
<td>123,447</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Creditors: amounts falling due within one year</strong></td>
<td>10</td>
<td>(24,351)</td>
<td>(48,623)</td>
<td></td>
</tr>
<tr>
<td><strong>Net current assets</strong></td>
<td></td>
<td>112,415</td>
<td>74,824</td>
<td></td>
</tr>
<tr>
<td><strong>Total assets less current liabilities</strong></td>
<td></td>
<td>112,415</td>
<td>74,893</td>
<td></td>
</tr>
<tr>
<td><strong>Net assets</strong></td>
<td></td>
<td>112,415</td>
<td>74,893</td>
<td></td>
</tr>
<tr>
<td><strong>Reserves</strong></td>
<td></td>
<td>112,415</td>
<td>74,893</td>
<td></td>
</tr>
<tr>
<td>Revenue reserves account</td>
<td>112,415</td>
<td>74,893</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Members' funds</strong></td>
<td>11</td>
<td>112,415</td>
<td>74,893</td>
<td></td>
</tr>
</tbody>
</table>

**Income and Expenditure Account**  
**for the year ended 31 December 2011**

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>€</th>
<th>2010</th>
<th>€</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Continuing operations</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td>2</td>
<td>198,182</td>
<td>289,976</td>
<td></td>
</tr>
<tr>
<td>Expenditure</td>
<td></td>
<td>(160,859)</td>
<td>(309,203)</td>
<td></td>
</tr>
<tr>
<td>Surplus/(deficit) on ordinary activities before interest</td>
<td>37,323</td>
<td>(19,227)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other interest receivable and similar income</td>
<td>199</td>
<td>136</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surplus/(deficit) on ordinary activities before taxation</td>
<td>37,522</td>
<td>(19,091)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tax on surplus/(deficit) on ordinary activities</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retained surplus/(deficit) for the year</td>
<td>37,522</td>
<td>(19,091)</td>
<td></td>
<td></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.
MEMBERSHIP 2012

The IPPOSI membership is made up of patients’ organisations, individuals from the scientific and research community and Industry members.

Patients’ Organisations:
22q11 Support Group Ireland
Alpha One
Alzheimers Society of Ireland
Ankylosing Spondylitis Association of Ireland (ASAI)
Arthritis Ireland
Bee For Battens, The Saoirse Foundation
Cystic Fibrosis Association of Ireland
Cystic Fibrosis Registry of Ireland
Cystinosis Foundation of Ireland
DEBRA Ireland
Dercum Disease Patient
Diabetes Action
Diabetes Federation of Ireland
Duchenne Ireland
Ehlers Danlos Syndrome
EPOS
Fabry Ireland
Federation of European Scleroderma Associations
Fighting Blindness
Friedreich's Ataxia Society Ireland
Genetic & Rare Disorders Organisation (GRDO)
Hospice Foundation
Huntingon’s Disease Association of Ireland
Ileostomy & Internal Pouch Support Group
IMD Action Group
Irish Cancer Society
Irish Fragile X Society
Irish Haemophilia Society
Irish Kidney Association
Irish Lupus Society
Irish ME/CFS Association
Irish Motor Neurone Disease Association (IMNDA)
Irish Osteoporosis Society
Irish Premature Babies
Irish Sarcoidosis Support Network (ISARC)
Irish Society for Mucopolysaccharide Diseases MPS
MPS Society
Medical Research Charities Group (MRCG)
Multiple System Atrophy (MSA)
Muscular Dystrophy Society of Ireland Ltd
Myasthenia Gravis Association
National Adult Literacy Agency (NALA)
OvaCare
Parkinson’s Association of Ireland
Prader-Willi Syndrome Association (PWSAI)
Raynaud’s & Scleroderma Ireland
Rett Syndrome Association of Ireland

Industry:
Abbott
Alexion
Bayer
BioMarin
Celgene
Genzyme
GSK
Janssen-Cilag
MSD
Novartis Ireland Limited
Pfizer
Sanofi
Shire Pharmaceuticals Ltd
Individual science and research members from:

Beaumont Hospital
Belfast City Hospital
Biobank Ireland Trust
Childrens University & Mater Hospitals & UCD
Clinical Research Centre Beaumont Hospital
CSTAR
Department of Public Health, HSE - Southern Area
Dr Steevens Hospital
Dublin Dental School & Hospital
EMA Paediatric Committee
HSE South - Department of Public Health
Mater University Hospital - National Pulmonary Hypertension Unit
Mater University Hospital
Midland Regional Hospital
Molecular Medicine Ireland
National Centre for Pharmaeconomics - St, James
National Children’s Research Centre (NCRC)
National Cancer Registry (NCRI)
NUI Galway
OHCAR - the National Out-of-Hospital Cardiac Arrest Register
Our Lady’s Childrens Hospital Crumlin (OLCHC)
Oncology Clinical Trials Cork University
Perinatal Ireland
Royal College of Surgeons Ireland (RCSI)
Regional Immunology Service The Belfast Trust
Research Foundation, Royal Victoria Eye & Ear Hosp.
Royal Victoria Eye & Ear Hospital
School of Health Sciences
Science Foundation Ireland (SFI)
Science Foundation Ireland (SFI) - Discover Science & Engineering
St. James Hospital
St. Vincent’s University Hospital
TCD
TCD/Adelaide & Meath Hospital
TCD - School of Nursing & Midwifery
The Children's Medical & Research Foundation (CMRF)
The Mater Foundation
The Research Foundation Royal Victoria Eye & Ear Hosp
Tril - Technology Research for Independent Living
UCD
UCD Clinical Research Centre St. Vincent’s Hospital
UCD Conway Institute
UCD Medical Genetics Research Group
UCD Research
UCD School of Law
UCD School of Medicine and Medical Science