

**THE SOCIETY FOR THE STUDY  
of  
INBORN ERRORS OF METABOLISM**

**NOTICE OF  
ANNUAL GENERAL MEETING – 2017**

to be held in

Rio de Janeiro

on

Wednesday 6th September 2017

at 12.45 p.m.

Dr Manuel Schiff  
Honorary Secretary

**THE SOCIETY FOR THE STUDY  
of  
INBORN ERRORS OF METABOLISM**

**ANNUAL GENERAL MEETING – 2017**

**AGENDA (Chair: Prof G S Salomons)**

1. To receive the minutes of the previous meeting held on Wednesday 7th September 2016 in Rome, Italy
2. Matters arising from the previous meeting
3. Honorary Treasurer's Report
4. Honorary Secretary's Report
5. JIMD Report
6. ETAC (Education, Training & Advisory Committee) Report
7. MetabERN
8. SSIEM – Special Interest Groups
9. Future SSIEM Symposia
10. IOC Report
11. Council Officers/Election of Council Members
12. Any other business



# HONORARY SECRETARY'S REPORT 2016-2017

## MEMBERSHIP

The membership at the end of 2016 had grown by just over 2.2% over the previous year and by more than 29% since the end of 2010. This was the first year of the new two-tier subscription rate being applicable to “high income countries” and the “rest of the world” and the standard rate of membership subscription is applied to those countries in the high income group as identified by the World Bank List of Economies. Also the categories increased to keep the SSIEM more accessible and affordable on a global scale. Membership came from 76 different countries.

Council remains very aware of the burden that the subscription may have on individuals in different countries, associated with the different pay scales of many of its members. A standard rate applies for membership subscription to citizens from the high income countries as identified by the World Bank List of Economies and a reduced rate to citizens from all other countries, making membership of the SSIEM more accessible and affordable on a global scale. A reduced fee was set for those who do not fit the category of the standard rate (i.e. fully qualified, tenured position applicable to physician, researcher, scientist, geneticist or equivalent). This scheme is deemed to be fair and equitable for all its members in the differing specialties and countries. The total revenue did not change significantly. The membership support scheme will remain in place for those requiring subscription support.

## COUNCIL

Council met on four occasions during the year; three times in London and once in Rome, under the Chairmanship of Prof P T Clayton until September 7th and Prof G S Salomons from September 7th. On September 7th 2016 during the annual general meeting, the chairman stated that he was stepping down and as decided at the 2015 AGM Prof Gajja Salomons was becoming the new chairman. The Chairman announced that Dr Manuel Schiff had been coopted as Honorary Secretary elect in March 2016 to become Honorary Secretary in September 2016, this was seconded by Cornelis Jakobs and carried by a show of hands unanimously by the members. The chairman announced that also Prof C Dionisi Vici (CDV), Prof B Plecko (BP) and Prof C Vianey Saban (CVS) resigned in September 2016. The changes in the composition of Council members were proposed by the Chairman to be as followed: Dr V Valayannopoulos, Chairman ETAC (Ex-officio) resigned in September 2016 and would be replaced by Dr A A M Morris, Chairman ETAC (Ex-officio). CDV, BP and CVS would be replaced by Dr J Häberle, Dr F Mochel and Prof H Michelakakis. This was proposed and seconded by Prof Ron Wevers and Prof Christine Vianey Saban respectively and carried by a show of hands unanimously by the members.

Membership of Council for 2016-2017 comprised of: Prof G S Salomons (Chairman), Dr M Schiff (Honorary Secretary), Ms A Y Brown (Honorary Treasurer), Prof I Baric, Dr J Häberle, Dr F Mochel and Prof H Michelakakis, Prof K Ounap, Dr A Ribes, Prof U Spiekerkötter, Ms A M J van Wegberg, Prof E Morava (Editor-in-Chief JIMD, Ex-Officio) and Dr A A M Morris (Chairman ETAC, Ex-Officio).

The Council has updated the detailed risk assessment relating to the Society's activities and it is reviewed on a regular basis. A new grant was installed to support patient carrier groups which was led by Dr J Häberle.

Mr N Law and the administration team at the Society's Registered Office at 130-132 Tooley Street, London have provided Council and the membership with invaluable support throughout the year.

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# Honorary Secretary's Report

## ADVISORY COUNCIL MEMBERS

Council appreciated the support and comments from individual Advisory Council members during the year. Advisory Council members can play an important role in choosing the venue for the Annual Symposium and in providing nominations for Council. Advisory Council members for 2016-2017 were:

Dr J M Fletcher (Australasia), Prof Dr D Karall (Austria), Dr J Songailiene (Baltic Countries), Dr M-C Nassogne (Belgium), Dr G A Mitchell (Canada), Prof K Fumic (Croatia), Dr P Martasek (Czech Republic/Slovakia), Dr A M Lund (Denmark), Dr R J Lapatto (Finland), Dr D Dobbelaere (France), Prof Dr R Santer (Germany), Dr H Michelakakis (Greece), Dr J Hui (Hong Kong), Dr S Bijarnia-Mahay (India), Dr T Z Zaman (Iran), Ms P Fitzsimons (Ireland), Prof Y Anikster (Israel), Dr A B Burlina (Italy), Prof H Ida (Japan), Prof L Chabraoui (Morocco), Dr B Woldseth (Norway), Prof J Sykut-Cegielska (Poland/Russia/Hungary), Prof M I Tavares de Almeida (Portugal), Prof L A Barrera (South America), Dr A García-Cazorla (Spain), Dr A Nordenstrom (Sweden), Dr M Baumgartner (Switzerland), Dr J-Y Wu (Taiwan), Prof N M Verhoeven Duif (The Netherlands), Prof Dr T Coskun (Turkey), Dr R Lachmann (United Kingdom), Dr B A Barshop (United States of America).

## 2016 ANNUAL SYMPOSIUM

The 50th SSIEM Symposium was held in Rome, Italy, organised on behalf of the Society by the LOC President Prof C Dionisi-Vici together with the Organising Committee, the PCO ALFA FCM SRL and SSIEM Corporate Liaison Officer Mr R Kerschbaumer. Prof C Dionisi-Vici and the partners are to be congratulated for hosting a most successful scientific meeting and social programme. The Symposium was attended by more than 2,877 delegates (55% Europeans) from in total 83 different countries. The meeting was supported by 29 corporate partners, nine of whom sponsored meet the expert sessions. The Komrower Memorial lecture was delivered by Prof M Zeviani entitled 'Mitochondrial Disorders: A journey through the magic circle'. Dr S Rahman was awarded the Archibald Garrod Medal for her paper "Paediatric single mitochondrial DNA deletion disorders: an overlapping spectrum of disease" which was published in the May issue of our society journal (*Journal of Inherited Metabolic Disease* 2014; **38**(3): 445-57).

## FUTURE SSIEM and ICIEM SYMPOSIA

The following are the venues for future SSIEM Symposia:

- ICIEM International Congress, Rio de Janeiro, Brazil, 2017
- SSIEM Annual Symposium, Athens, Greece, 2018
- SSIEM Annual Symposium, Rotterdam, The Netherlands, 2019
- SSIEM Annual Symposium, Freiburg, Germany, 2020
- ICIEM International Congress, Sydney, Australia, 2021
- SSIEM Annual Symposium, 2022, BID will be announced in early 2018

## TRAINING

The 10th SSIEM Training Academy took place in Lyon, France in April 2017, covering Organic Acidaemias, Fatty Acid Oxidation defects, and Metabolic Causes of Cardiomyopathy. This was the second meeting in the third four year training cycle. The number of applications (123 for the 80 places) was similar to previous years, with slightly more applications from clinicians (66) than scientists (57). The majority of those who attended came from Europe (22 countries, with largest numbers from France & UK), but others came from the Middle East (Bahrain, Israel, Oman, Saudi Arabia), South America

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# Honorary Secretary's Report

(Argentina, Brazil, Colombia), North America (Canada, USA), Asia (India, Malaysia), North Africa (Morocco, Tunisia) and Australia. The majority of sessions are now workshops and most sessions are held jointly with clinicians and laboratory scientists together; the course concludes with a quiz, which is always well received by those attending. Council acknowledges the contribution of all those who give of their time to teach on the Course and to the officers of ETAC, Dr A A M Morris (Chair), Prof S Heales (Secretary) and Dr S Gardner (Administrator). Two applicants who were too junior for the SSIEM Academy attended the North American Metabolic Course (NAMA) with support from SIMD and SSIEM.

ETAC proposes to hold the 11th SSIEM Training Academy in April 2018 in London, covering disorders lysosomes, peroxisomes, purines & pyrimidines. The current ETAC members are Dr A A M Morris (Chair, leaving 2019), Prof S Heales (Secretary, started 2015), Dr C Vianey-Saban (leaving 2019), Dr J Bierau (leaving 2018), Dr R Carling (started 2016), Dr J Häberle (started 2016) and Dr E Murphy (started 2017).

### **WEBSITE/Society and Conference App**

Council acknowledges the support of Mr M McConnell of Blackcat Websites in maintaining and developing the site as well as that of Mr N Law from the Admin Team. The website is an important mechanism for communicating with the membership and Council would welcome material for inclusion of the site. Mr M McConnell also has a valuable role in the Symposium in 2016, and was extremely helpful with the launch of the SSIEM Conference App (Conference Compass), abstract submission, selection and processing and his contribution is very much appreciated.

### **JOURNAL OF INHERITED METABOLIC DISEASE (JIMD)**

JIMD received its 2016 Impact Factor (IF), and it increased: from 3.541 (2015 IF) to 3.970 (2016 IF). In 2016 there were 4935 citations to 242 items published in 2014 and 2015.

JIMD is currently ranked:

- 38 of 138 titles in Endocrinology and Metabolism (compared to 52/128 last year).
- 43 of 166 titles in Genetics & Hereditary (compared to 55/167 last year).
- 25 of 128 titles in Medicine, Research and Experimental (first year).

JIMD Reports is published as a book and is freely available online after one year. So far no IF has been obtained. Currently council and editors are exploring alternative publishing options.

The editors and council thank all for supporting JIMD. A more detailed report on the Journal is covered elsewhere within this Annual General Meeting (AGM) bulletin. Council appreciates the significant contribution of the Editorial team, the communicating editors and the publishers, Springer, for their commitment in maintaining the continuing success of the Journals.

### **SSIEM SUBGROUPS**

After 5 years, Dr R Lachmann, will step down as Chairman of The SSIEM-Adult Metabolic Physicians' Group. The election of the new Chairman shall take place over the summer 2017. The adult group continues to organise a successful session on adult metabolic disorders on the morning of the opening day of the Annual SSIEM Symposium. A scientific committee (Dr R Lachmann, Prof C Hollak, Dr F Mochel, Dr S Sirrs and Dr M Tchan) has been set up in order to select oral communications for the adult session.

The SSIEM-Dietitians' Group (SSIEM-DG) led by Ms L Robertson, continues to make an important contribution to the organisation of the dietetic component of the scientific programme of the Symposium.

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# Honorary Secretary's Report

## **METAB-ERN**

The EU, from 1st March 2017 on, officially launched the European Reference Network program (ERN). MetabERN is elected and funded by the European Commission as one of the 24 ERNs and is lead by Prof M Scarpa. MetabERN involves 69 European HCPs specialized in IEMs. MetabERN has been intensively structured in 7 different subnetworks each of them working under the same operating frame. SSIEM and MetabERN are fully collaborating. For more details, see <http://www.ssiem.org/centralstore/news/KOKIHEBO938377-06-03-2017.pdf>

*Dr M Schiff*  
*Honorary Secretary*  
*14 July 2017*

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# Honorary Secretary's Report

# HONORARY TREASURER'S REPORT 2016

## INCOME

A new membership fee structure was introduced for 2016 reflecting the need to make the membership fee financially acceptable across member's professions and countries. It was therefore encouraging that the receipt of subscriptions for 2016 exceeded the budget and compared favourably with 2015. A surplus was also realised from the 2016 SSIEM Symposium in Rome, Italy.

Under the contract with the publishers of the JIMD we receive a share of the Royalties; in 2016 Council was pleased to receive €112,005 for 2016, together with editorial expenses of €46,388.

A small income of €10,364 was also generated from modest investments.

The net income for 2016 had increased over the net income of 2015. This is primarily due to the continual success of the SSIEM symposium and the JIMD.

The budget for 2017 reflects a deficit of €148k, this is a conservative estimate. As the ICIEM will be held in Rio de Janeiro in 2017 there will be no symposium surplus. A minimum of €50k set aside for development costs.

## EXPENDITURE

The overall expenditure, excluding the symposium, for 2016 has increased significantly compared to 2015. This is due to the increase in charitable activities and administrative workload:

- Travel scholarship support.
- Support for the Vademecum Metabolicum app.
- An increase in Governance Costs relating to the Society and Symposium.
- Increase in legal advice.
- General expenses.
- MetabERN

Future expenditure 2017:

- Travel support for educational activities
  - Any healthcare professional seeking experience in centres of excellence.
  - ETAC-NAMA collaboration
- ERNDIM-SSIEM collaboration
  - Funding support agreed at 2015 AGM
- Symposium and SSIEM app
- Support for parent support groups or societies.

## BALANCE SHEET

Total amount in accumulative fund increased in 2016, by €54,424 and stands at €2,277,743.

## FINANCIAL POLICY

Publishing and administration – our policy is to cover the majority of the journal and administrative costs from subscriptions paid by members.

Low risk investments are in place to realise a better financial return on our accumulated funds. A financial sub-committee of Council has been created to review the Society's financial activities.

## **RESERVES**

It is the policy of the Society to maintain unrestricted funds, which are the pre-reserves, at a level that is sufficient to cover management, and administration support costs, and allows the Society to be managed efficiently. It is the policy of Council to use some of the unrestricted funds to encourage the sharing of experience and training between Centres. Part of the reserves includes the gift from Prof Komrower which was been invested and the interest on that investment is used to fund expenses relating to the Komrower Lecture. Although the reserves appear substantial, Council has always considered that such reserves be maintained in order to cover the eventuality of a major disaster with an Annual Symposium and also running costs of the Society for 12 months.

The reserves will also be used to develop:

- The SSIEM Academy.
- Future-proof the SSIEM administrative functions.
- Education and practical support for countries introducing investigation and treatment of inborn errors of metabolism.

Those members who have colleagues who find difficulty in joining the society and thereby receive the journal without financial support are encouraged to apply directly to the Hon. Treasurer for a Membership Support Grant for 3 to 5 years.

## **SECRETARIAT**

The SSIEM uses the administrative services of the Association for Clinical Biochemistry and Laboratory Medicine (ACB) in London and has established systems to help the Society in future years.

## **RISK MANAGEMENT**

A thorough risk assessment has been undertaken. The trustees have examined the major strategic, business and operational risks that the Society faces and have established systems so that the necessary steps can be taken to lessen these risks.

## **AUDITORS**

It is proposed that the auditors Buzzacott LLP be reappointed.

A copy of the full accounts are appended to this report and are also available on the SSIEM website.

*Ms A Y Brown  
Honorary Treasurer  
July 2017*

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# Honorary Treasurer's Report

# JOURNAL OF INHERITED METABOLIC DISEASE (JIMD) REPORT 2016-2017

The number of submissions to JIMD and JIMD Reports was similar to 2015 (477 in 2016 vs 498 in 2015). Submissions came from 54 different countries, with the majority from USA (18%), United Kingdom (7%), the Netherlands (7%), Italy (5%), Germany (5%), Turkey (5%) and China (4%). 80 articles were printed in JIMD (original articles, reviews, rapid communications and symposium articles). 75 articles were printed in the online journal “JIMD Reports”. This year the JIMD Impact Factor has increased from 3.54 to 3.97. There are no publication fees for either journal, and all SSIEM members can download all articles published in JIMD or JIMD Reports for free via the homepage. JIMD Reports articles are available for everybody free of charge one year after publication.

**The Archibald Garrod Award 2017** was awarded to Terry Derks, Groningen, The Netherlands for the article “Glycogen storage disease type III: diagnosis, genotype, management, clinical course and outcome”, published in JIMD issue 5, 2016.

**The Communicating Editor Awards 2017** for work in 2016 were presented to Robert Steiner, Ivo Baric and Carlo Dionisi-Vici as busiest Editors, to Jerry Vockley as fastest Editor, and to Christine Vianey-Saban as Guest Editor. Stephanie Grunewald, Markus Grompe and Nicole Wolf decided to step down from the Editorial Board at the end of 2016. We very much welcome Sander Houten, Martina Huemer and Saskia Wortmann as new Communicating Editors (CEs) within the Editorial Team.

We remain indebted to all CEs and reviewers who have added invaluable expertise and invested considerable effort, contributing to the continuing success of the Journal of Inherited Metabolic Disease. A special thanks to them for their great support of the journal during their time as CEs, especially Peter Stenson as Mutation Nomenclature Editor and Lars Morkrid as Statistical Editor.

JIMD is particularly interested in publishing studies that provide a comprehensive, representative analysis of the clinical features, treatment and outcome of an inherited metabolic disease, and such papers also qualify for the annual Archibald Garrod Award. We obviously continue to welcome other articles that provide important novel information about an inherited metabolic disease or relevant research findings, as well as Guidelines, Metabolic Dissertations, Letters to the Editors and Metabolic Images. We are also interested in receiving material for our Extras section.

Follow us on Twitter @JIMD\_Editors

*On behalf of the Editorial Team  
Prof E Morava, Editor in Chief  
Prof M Baumgartner, Prof M C Patterson,  
PD Dr V Peters, Prof S Rahman and Prof J Zschocke*

# REFERENCE AND ADMINISTRATIVE DETAILS

## For the year ended 31 December 2016

### **Trustees**

Prof P T Clayton, Chair (resigned 7 September 2016)  
Prof G S Salomons, Chair (from 7 September 2016, Secretary until 7 September 2016)  
Dr M Schiff, Secretary (appointed 7 September 2016)  
Ms A Y Brown, Treasurer  
Prof I Baric  
Dr C Dionisi-Vici (resigned 7 September 2016)  
Prof J Haberle (appointed 7 September 2016)  
Dr H Micheakakis (appointed 7 September 2016)  
Dr F Mochel (appointed 7 September 2016)  
Dr E Morava-Kozicz (appointed 1 January 2016)  
Dr A A M Morris (appointed 7 September 2016)  
Prof K Ounap  
Prof B Plecko (resigned 7 September 2016)  
Dr A Ribes  
Prof U Spiekerkötter  
Dr C Vianey-Saban (resigned 7 September 2016)  
Dr V Valayannopoulos, Chairman ETAC (Ex-officio) (resigned 7 September 2016)  
Ms A M J van Wegberg  
Prof J Zschocke, Editor in Chief JIMD (Ex-officio) (resigned 1 January 2016)

### **Company Registered Number**

02567711 (England and Wales)

### **Charity Registered Number**

1010639

### **Registered Office**

130-132 Tooley Street  
London SE1 2TU

### **Independent Auditor**

Buzzacott LLP  
130 Wood Street  
London  
EC2V 6DL

### **Bankers**

Barclays Bank PLC  
PO Box 43  
Sheffield S9 2LF

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# General Information

# TRUSTEES' REPORT

## **For the year ended 31 December 2016**

The Trustees present their annual report together with the financial statements of The Society for the Study of Inborn Errors of Metabolism ('SSIEM') ('the Society') ('the charitable company') for the year ended 31 December 2016.

Since the charitable company qualifies as small under section 383, the Strategic report required of medium and large companies under The Companies Act 2006 (Strategic report and Directors' report) Regulations 2013 is not required.

## **STRUCTURE, GOVERNANCE AND MANAGEMENT**

### ***Constitution***

The charitable company is constituted under a Memorandum of Association dated 12 December 1990 and amended by Resolutions dated 13 September 1991, 6 September 2007, 31 August 2011 and 3 September 2014. It is a registered charity, number 1010639.

The charitable company is limited by guarantee and does not have share capital. All Trustees are members of the charitable company and guarantee to contribute £1 in the event of a winding up.

### ***Organisational structure and decision making***

A General Council made up of Honorary Officers of the Society and additional members manage the organisation. The Honorary Officers are a Chair, a Secretary and a Treasurer. Council Members are elected at the Annual General Meeting. Honorary Officers are appointed by the General Council. Honorary Officers of the Society may hold office for three years and are eligible for re-appointment to the same office for a further three years. Members of the General Council other than Honorary Officers may hold office for three years; they may be re-elected for a further three years.

All Honorary Officers of the Society and Members of the General Council are considered to be key management of SSIEM although all are non-paid volunteers.

It should be noted that the current SSIEM Treasurer is also on the European Research Network for Evaluation and Improvement of Screening, Diagnosis and Treatment of Inborn Errors of Metabolism ('ERNDIM') Board of Trustees and that the SSIEM pays ERNDIM for Education and Training Society ('ETAC') administrative functions. The Finance Sub-Committee ('FSC') to help run the financial side of the Society was announced at the 2014 AGM and installed in 2015. The FSC comprises the current Honorary Treasurer, a Council member (currently the SSIEM Chair), a previous SSIEM Honorary Treasurer or Ex-Officio member of Council and an independent financial advisor.

### ***Trustees' responsibilities statements***

The Trustees (who are also directors of The Society for the Study of Inborn Errors of Metabolism for the purposes of company law) are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year. Under company law the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period.

In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable to the UK and Republic of Ireland (FRS 102);
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable United Kingdom Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

#### ***Disclosure of information to auditor***

Each of the persons who are Trustees at the time when this Trustees' report is approved has confirmed that:

- So far as that Trustee is aware, there is no relevant audit information of which the charitable company's auditor is unaware, and
- The Trustee has taken all the steps that ought to have been taken as a Trustee in order to be aware of any relevant audit information and to establish that the charitable company's auditor is aware of that information.

## **OBJECTIVES AND ACTIVITIES**

### ***Policies and objectives***

The principal objective of the charitable company is to foster the study of inherited metabolic disorders and related topics.

In order to further these objectives, membership of the Society promotes the exchange of ideas between professional workers in different disciplines who are interested in inherited metabolic disorders. The aim is pursued in scientific meetings and publications. The Society supports an annual symposium concentrating on different topics relating to inborn errors of metabolism each year and publishes its journals (Journal of Inherited Metabolic Disease (JIMD) and JIMD reports).

Membership of the Society is open to all and especially to those who are professionally involved in metabolic disorders or related topics.

### ***Public benefit***

In supporting an annual symposium and publishing its journal, the Society aims to advance health by sharing ideas on different topics relating to Inborn Errors of Metabolism. In doing so, the Society has considered the Charity Commission's guidance on public benefit.

## **ACHIEVEMENTS AND PERFORMANCE**

### ***Review of activities***

During the year ended 31 December 2016 the Society published Journals and continued development of its own website and App. In addition, arrangements progressed with the LOC & PCO for the SSIEM symposium Athens (2018), Rotterdam (2019) & Freiburg (2020) together with the 14th ICIEM Congress in Sydney (2021).

The membership subscription structure was amended for 2016 reflecting the need to make the membership fee financially acceptable across member's professions and countries. This did not impede the continued increase in membership numbers from 2015 or the total subscription income received.

SSIEM Education and Training Advisory Committee (ETAC) exercised its responsibilities for the training syllabi and the recognition of training centres for paediatric metabolic medicine. ETAC also organised the annual SSIEM Academy course which was held April 2017 in Lyon, France.

The SSIEM Journal of Inherited Metabolic Disease (JIMD) increased its impact factor again in 2016 to 3.970 and was again run from the JIMD Editorial Office in Heidelberg. New contracts and agreements with the JIMD Editorial Office and Publisher will be sought in 2017.

The Society held its 50th Symposium in Rome, Italy. The number of delegates attending continues to increase; more than 2,800 individuals attended representing over 80 countries. The next SSIEM symposium will be held in 2018 in Athens and in 2017 the 13th ICIEM Congress will be held in Rio de Janeiro.

The SSIEM again gave grants for SSIEM membership attendance at the SSIEM symposium in Rome and in 2017 will be giving grants in support for parent support groups or societies and travel support for educational activities for healthcare professionals seeking experience in centres of excellence.

## **FINANCIAL REVIEW**

### ***Principal funding***

The overall income excluding any surplus from the symposium is used to pay the administrative and running costs of the Society including ETAC and to allow for publication of educational journals devoted to the study of the inborn errors of metabolism. Surplus funds are invested. Interest from investments is used in pursuance of the educational objectives of the Society.

The Council is cognisant of the current global financial crisis and has taken steps to protect investment and secure the financial position of the Society so that it can continue to meet its objectives.

The Society is truly international with membership drawn from more than 74 countries. The Society exists to promote the exchange of ideas between all who are professionally interested in Inherited Metabolic Disease. It is the wish of the Council that this exchange should occur between members in as many countries as possible. The Council has agreed to set aside an amount of money from any surplus generated from normal activities to make

membership more widely available to those who would otherwise be unable to participate without support from the

Society. In 2016 the annual subscriptions of 5 (2015: 6) members were paid by the Society; in addition, members and non-members were given financial assistance to attend the SSIEM Symposium in Rome.

### ***Results for the year***

Overall the financial result for the year was a net increase in the reserves of €54,424 to a year-end figure of €2,277,743. However this figure will be reduced in 2017 due to the relative higher costs of the ICIEM congress held in Brazil and the implementation of the additional support for ETAC and ERNDIM.

### ***Reserves policy***

As at 31 December 2016 unrestricted funds of €2,277,743 (2015: €2,223,319) were held. It is the policy of the Society to maintain ‘free reserves’, which are the unrestricted funds less designated funds, at a level that is sufficient to cover management and administration, and support costs and allows the Society to be managed efficiently. Due to the continued success of the SSIEM over the last few years these costs have increased. In view of this the required level of free reserves has been set at €800,000 (2015: €700,000). The Council proposes that a proportion of the surplus funds are invested, currently £650,000 (2015: £650,000 (€881,790)), there is an intention to increase this in 2017. This is to provide some financial security for the Society in years when the Society's income may be reduced, e.g. ICIEM\* Symposium years when the SSIEM is not the host, and in the long term to enable the Society to further develop its educational and charitable objectives. The remaining surplus is used in pursuance of the educational objectives of the Society. A limited number of grants are available to finance individual members to visit, or work for short periods of time, in other centres of expertise. In 2016 the SSIEM were able to financially assist a Greek Doctor visiting Manchester Children’s hospital where they were able to participate in a variety of clinics and discuss cases with the Manchester Metabolic Team.

During 2016, the Council was pleased to give financial assistance to 28 (2015: 22) individuals enabling them to attend the SSIEM Symposium in Rome. The Council has also agreed to utilise some of the reserves to develop the SSIEM Academy and to make training more readily available. Funds (€30,000) were also made available, with other interested societies, to support the development of an electronic app for the Vademecum Metabolicum (the “little yellow book” previously published by Milupa). An annual subscription fee of €3,000 is anticipated, which the SSIEM will support. In March 2016 Council agreed to support 3.5 years funding of a Scientific Deputy for the ERNDIM Office. €350,000 has been set aside to fund this position as a designated fund and this does not form part of the Society’s free reserves. A Scientific Deputy was appointed and commenced in post 1 August 2017. MetabERN, an EU networking Health initiative for inherited disorders, also received €30,000 to enable stakeholder meetings to discuss the structure and statutes of MetabERN. Future funding will depend on the SSIEM receiving a detailed business case.

Future developments include making funds available, from 2017, to support parents/carers to attend meetings or events held by support groups or societies. The SSIEM was approached to sponsor the XIV International Congress Paediatric Laboratory Medicine to be held in Durban, S Africa in 2017. Council decided to offer nominally 10 travel scholarships, dependent on response, to laboratory scientists to attend the meeting. The SSIEM has also purchased space in the trade exhibition to promote the SSIEM and ERNDIM thereby increasing awareness of inherited disorders and reliable laboratory testing and diagnosis. Also see the section on Future Developments in the Trustees’ report.

\* ICIEM (International Congress of Inborn Errors of Metabolism); global symposium hosted by SSIEM and its sister societies on a rotation basis. Symposium surplus goes to the hosting society.

### ***Investments policy and performance***

All investments have been acquired in accordance with powers available to the Council. The assets are sufficient to guarantee normal running of the Society for a period of not less than one year and to support the SSIEM Symposium if there were financial difficulties. The Council considers that this is the best way

of ensuring the independence of the Society and that its educational objectives can be fulfilled. Since the majority of assets are financial investments there is unlikely to be any delay or shortfall in realising the assets into cash if this became necessary.

### ***Risk Management***

The Trustees have assessed the major risks to which the charitable company is exposed, in particular those related to the operations and finances of the charitable company, and are satisfied that systems and procedures are in place to mitigate our exposure to the major risks.

The main risks are:

#### Symposia risk:

- Insurance against bodily or material harm including third parties.
- Insurance against cancellation for major risks.
- Agreement re a force majeure event.

It is expected that the above insurance policies and agreements are included in any contract with any Professional Conference Organiser (PCO) providing services for the annual Symposium.

#### Data risk:

- The IT and data facilities are run under contract with the Association for Clinical Biochemistry and Laboratory Medicine Office. A back-up of data is routinely scheduled and held off-site.

#### Financial risk:

- The major risk to SSIEM is the success of the annual symposium which is covered above.
- The financial surplus of the Society is conservatively managed and is considered to be low risk as funds are held in Sterling and Euro.

#### SSIEM Administration:

- The UK and Europe - Brexit

## **PLANS FOR FUTURE PERIODS**

### ***Future developments***

Council will continue to:

- Review and develop corporate governance
- Continually assess and manage risk
- Update and develop Admin IT
- Symposium and SSIEM app
- MetabERN
- Support for the Vademecum Metabolicum app
- Support for parent support groups or societies
- Support for healthcare professional seeking experience in centres of excellence.
- ERNDIM-SSIEM Collaboration

ETAC will continue to:

- Canvas the views of SSIEM members on training issues
- Undertake accreditation visits when requested
- Update the training syllabus on a regular basis
- Consider whether courses in inborn errors of metabolism are suitable for training needs
- Organise further specific training programmes as part of the SSIEM academy
- ETAC-NAMA Collaboration

The Society actively encourages the formation of National Societies which can communicate with each other through the SSIEM to raise awareness of metabolic diseases so that standards of care and research are improved.

***Going concern***

After making appropriate enquiries, the Trustees have a reasonable expectation that the charitable company has adequate resources to continue in operational existence for the foreseeable future. For this reason, they continue to adopt the going concern basis in preparing the financial statements.

This report was approved by the Trustees and signed on their behalf by

***Prof G S Salomons, Chair  
Trustee  
11th August 2017***

# INDEPENDENT AUDITORS' REPORT

We have audited the financial statements of The Society for the Study of Inborn Errors of Metabolism for the year ended 31 December 2016 set out on pages 20 to 27. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland.

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and its members, as a body, for our audit work, for this report, or for the opinion we have formed.

## ***Respective responsibilities of Trustees and auditor***

As explained more fully in the Trustees' responsibilities statement, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

## ***Scope of the audit of the financial statements***

A description of the scope of an audit of financial statements is provided on the Financial Reporting Council's website at [www.frc.org.uk/auditscopeukprivate](http://www.frc.org.uk/auditscopeukprivate)

## ***Opinion on financial statements***

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2016 and of its income and expenditure for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

## ***Opinion on other matter prescribed by the Companies Act 2006***

In our opinion the information given in Trustees' report for the financial year for which the financial statements are prepared is consistent with the financial statements and the Trustees' report has been prepared in accordance with applicable legal requirements.

## ***Matters on which we are required to report by exception***

In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' report.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

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# Independent Auditor's Report

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of Trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies exemption from the requirements to prepare a Strategic report.

*Mark Worsey (Senior Statutory Auditor)  
for and on behalf of  
Buzacott LLP  
Statutory Auditor  
130 Wood Street  
London  
EC2V 6DL  
11th August 2017*

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# Independent Auditor's Report

# STATEMENT OF FINANCIAL ACTIVITIES

## For the year ended 31 December 2016

	Note	Unrestricted funds 2016 €	Unrestricted funds 2015 €
<b>Income from:</b>			
Charitable activities	3	2,084,765	1,967,742
Investments	4	10,364	6,840
Other income	5	158,393	165,698
<b>Total income</b>		<b><u>2,253,522</u></b>	<b><u>2,140,280</u></b>
<b>Expenditure on:</b>			
Charitable activities	6	2,150,107	1,787,134
<b>Total expenditure</b>		<b><u>2,150,107</u></b>	<b><u>1,787,134</u></b>
<b>Net income before investment gains</b>		<b>103,415</b>	353,146
Unrealised gain on revaluation of fixed asset investment assets			
	9	46,824	–
Net gain on disposal of listed investments	9	2,031	–
(Loss)/gain on retranslation of fixed asset investments	9	(97,846)	31,564
<b>Net movement in funds</b>		<b>54,424</b>	384,710
<b>Reconciliation of funds:</b>			
Total funds at 1 January 2016	12	2,223,319	1,838,609
<b>Total funds at 31 December 2016</b>		<b><u>2,277,743</u></b>	<b><u>2,223,319</u></b>

The Statement of financial activities includes all gains and losses recognised in the year.

All of the charity's activities derived from continuing operations during the above two financial periods.

The notes on pages 22 to 27 form part of these financial statements.

# BALANCE SHEET

## As at 31 December 2016

	Note	€	2016 €	€	2015 €
<b>Fixed assets</b>					
Investments	9		792,279		542,644
<b>Current assets</b>					
Debtors	10	94,749		595,226	
Cash at bank and in hand		<u>1,592,968</u>		<u>1,193,985</u>	
			<u>1,687,717</u>	1,789,211	
<b>Creditors: amounts falling due within one year</b>					
	11	(202,253)		(108,536)	
<b>Net current assets</b>			<u>1,485,464</u>		1,680,675
<b>Net assets</b>			<u>2,277,743</u>		<u>2,223,319</u>
<b>Charity funds</b>					
Unrestricted funds					
General funds	12	1,927,743		2,223,319	
Designated funds	12	<u>350,000</u>		—	
			<u>2,277,743</u>		<u>2,223,319</u>
<b>Total unrestricted funds</b>			<u>2,277,743</u>		<u>2,223,319</u>

The Trustees acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The financial statements were approved by the Trustees on 11th August 2017 and signed on their behalf, by

*Ms A Y Brown*  
*Trustee*

The notes on pages 22 to 27 form part of these financial statements.

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# Balance Sheet

# STATEMENT OF CASH FLOWS

## For the year ended 31 December 2016

		2016	2015
		€	€
<b>Cash flow from operating activities</b>			
Net cash generated from/(used in) operating activities	A	<u>687,245</u>	<u>(209,329)</u>
<b>Cash flow from investing activities</b>			
Purchase of investments		(328,732)	–
Disposal of investments		30,106	–
Investment income		<u>10,364</u>	6,840
Net cash (used in)/generated from investing activities		<u>(288,262)</u>	6,840
<b>Change in cash and cash equivalents in the year</b>		<u>398,983</u>	<u>(202,489)</u>
<b>Cash and cash equivalents at 1 January 2016</b>	B	<u>1,193,985</u>	1,396,474
<b>Cash and cash equivalents at 31 December 2016</b>	B	<u>1,592,968</u>	1,193,985

### A Reconciliation of net income to net cash flow from operating activities

		2016	2015
		€	€
Net income for the year (as per the Statement of financial activities)		54,424	384,710
<b>Adjustments for:</b>			
Gains on revaluation of investments		(46,724)	–
Gain on disposal of investments		(2,031)	–
Loss/(gain) on retranslation of fixed asset investments		97,846	(31,564)
Investment income		(10,354)	(6,840)
Decrease/(increase) in debtors		500,477	(399,467)
Increase/(decrease) in creditors		<u>93,717</u>	<u>(156,168)</u>
Net cash generated from/(used in) operating activities		<u>687,245</u>	<u>(209,329)</u>

### B Analysis of cash and cash equivalents

		2016	2015
		€	€
Cash at bank and in hand		1,575,831	1,193,985
Cash held by investment managers		<u>17,137</u>	–
<b>Total cash and cash equivalents</b>		<u>1,592,968</u>	<u>1,193,985</u>

The notes on pages 22 to 27 form part of these financial statements.

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# Statement of Cash Flows

# NOTES TO THE FINANCIAL STATEMENTS

## For the year ended 31 December 2016

### 1. COMPANY STATUS

The charitable company is a company limited by guarantee. The members of the company are the Trustees named on page 10. In the event of the charitable company being wound up, the liability in respect of the guarantee is limited to £1 per member of the charitable company.

### 2. ACCOUNTING POLICIES

#### 2.1 Basis of preparation of financial statements

The financial statements have been prepared under the historical cost convention, with the exception of investments, which are included on a market value basis. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (effective 1 January 2015) (Charities SORP FRS 102), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), the Charities Act 2011 and the Companies Act 2006.

The charity constitutes a public benefit entity as defined by FRS 102.

The financial statements are presented in Euros (€).

The principal accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

#### 2.2 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charitable company and which have not been designated for other purposes.

#### 2.3 Income

All income is recognised in the Statement of Financial Activities when the charitable company has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

##### *Annual Symposium*

Symposium income is the gross revenue generated by the symposium organiser on behalf of SSIEM delegate registration fees and sponsorship at the event.

##### *Subscription income*

Income from subscriptions is recognised in the period the membership relates to.

##### *Investment income*

This comprises of interest on bank deposits, National Savings Bank income bonds and dividend income. Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charitable company. This is normally upon notification of the interest paid or payable by the bank. Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

##### *Other income*

Other income includes journal royalties which are accounted for on a receivable basis.

## **2.4 Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to make a payment to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. All expenditure is stated inclusive of irrecoverable VAT.

All expenditure is accounted for on an accurate basis. Expenditure comprises direct costs and support costs. All expenses, including support costs, relate to the charitable activities of the charitable company.

Expenditure on charitable activities includes all costs associated with furthering the charitable purposes of the charity through the provision of its charitable activities. Such costs have been apportioned as follows:

- Direct costs – These are the costs associated directly to meeting the charitable objects of SSIEM and include annual symposium expenditure, grants payable and costs incurred in respect of producing journals.
- Support costs – These are the costs incurred directly in support of expenditure on the objects of the charity and include project management carried out at Headquarters.
- Governance costs – These are the costs directly attributable to the Trustees' meetings and audit process such as staff costs, printing, meetings and travel costs.

### *Annual symposium*

Symposium expenditure is the gross expenses incurred by the symposium organiser on behalf of SSIEM.

### *Grants payable*

Grants payable are charged in the year when the offer is made except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attached are fulfilled. Grants offered subject to conditions which have not been met at the year-end are noted as a commitment, but not accrued as expenditure.

## **2.5 Fixed asset investments**

Investments are stated at market value at the Balance Sheet date. The Statement of Financial Activities includes the net gains and losses arising on revaluations and disposals throughout the year.

## **2.6 Debtors**

Trade and other debtors are recognised at the settlement amount after any trade discount offered and net of any provision. Prepayments are valued at the gross amount prepaid.

## **2.7 Cash at bank and in hand**

Cash at bank and in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

## **2.8 Liabilities and provisions**

Liabilities are recognised when there is an obligation at the reporting date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably. Liabilities are recognised at the amount that the charitable company anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

Provisions are measured at the best estimate of the amounts required to settle the obligation. Where the effect of the time value of money is material, the provision is based on the present value of those amounts, discounted at the pre-tax discount rate that reflects the risks specific to the liability. The unwinding of the discount is recognised within interest payable and similar charges.

## 2.9 Financial instruments

The charitable company only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

## 2.10 Foreign currencies

Monetary assets and liabilities denominated in foreign currencies are translated into Euros at rates of exchange ruling at the balance sheet date.

Transactions in foreign currencies are translated into Euros at the rate ruling on the date of the transaction.

Exchange gains and losses are recognised in the Statement of financial activities incorporating income and expenditure account.

## 3. INCOME FROM CHARITABLE ACTIVITIES

	Unrestricted funds 2016 €	Total funds 2016 €	Total funds 2015 €
Annual Symposium	1,944,200	1,944,200	1,822,644
Subscriptions	135,357	135,357	138,136
Academy income	<u>5,208</u>	<u>5,208</u>	<u>6,962</u>
	<u>2,084,765</u>	<u>2,084,765</u>	<u>1,967,742</u>

## 4. INCOME FROM INVESTMENTS

	Unrestricted funds 2016 €	Total funds 2016 €	Total funds 2015 €
Income bonds	5,763	5,763	6,840
Dividend income	<u>4,601</u>	<u>4,601</u>	–
	<u>10,364</u>	<u>10,364</u>	<u>6,840</u>

## 5. OTHER INCOME

	Unrestricted funds 2016 €	Total funds 2016 €	Total funds 2015 €
Journal royalties	112,005	112,005	120,388
Editorial expenses contribution	<u>46,388</u>	<u>46,388</u>	<u>45,310</u>
	<u>158,393</u>	<u>158,393</u>	<u>165,698</u>

## 6. ANALYSIS OF CHARITABLE ACTIVITIES

	Unrestricted funds 2016 €	Total funds 2016 €	Total funds 2015 €
<b>Direct costs</b>			
Council symposium expenses	13,454	13,454	6,531
Publication of journal	124,066	124,066	137,895
Academy expenses	68,300	68,300	61,209
Symposium awards	500	500	9,116
Symposium expenses	1,615,383	1,615,383	1,397,077
Grants payable	35,131	35,131	30,119
MetabERN	30,000	30,000	–
Komrower Lecture	<u>1,000</u>	<u>1,000</u>	<u>–</u>
<b>Total direct costs</b>	<b>1,887,834</b>	<b>1,887,834</b>	<b>1,641,947</b>
<b>Support costs</b>			
Council travel and subsistence	44,375	44,375	19,569
Printing, postage, stationery and carriage	15,858	15,858	13,607
Exchange rate variance	17,067	17,067	12,007
Website costs	4,659	4,659	4,043
Other administration expenses	3,337	3,337	17,816
Secretarial expenses	51,074	51,074	60,799
Irrecoverable VAT	<u>97,031</u>	<u>97,031</u>	<u>–</u>
<b>Total support costs</b>	<b>233,401</b>	<b>233,401</b>	<b>127,841</b>
<b>Governance costs</b>			
Accountancy fees	27,460	27,460	12,752
Professional charges	1,412	1,412	3,304
Other governance costs	<u>–</u>	<u>–</u>	<u>1,290</u>
<b>Total governance costs</b>	<b>28,872</b>	<b>28,872</b>	<b>17,346</b>
<b>Total expenditure on Charitable Activities</b>	<b><u>2,150,107</u></b>	<b><u>2,150,107</u></b>	<b><u>1,787,134</u></b>

28 (2015: 22) delegates were supported with financial grants totalling €35,435 (2015: €30,119).

## 7. TRUSTEES' REMUNERATION

No Trustees received any remuneration or benefits in kind in respect of their services during the year (2015: nil). During the year, 17 (2015:13) Trustees received reimbursement of expenses totalling €31,459 (2015: €25,047).

## 8. AUDITOR'S REMUNERATION

Auditor's remuneration amounts to a current year audit fee of €9,339 (2015: €nil), and fees for other services of €3,969 (2015: €nil).

Fees payable to the former auditor amounted to €14,152 (2015: €12,752).

## 9. FIXED ASSET INVESTMENTS

	Listed securities	Other investments	Total
	€	€	€
Market value			
At 1 January 2016	–	542,644	<b>542,644</b>
Additions at cost	328,732	–	<b>328,732</b>
Disposals at book value (proceeds: €30,106, gain: €2,031)	(28,075)	–	<b>(28,075)</b>
Foreign exchange movement	(22,142)	(75,704)	<b>(97,846)</b>
Revaluations	<u>46,824</u>	<u>–</u>	<u><b>46,824</b></u>
At 31 December 2016	<u><u>325,339</u></u>	<u><u>466,940</u></u>	<u><u><b>792,279</b></u></u>
Historical cost	<u><u>295,651</u></u>	<u><u>471,000</u></u>	<u><u><b>766,651</b></u></u>

### Investments at market value comprise of the following:

	2016	2015
	€	€
Listed investments	<b>325,339</b>	–
Other investments	<u><b>466,940</b></u>	<u>542,644</u>
	<u><u><b>792,279</b></u></u>	<u><u>542,644</u></u>

Other investments comprise £400,000 National Savings Bank income bonds which have been retranslated into Euros at the year-end rate. Accordingly, they are included at cost which represents the capital value of the bonds to the charitable company. Investments are held to provide an investment return.

All fixed asset investments are held in the UK.

## 10. DEBTORS

	2016	2015
	€	€
Trade debtors	<b>2,876</b>	471,955
Other debtors	<b>8,058</b>	32,658
Prepayments and accrued income	<u><b>83,815</b></u>	<u>90,613</u>
	<u><u><b>94,749</b></u></u>	<u><u>595,226</u></u>

## 12. CREDITORS:

### Amounts falling due within one year

	2016	2015
	€	€
Accruals and deferred income	<u><b>202,353</b></u>	<u>108,536</u>

### Deferred income

	€
Deferred income at 1 January 2016	<b>26,293</b>
Resources deferred during the year	<b>53,746</b>
Amounts released from previous years	<b>(26,293)</b>
Deferred income at 31 December 2016	<u><u><b>53,746</b></u></u>

Deferred income relates to the deferral of subscription income over the period to which it relates.

# Notes to the Financial Statements

## 12. UNRESTRICTED FUNDS

	Balance at 1 January 2016 €	Income €	Expenditure €	Gains/ (Losses) €	Transfers between funds €	Balance at 31 Dec 2016 €
General fund	2,223,319	2,253,522	(2,150,107)	(48,991)	(350,000)	<b>1,927,743</b>
Designated fund	–	–	–	–	350,000	<b>350,000</b>
	<u>2,223,319</u>	<u>2,253,522</u>	<u>(2,150,107)</u>	<u>(48,991)</u>	<u>–</u>	<u><b>2,277,743</b></u>

The general fund represents the ‘free reserves’ and the designated fund represents ring-fenced funding in respect of providing three and a half years of funding for a Scientific Deputy in the ERNDIM office.

## 13. RELATED PARTY TRANSACTIONS

Certain trustees are also members of the charitable company. During the year, Trustees have paid membership fees on an arm’s length basis and no balances were outstanding as at 31 December 2016 (2015: €nil).

A Trustee of the charitable company is also a Trustee of the European Research Network for Evaluation and Improvement of Screening, Diagnosis and Treatment of Inborn Errors of Metabolism (ERNDIM). During the year, the charitable company paid €21,676 (2015: €19,472) to ERNDIM for Education and Training Society (ETAC) administrative functions. There were no balances outstanding as at 31 December 2016 (2015: €nil).



