2016 was a memorable year for IPPOSI and for our membership. It was the first year under our new four-year strategy, developed following a comprehensive strategic review, led by the IPPOSI board of directors.

The implementation of the new strategy was bolstered by a very positive international review of our associated business plan (2016-2020), a return to a multi-annual funding model from the Department of Health, via the Health Research Board, as well as increasing membership.

All of which is a demonstration of confidence in IPPOSI, a recognition of the organisation’s value to the patient, science, industry and policy communities, and has resulted in a ramping up of our ambitions and activity levels.

Already we saw evidence of this in 2016 with achievements including the establishment of new priority areas, new training and engagement initiatives, a new IPPOSI website and communications channels, while still remaining faithful to the core principle IPPOSI is founded on: patient-led partnerships.

2016 will be remembered for the celebration of our 10-year anniversary in October. The atmosphere at the event in Dublin Castle was both exciting and poignant, thanks in no small part to the presence of long-time IPPOSI supporters, members, past chairpersons, and also some new friends. Many memories were shared and (happy) tears were shed.

Through our motivated executive team, IPPOSI continues to punch far above its weight in terms of the influence it exerts, the quality of its events, and the outputs it produces. We are in a confident position for 2017 and undergoing a period of growth and optimism for our future.

We 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 know that patients can lead the agenda.

It was another year of loyal support from our membership in all our activities, and we would like to extend our thanks for your continued support. We look forward to more enlightening discussions, partnerships and new thinking going forward into 2017 and beyond.

Dr Tomás Carroll, Chairperson
Dr Derick Mitchell, CEO
<table>
<thead>
<tr>
<th>Month</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>JAN</td>
<td>STRATEGY DEVELOPMENT</td>
</tr>
<tr>
<td>MAR</td>
<td>NCPE TRAINING DAY</td>
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<tr>
<td>MAY</td>
<td>FUTURE HEALTH SUMMIT</td>
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<td>FEB</td>
<td>RARE DISEASE DAY</td>
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<td>APR</td>
<td>BIOSIMILARS</td>
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<tr>
<td>JUN</td>
<td>eHEALTH ROUND TABLE MEETING</td>
</tr>
<tr>
<td>JUL</td>
<td>HTA TRAINING DAY</td>
</tr>
<tr>
<td>AUG</td>
<td>INTERNATIONAL SOCIETY FOR PHARMACO-EPIDEMILOGY</td>
</tr>
<tr>
<td>SEPT</td>
<td>DCU ALPHA HACKATHON</td>
</tr>
<tr>
<td>OCT</td>
<td>IPPOSI 10</td>
</tr>
<tr>
<td>DEC</td>
<td>HISI CONFERENCE</td>
</tr>
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</table>
Developing the new strategy was an invigorating process that involved a membership-wide consultation, followed by a number of strategy sessions that honed membership and board member feedback and resulted in the following revised vision, mission and strategic priorities:

**IPPOSI High Level Strategy (2016-2020)**

**Vision**
Early, equitable access to Health Innovation for improved patient outcomes

**Mission**
We are the collective voice of Patients, Science and Industry in enabling meaningful involvement in, and improved access to, Health Innovation

**Strategic Priorities**
- Build IPPOSI brand and profile as a consensus-building group that influences access to Health Innovation
- Actively advocate through our patient-led perspective for improved and equitable patient access to Health Innovation
- Promote meaningful patient involvement in Health Research and Policy

**Principles**
Building consensus; Contributing constructively; Developing evidence-based positions; Providing call-to-actions; Empowering patients

These priorities helped us develop the following goals:

**Goal 1:** Position IPPOSI as the collective voice of Patients, Science and Industry in enabling involvement in, and improving access to Health Innovation

**Goal 2:** Raise understanding of patient issues related to access to health innovation, with IPPOSI seen as a key player in developing solutions

**Goal 3:** Create a cohort of patients and patient advocates who are trained, and playing an increased role in health research and policy

**Goal 4:** Be leaders in influencing health reform, regulation, legislation related to the IPPOSI strategy
Training & patient involvement

IPPOSI continued to bring a patient perspective to health research through its dual approach of preparing both the research environment to accept the input of patients, and preparing patients to provide that input in an informed way.

The highlight of our year in this area was the ‘Patients Driving Health Innovation’ Conference, which took place in Dublin Castle in October. This was a special event that tied together the conference, our AGM, and a celebration of IPPOSI’s 10-year anniversary. It was an event to remember with contributions from the Department of Health’s Secretary General Mr Jim Breslin, Mr. Alastair Kent of Genetic Alliance UK, as well as a number of Irish patients and patient organisations who are driving health innovations in a number of key IPPOSI priority areas. It was energising to experience the support and affection that IPPOSI enjoys among the Irish health community and we will treasure this event as a reminder of that fact over the next decade.

In terms of Public & Patient Involvement (PPI) in Health Research, IPPOSI was involved in two new national events this year – the PPI in Research event in Galway in April, led by the HRB-Primary Care Clinical Trials Network and the PPI Summer School in June in the University of Limerick. A number of the EUPATI fellows led many of the interventions at these events, helping to bring PPI alive for new audiences of researchers, patients and health students. In addition, the IPPOSI CEO chaired a panel at the MRCG event on ‘PPI in Research’ and continued to work on an almost daily basis to create meaningful PPI opportunities for Irish patients.

Ending the year was our ‘Clinical Research for non-Clinical Researchers’ training day that took place in December. This year we welcomed a host of new contributors (and participants) including Dr Tim Grant from StatisticaMedica, Dr Blanaid Mee from Biobank Trust Ireland, Dr Ruben Keane from UCC, Deirdre Hyland of RCSI, and Dr Rob O’Connor from the Irish Cancer Society.

Other PPI initiatives that included IPPOSI participation was the Irish Health Research Forum in May, the IRNN ‘putting research into practice’ meeting in November, and we took part in the Exploratory Clinical Development Conference in Berlin in October to explore ways to involve patients in research at the earliest possible stages of research. IPPOSI also acted as a mentor at the MIT-DCU Alpha’s Health Hackathon in September, where Irish patients and researchers explored connected health solutions to ongoing health / health delivery problems.

EUPATI

2016 was the final year of the five-year EUPATI project (in its original IMI form) and the programme is continuing on under the umbrella of the European Patients Forum. The IMI project culminated in an excellent conference in Brussels in December which IPPOSI was heavily involved in. It was wonderful to see the nine Irish-based EUPATI fellows graduate through the Expert Patient Training Programme. That’s nine of out a total of 97 expert patients from all over Europe seeking to drive meaningful patient involvement in medicines R&D. Not a bad result for Ireland!

February 2016 saw the launch of the EUPATI Toolbox (www.eupati.eu). This is a massive online resource of more than 3,000 user-friendly web pages, presentations, and videos about every element of clinical research. This toolbox was adapted from the course material of the Patient Expert Training Course, thereby allowing patients in Ireland and all over Europe to understand the research process and thus engage with it more effectively. IPPOSI played a significant role in the development of the Toolbox by being one of the patient members of an editorial board that reviewed every piece of content from a patient’s perspective, and will continue in this role as part of the EPF-led programme.

On the national level, the Irish EUPATI National Platform met three times in 2016 and it was great to see the EUPATI fellows host an Irishled tweet chat around the topic of ‘Expert Patients’. This is precisely the sort of leadership that EUPATI was meant to inspire in patients. IPPOSI meanwhile led the EUPATI National Platform workshop in Berlin in June, bringing together 18 IPPOSI-like national platforms to share experiences and practices in their countries.

Overall, IPPOSI has played a central role in the roll-out of EUPATI project as a leader, exemplar and influencer on the European stage. As EUPATI moves into a new phase, with a new funding model, and objectives more appropriate to its capacity, IPPOSI continues to play a leading role.

HRB-CRCI and HRB-TMRN

In April 2016 IPPOSI chaired the first meeting of a PPI Working Group in Clinical Research, in partnership with Clinical Research Coordination Ireland (HRB-CRCI). This working group consists of IPPOSI board members, the network of Clinical Research Centres/Facilities in Ireland, as well as CRCI and IPPOSI representatives. The group is working collaboratively on a number of activities under the CRCI and IPPOSI umbrellas, to promote active PPI as part of the infrastructure for clinical research in Ireland. The group continues to meet on a quarterly basis, usually in one of the CRCs/CRFs around Ireland. Information on this group is available on the IPPOSI website.

IPPOSI and HRB-TMRN (HRB-Trials Methodology Research Network) collaborated on the HRB-and James Lind Alliance-funded Priority (Prioritising Recruitment in Randomised Trials) Project which is designed to create the top 10 unanswered questions in relation to recruitment to randomised trials in Ireland and the UK. The top 10 list is
Health Information

IPPOSI devoted considerable resource to this area in 2016. A health-information-related theme informed our Annual Round Table meeting in June with the Dept. of Health. Under the theme of ‘Person-centred eHealth’, the event was run in partnership with eHealth Ireland, and was followed by a meeting of the eHealth Ireland Committee, of which the IPPOSI CEO is a member.

This meeting drew participation from a wide range of IPPOSI members who travelled to Farmleigh House in Phoenix Park to interact with a number of speakers that included Muiris O’Connor (Department of Health), Richard Corbridge (eHealth Ireland), Dr Graham Love (HRB), Brian O’Mahony (Irish Haemophilia Society), Dr Aine Carroll (HSE), Professor Martin Curley (Intel), and Scott Henderson from the Scottish Centre for Telehealth and Telecare.

The first session addressed the policies that are necessary to support person-centred eHealth, while the second session provided patient, clinical and industry perspectives on the topic. As ever there was an engaged audience who took full advantage of opportunities to ask questions of the speakers and interrogate the question of eHealth in terms of their own concerns. The meeting was followed quickly by the publication of a popular Outcome Report emphasizing that keeping the person at the centre of every eHealth initiative was vital for its ultimate success.

In November, IPPOSI organised a patient-led workshop on electronic health records at the Health Informatics Society of Ireland (HISI) Annual Conference. The workshop title was ‘In Electronic Health Records we Trust?’ and featured a number of excellent contributions, including from Dr Amir Hannan and Ingrid Brindle (Haughton Thornley Medical Centres, UK), Ros Moran (HRB) and Tony Shannon (Ripple OSI). Some 75 conference delegates – including 20 invited IPPOSI patient member contributors took part in the workshop. This work culminated in an Outcome Report that captures a flavour of the discussions that took place, and is available on the IPPOSI website – www.ipposi.ie.

Elsewhere in Health Information, IPPOSI hosted a patient-led workshop at the Future Health Summit in May. The IPPOSI CEO was also a panellist at the third Annual eHealth Summit in September, which focused on data privacy and data protection. Separately, IPPOSI took part in a discussion about the implications of a National Data Dictionary & Data Model at an event hosted by HIQA and the HSE.

Health Innovation

In April, IPPOSI hosted a half-day seminar in the Royal College of Physicians to discuss biologic and biosimilar medicines in the context of what patients need to know about these medicines. The meeting was prefaced by an IPPOSI patient member survey that sought to ascertain patient awareness levels of these medicines, and the survey findings were presented at the seminar.

IPPOSI is grateful to our speakers Joan O’Callaghan (HPRA), Professor Laurence Egan (NUI Galway) and Professor Bjorn Moum from Oslo University Hospital in Norway for their contributions at the seminar, which helped to pave the way for a panel discussion featuring the speakers and Professor Michael Barry from the National Centre for Pharmacoeconomics (NCPE), and John Church (CEO, Arthritis Ireland)

The seminar Outcome Report concluded that patient awareness of biologic and biosimilar medicines was low; that there was little information available to patients to address this; and that biosimilars have the potential to provide benefits in terms of cost savings.

Rare Diseases

Rare Diseases continues to be a major focus for IPPOSI and in 2016 IPPOSI partnered with the MRCG, and Rare Disease Ireland (formerly GRDO) to organise the 2016 Rare Disease Day event, which took place in Dublin Castle. This awareness event was a great success with over 150 attendees, and garnered significant media coverage in the national print and broadcast media.

The event itself was very well attended by the Irish and Northern Irish rare disease communities and speakers on the day included the IPPOSI CEO Derick Mitchell, Richard Corbridge, Eilish Hardiman, CEO of the Children’s Hospital Group. There were also contributions from Philip Watt (CF Ireland and Chair of the Rare Disease Taskforce), Professor Kevin Mitchell (Genetics, TCD) and Rachel Martin of the Marfan Syndrome Support Group Ireland, who gave a compelling patient perspective of having a rare disease in Ireland. Rare Disease Day continues to be an excellent rallying point for patients, advocates and policy-makers to meet on an annual basis.

Elsewhere under this heading, IPPOSI continues to be an active member of the Rare Disease Taskforce, and the Oversight Committee for the Implementation of the National Rare Disease Plan. Our focus is very much on access to, reimbursement of, medicines, treatments and innovations that exist for people with rare diseases.

IPPOSI

Actively advocate for improved, equitable access to health innovations
Submissions
IPPOSI made a number of additional submissions in 2016, including:
- The work of the Oireachtas Committee on the Future of Healthcare
- The Health Research Board PPI Ignite consultation
- The Individual Health Identifier Public Consultation

HTA Training
The 2016 IPPOSI HTA training event took place in July this year, in EU House, Dublin 2. We had a great line-up of speakers, including Professor Michael Barry (NCPE), Philip Watt (CF Ireland), Jennifer Dickson (Scottish Medicines Consortium), Yvonne Hughes (Cystic Fibrosis Trust, UK) and Claire Gorry (NCPE). It was a very informative session that provided valuable insights of how HTA and reimbursement is conducted in other jurisdictions, and how the question of transparency might be tackled in Ireland.

In March, IPPOSI presented at the annual NCPE Training Event, and IPPOSI wishes to thank both the NCPE and a number of industry members for facilitating the attendance of four IPPOSI patient members at the event.

Actively advocate for improved, equitable access to health innovations

Photos from 2016
Internationally, IPPOSI’s work on the EUPATI project continues to maintain a large degree of awareness of our organisation among key European and international groups. This year the launch of the EUPATI Toolbox in February and the EUPATI conference in December helped to showcase the central European role that IPPOSI plays in the sphere of patient involvement.

Domestically, IPPOSI continued to deliver strategic presentations, events, which also generate media coverage to inform key audiences of our work. As can be seen below, IPPOSI continues to deliver a high volume of presentations to a range of key audiences and influencers. IPPOSI representatives made a number of other presentations in 2016, including:

- INSIGHT / BBMRI Biobanking & Data Analytics event (Jan)
- 12th National Health Summit (Feb)
- NCPE Training Programme (March)
- Annual Conference of the Irish Pharmacy Union (April)
- 4th National Medicines Forum, (May)
- Heart Failure Patient Alliance, Croi, Galway, with EUPATI fellow Noirin O’Neill (May)
- PPI Summer School, UL (June)
- International Society for Pharmaco-Epidemiology - plenary session (Aug)
- 3rd Annual eHealth Summit (Sept)
- MRCG PPI in Research meeting, (Sept)
- European Federation of Neurological Associations Training day (Oct)
- HRB National Conference (Nov)
- IRNN - ‘putting research into practice’ (Nov)
- EUPATI Annual Conference (Dec)

**Website**

In December 2016 IPPOSI unveiled a new, revamped and modernised website that is now the focal point and repository for much of what IPPOSI does online and offline. The new website includes:

- An introductory animated video – ‘Our Story’ – that explains the purpose of IPPOSI
- Specific sections for attracting new members to join IPPOSI
- A comprehensive structure, and showcasing tool (the Our Work ‘super-menu’) that quickly allows users to explore the breadth of what IPPOSI does
- New ‘resources’ and ‘publications’ sections that chart the work we have done and outputs we have produced in IPPOSI priority areas

**Social media**

- Twitter – our followers increased by more than 50% in 2016.

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**Building IPPOSI brand as consensus-building group influencing access to health innovation**

- SlideShare – Uploaded 31 presentations in 2016 (12,700+ views; 350 downloads)
- Facebook – increased ‘likes’ and engagements and grew number of posts
- Vimeo – ten new videos in 2016, including animated clips, vox pops and several live presentations
- Flickr online photo album – 7 albums of event photographs

**Webinars**

IPPOSI / EUPATI hosted two webinars in 2016:

- EUPATI Toolbox launch (Feb)
- MIT-DCU Alpha Hackathon (Sept)

**Publications**

- Three new Outcome Reports
  - Biologics & Biosimilars
  - Person-centred eHealth
  - HISI Workshop Report
- Priorities & Impacts Brochure
- PPI discussion papers on Patient Reported Outcomes and HTA

**Media**

Highlights for 2016:

- Clinical Trials, Irish Times – November 2016
- Patients Driving Health Innovation, Irish Times – October 2016
- Person-centred eHealth, Irish Times - July 2016
- EUPATI Toolbox, Irish Times – February 2016
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 patient organisation.

The Board of Directors

The Board of Directors of IPPOSI met 5 times in 2016. 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 spending, 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 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 2016 is available in this report.

EUPATI National Platform, Ireland

All IPPOSI members are members of the EUPATI National Platform in Ireland (the national network of the European Patients’ Academy for Therapeutic Innovation). A subcommittee of the Board oversees the management of the EUPATI National Platform and helps sets the strategic direction around patient involvement in Irish medicines research and development. The subcommittee is led by a patient chairperson, and supported by several other patient, academic and industry representatives.
IPPOSI Board Members 2016

Dr Tomás Carroll
Alpha One
Chairperson, IPPOSI

Mr Philip Watt
The Cystic Fibrosis Association of Ireland

Mr Hugh Hardiman
Bayer

Mr John Church
Arthritis Ireland

Deirdre Hyland
Royal College of Surgeons Ireland

Ms Ava Battles
MS Ireland

Prof Seamas Donnelly
TCD

Mr Godfrey Fletcher
Cystic Fibrosis Registry of Ireland

Dr Jason Last
UCD School of Medicine

Ms Averil Power
Asthma Society

Ms Paula Guerin
AbbVie

Mr Kevin Whelan
Fighting Blindness

Mr Martijn Akveld
GSK

Dr Rob O’Connor
Irish Cancer Society

Dr Catherine Darker
TCD

Ms Karen O’Keeffe
Pfizer

Ms Susanne O’Reilly
Novartis

Mr Tom O’Leary
ICON

Ms Ava Battles
MS Ireland

Prof Gaye Stephens
Trinity College Dublin

Ms Averil Power
Asthma Society

Ms Paula Guerin
AbbVie

Mr Kevin Whelan
Fighting Blindness

Mr Tom O’Leary
ICON

Prof Gaye Stephens
Trinity College Dublin
### Profit and loss account

**Financial year ended 31 December 2016**

<table>
<thead>
<tr>
<th>Note</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>€</td>
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<tr>
<td>Turnover 4</td>
<td>296,683</td>
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<tr>
<td>Direct costs</td>
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<td>(221,860)</td>
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<td>Gross profit</td>
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<td>Administrative expenses</td>
<td>(51,506)</td>
<td>(68,334)</td>
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<td>Operating (loss)/profit 5</td>
<td>(16,363)</td>
<td>36,292</td>
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<tr>
<td>Other interest receivable and similar income 7</td>
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<td>30</td>
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<tr>
<td>(Loss)/profit on ordinary activities before taxation</td>
<td>(16,334)</td>
<td>36,322</td>
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<td>Tax on (loss)/profit on ordinary activities</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>(Loss)/profit for the financial year</td>
<td>(16,334)</td>
<td>36,322</td>
</tr>
</tbody>
</table>

All the activities of the company are from continuing operations.

The company has no other recognised items of income and expenses other than the results for the financial year as set out above.

### Balance sheet

**As at 31 December 2016**

<table>
<thead>
<tr>
<th>Note</th>
<th>2016</th>
<th>2015</th>
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<tbody>
<tr>
<td></td>
<td>€</td>
<td>€</td>
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<tr>
<td>Fixed assets</td>
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<td>Tangible assets</td>
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<td>904</td>
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<tr>
<td></td>
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<td>904</td>
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<tr>
<td>Current assets</td>
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<tr>
<td>Debtors</td>
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<tr>
<td>Cash at bank and in hand</td>
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<td></td>
<td>170,205</td>
<td>223,498</td>
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<tr>
<td>Creditors: amounts falling due within one year</td>
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<td>(56,691)</td>
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<tr>
<td>Net current assets</td>
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<td>128,319</td>
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<tr>
<td>Total assets less current liabilities</td>
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<tr>
<td>Net assets</td>
<td>114,418</td>
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<td>Capital and reserves</td>
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<tr>
<td>Profit and loss account</td>
<td>13</td>
<td>114,418</td>
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<tr>
<td>Members funds</td>
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<td>130,750</td>
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