THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM FINANCIAL STATEMENTS

31 DECEMBER 2009

Company Registration Number: 2567711 Charity Registration Number: 1010639

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THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM FINANCIAL STATEMENTS YEAR ENDED 31 DECEMBER 2009

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GENERAL INFORMATION

Directors and trustees:

C Jakobs
N Blau
J R Bonham
J Campistol
P T Clayton
M A Dixon
J Gartner
V Kozich
P D Mayne

M I Tavares de Almeida

J Zschocke

Honorary Secretary:

P D Mayne

Registered Office:

Third Floor

130-132 Tooley Street London SE1 2TU

Bankers:

Barclays Bank plc

Sheffield Arena Square Branch

PO Box 43 Sheffield S9 2LF

Honorary Treasurer:

J R Bonham

Auditors:

Baker Tilly UK Audit LLP

Chartered Accountants and Registered Auditors

No 1 Old Hall Street

Liverpool L3 9SX

The trustees present their report together with financial statements for the year ended 31 December 2009. The trustees confirm that the financial statements comply with current statutory requirements and with those of the company's Memorandum and Articles of Association.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing Document

The company which is governed by its Memorandum and Articles of Association dated 12 December 1990, is constituted as a company limited by guarantee and has been given the registered company number 2567711

The company is also a registered charity and has been given the registered charity number 1010639

Trustees

The directors, who are also the trustees of the charity, are listed below

C Jakobs

N Blau

J R Bonham

J Campistol

P T Clayton

M A Dixon

J Gartner

V Kozich

P D Mayne

M I Tavares de Almeida

J Zschocke

Being a company limited by guarantee, there is no share capital

Organisation

A General Council made up of officers of the Society and additional members manage the organisation. The officers are a Chairman, an Honorary Secretary, and an Honorary Treasurer. Officers and Council members are elected at the Annual General Meeting. Another SSIEM member must nominate members standing for election. Officers of the Society may hold office for 3 years and are eligible for re-election to the same office for a further 3 years. Members of the General Council other than officers may hold office for 3 years, they may be re-elected for a further 3 years. All officers of the Society and members of the General Council are non-paid volunteers.

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

Risk Management

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

OBJECTIVES AND ACTIVITIES

The objects of The Society for the Study of Inborn Errors of Metabolism ("SSIEM") are to foster the study of inherited metabolic disorders and related topics

In order to further these objects, 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 Journal, the *Journal of Inherited Metabolic Disease* (JIMD)

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

ACHIEVEMENTS AND PERFORMANCE

During the year ended 31 December 2009 the Society published its Journal and continued development of its own internet web site. In addition, arrangements progressed with the Society for Inherited Metabolic Diseases (SIMD), the Japanese Society for Inherited Metabolism Diseases (JSIMD), the Australian Society for Inborn Errors of Metabolism (ASIEM), Sociedad Latinoamericana de Errores Innatos del Metabolismo y Pesquisa Neonatal (SLEIMPN), within the International Congress of Inborn Errors of Metabolism (ICIEM) for closer relationship A new constitution has been formulated and agreed

Its membership has continued to increase The General Council has met on a number of occasions to pursue the objectives of the Society

SSIEM Education and Training Advisory Committee (ETAC)

Purpose

Paediatric Metabolic Medicine (PMM) is a recognised subsection of the European Academy of Paediatrics (EAP), which is a section of the Union of European Medical Specialists (UEMS) Although the SSIEM has no formal role within the EU in the assessment of training for laboratory scientists, the SSIEM recognises a responsibility in this area. Consequently ETAC is now comprised of both clinicians and laboratory scientists

The current membership of the committee is as follows

Chairman John Walter
Senior Advisor, Jean-Marie Saudubray

Clinical
Andrew Morris
Vassili Valayannopoulos
Ute Spiekerkoetter
Shamima Rahman

Laboratory
Brian Fowler
Mick Henderson
Christine Vianey-Saban
Jorgen Bierau

The responsibilities of ETAC are currently as follows

Syllabus

Syllabi are published on the SSIEM website for both clinical and laboratory training

Formal assessment of clinical training centres and training programmes

National societies can apply for centres within their country to be approved for training in PMM. This process requires a formal written application followed by a site visit by two members of ETAC. ETAC will then submit their recommendation to EAP. As part of the process for training centre approval the committee will require information about local training programmes and trainee assessment. Training programmes should aim to ensure the syllabus is covered. This may be a problem in small countries as experience may be limited. The authorities have to recognise any limitation and be prepared to fund training elsewhere, if there is insufficient experience in one country the importance of obtaining experience abroad will need to be emphasised. Such work needs to be properly funded and the experience in another country recognised for training. At the present time ETAC will not be responsible for the assessment of individual trainees but may be in a position to provide career guidance.

SSIEM Academy

ETAC now organises an SSIEM Academy course for training in areas of inherited metabolic disease. In 2008 this consisted of a one day concurrent course for both paediatricians and laboratory scientists. In 2009 this was increased to two days. It is planned that there will be a continued expansion in training courses as part of the role of the Academy.

JIMD

The JIMD Editorial Office is now well established in Heidelberg, Germany, run by two Editors in Chief together with an Editorial manager The aim of the office is to facilitate the flow of articles for the journal

Although the net payment to the Publishers of the JIMD is higher under the new contract, the Society will receive a share of the Royalties During 2009 the Trustees were happy to receive a payment for Royalties of £75,698

SYMPOSIUM

In 2009 the International Society for Inborn Errors of Metabolism organised a Symposium in San Diego and as a consequence the SSIEM did not organise a meeting Plans are well advanced with the organisation of the annual symposium to be held in Istanbul

FUNDING

The majority of the income of the Society is raised from subscriptions paid by individual members. This income is used to pay the administrative and running costs of the Society including ETAC and to allow for publication of an educational journal 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, to subsidise the journal to make it more widely available and to meet the expenses of an invited speaker at the annual symposia (Komrower Lecture)

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 annual subscription has been increased for the first time in over 5 years with a subsidised rate for those under 35 years of age.

The Society is truly international with membership drawn from more than 60 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 2009 the Annual Subscription of 6 members was paid by the Society, in addition 7 members were given financial assistance to attend the ICIEM Symposium in San Diego.

FINANCIAL REVIEW

The net outgoing resources for the year amounted to £49,261 (2008 incoming £109,050), which was the amount attributable to general reserves, which at the year end stood at £550,128 (2008 £599,389)

There have been no important events since the balance sheet date

Investment powers and policy

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. 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.

The Society has made no commitments or guarantees other than those covered in this report

Reserves policy

It is the policy of the Society to maintain unrestricted funds, which are the free reserves, at a level that is sufficient to cover management and administration, and support costs and allows the Society to be managed efficiently. Council proposes to use some of the unrestricted funds to encourage the sharing of experience and training between centres. This will take the form of a limited number of grants to finance individual members to visit, or work for short periods of time in, other centres of expertise. During 2009, the Council was pleased to give financial assistance to 7 members to attend the Symposium in San Diego. Council has also agreed to utilise some of the reserves to develop the SSIEM Academy and to make training more readily available.

Plans for the future

Future work - 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
- to consider whether courses in inborn errors of metabolism are suitable for training needs
- organise further specific training programmes as part of the SSIEM academy

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

Trustees' responsibilities for the financial 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 which 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 the charities SORP,
- make judgments and estimates that are reasonable and prudent,
- state whether applicable UK standards have been followed, subject to any material departures disclosed and explained in the financial statements,
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business

The trustees are responsible for keeping proper accounting records that 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.

In so far as the trustees are aware

- there is no relevant audit information of which the charitable company's auditor is unaware, and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information

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 the legislation in other jurisdictions

Small company exemptions

This report has been prepared in accordance with the provisions applicable to companies entitled to the small companies' exemption

Auditors

A resolution to reappoint Baker Tilly UK Audit LLP, Chartered Accountants, as auditors was endorsed by the members at the Annual General Meeting, Baker Tilly UK Audit LLP having indicated its willingness to continue in office

By order of the Board

P D Mayne Hon Secretary

INDEPENDENT AUDITORS' REPORT TO THE MEMBERS OF THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM

We have audited the financial statements of The Society for the Study of Inborn Errors of Metabolism for the year ended 31 December 2009 on pages 10 to 16

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 2006. 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 auditors' 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 the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed

Respective responsibilities of trustees and auditors

The trustees' (who are also the directors of the company for the purposes of company law) responsibilities for preparing the Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and for being satisfied that the financial statements give a true and fair view are set out in the Statement of Trustees' Responsibilities

Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (UK and Ireland)

We report to you our opinion as to whether the financial statements give a true and fair view, have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice and have been prepared in accordance with the Companies Act 2006 We also report to you whether in our opinion the information given in the Trustees' Report is consistent with those financial statements

In addition we report to you if, in our opinion, the charitable company has not kept adequate accounting records, if the charitable company's financial statements are not in agreement with the accounting records and returns, if we have not received all the information and explanations we require for our audit, or if certain disclosures of trustees' remuneration specified by law are not made

We read the Trustees' Report and consider the implications for our report if we become aware of any apparent misstatements within it

Basis of audit opinion

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgments made by the trustees in the preparation of the financial statements, and of whether the accounting policies are appropriate to the charitable company's circumstances, consistently applied and adequately disclosed

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM INDEPENDENT AUDITORS' REPORT TO THE MEMBERS OF THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM Continued

Opinion

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 2009 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended,
- the financial statements have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice,
- the financial statements have been prepared in accordance with the Companies Act 2006, and
- the information given in the Trustees' Report is consistent with the financial statements

E ROBERT AITKEN (Senior Statutory Auditor)

11 August 2010 For and on behalf of BAKER TILLY UK AUDIT LLP, Statutory Auditor

Chartered Accountants No 1 Old Hall Street

Liverpool L3 9SX

STATEMENT OF FINANCIAL ACTIVITIES AND INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31 DECEMBER 2009

		Unrestricted and total funds 2009	Unrestricted and total funds 2008
Incoming resources	Note	£	£
Incoming resources from generating funds: Activities for generating funds			
Investment Income		8,197	19,709
Incoming Resources from Charitable Activities	2	71,925	161,155
Other incoming resources	2	76,176	87,255
Total incoming resources		156,298	268,119
Resources expended			
Charitable Activities			
Symposium	3	38,351	33,699
Publication of Journal	3	122,299	109,026
ETAC	3	31,483	7,937
		192,133	150,662
Governance Costs	6	13,426	8,407
Total resources expended		205,559	159,069
Net incoming/ (outgoing) resources for the year		(49,261)	109,050
Fund balances brought forward at 1 January 2009		599,389	490,339
Fund balances carried forward at 31 December 2009	10	550,128	599,389

There are no recognised gains or losses other than those included in the statement of financial activities for the two financial years

The above results are derived from continuing operations

Company Registration no. 2567711

BALANCE SHEET AT 31 DECEMBER 2009

	Note	200		200	
		£	£	£	£
Fixed assets	_		400.000		
Investments	7		400,000		250,000
Current assets					
Debtors	8	4,875		101,566	
Cash at bank and in hand		187,662		286,636	
		192,537		388,202	
Creditors: amounts falling due within	•	(40.400)		(0.0.01.0)	
one year	9	(42,409)		(38,813)	
Net current assets			150,128		349,389
Total net assets			550,128		599,389
Funds					
Unrestricted funds	10		550,128		599,389

The financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime

The financial statements on pages 10 to 16 were approved by the board of directors and authorised for issue on 2010 and are signed on their behalf by

J R Bonham

Hon Treasurer and Director

THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM NOTES TO THE ACCOUNTS YEAR ENDED 31 DECEMBER 2009

1 Accounting policies

Basis of accounting

The accounts have been prepared in accordance with applicable accounting standards under the historical cost convention and in accordance with the recommendations of the Statement of Recommended Practice "Accounting and Reporting by Charities" (SORP 2005) issued in March 2005, applicable UK accounting standards, the Companies Act 2006

Going Concern

The financial position on page 11 demonstrates that the charity is operating within its available cash funds and has net current assets at the year end. The charity has maintained income from journal publications and royalties and expects similar levels of this income in the future. Additional income is also expected to be generated from organising an annual symposium in future years. The Trustees believe the charity is well placed to manage its business risk despite the difficult economic climate.

The Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future and thus the trustees have concluded that it is appropriate to prepare the accounts on a going concern basis

Incoming resources

Income from charitable activities includes subscriptions income which is accounted for in the accounting period in which it is receivable and symposium income which is accounted for on a receivable basis

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

Investment income comprises interest received on bank deposits and National Savings bank income bonds and is recognised on a receivable basis

Grants receivable are charged to the Statement of Financial Activities in the period in which they are receivable

Resources expended

Resources expended are included in the Statement of Financial Activities on an accruals basis Expenditure is directly attributable to specific activities and has been included in those cost categories Resources expended include attributable VAT which cannot be recovered

Charitable activities include expenditure associated with the publication of the journal, expenditure associated with the annual symposium and expenditure associated with ETAC. These include both the direct costs and support costs relating to those activities

Governance costs include those incurred in the governance of the charity and its assets and are primarily associated with constitutional and statutory requirements

Support costs include central functions and have been allocated to activity cost categories on an income generated basis

Grants payable are charged to the Statement of Financial Activities when they have been approved by the Board of Trustees

THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM NOTES TO THE ACCOUNTS YEAR ENDED 31 DECEMBER 2009 Continued

1 Accounting policies (continued)

Cash flow statement

The company has taken advantage of the exemption from preparing a cash flow statement conferred by Financial Reporting Standard No 1 on the grounds that it is entitled to the exemptions available for small companies

Fund accounting

The charity's accumulated funds consist of funds which the company may use at the discretion of its trustees

Foreign currencies

Transactions expressed in foreign currencies are translated into sterling and recorded at rates of exchange approximating to those ruling at the date of the transaction. Monetary assets and liabilities are translated at rates ruling at the balance sheet date. All differences are taken to the profit and loss account

2 Incoming resources from Charitable Activities

	2009 £	2008 £
Annual Symposium (note 2(a)) Publication of journal	- 71,925	89,095 72,060
	71,925	161,155

a) Symposium

There was no income for SSIEM arising from the ICIEM Symposium in 2009

	200	9	2008	3
	£	£	£	£
Income				
Registration fees		-		485,820
Sponsorship		-		328,355
Other income		-		24,160
				838,335
Expenditure				
Accommodation	-		256,748	
Printing	-		38,649	
Meals, entertainment and transport	-		298,631	
Speakers' expenses	-		51,195	
Administration	-		81,743	
Miscellaneous	-		22,274	
		-		749,240
Symposium surplus		<u>-</u>		89,095
Surplus donated to the charity				89,095

THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM NOTES TO THE ACCOUNTS YEAR ENDED 31 DECEMBER 2009

Continued

b)	Other	Income
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-,	one meom				2009 £	2008 £
	Journal Royalties				75,698	72,732
	Revaluation of Foreign Curre	ency Bank Accor	ınts		-	13,714
	Charges for payment by Cree	dit/Debit Card			478	809
					76,176	87,255
3	Analysis of Charitable Expe	nditure				
		Symposium £	Journal £	ETAC £	2009 £	2008 £
	Direct Costs					
	Publication of Journal	-	105,004	-	105,004	93,675
	Council symposium expenses	8,623	-	-	8,623	4,325
	Support for delegates to attend symposium (Note 5)	6,813	-	-	6,813	11,408
	SSIEM Academy (ETAC)	-	_	29,818	29,818	7,083
	Awards	1,436	-	-	1,436	1,469
	Komrower Lecture	<u> </u>			-	1,525
		16,872	105,004	29,818	151,694	119,485
	Support Costs (Note 4)	21,479	17,295	1,665	40,439	31,177
		38,351	122,299	31,483	192,133	150,662
						<u></u>

Allocation of Support Costs

Support costs include central functions and have been allocated to activity costs categories on an income generated basis

	Symposium £	Journal £	ETAC £	2009 £	2008 £
Council travel and subsistence	9,040	1,508	753	11,301	8,956
Secretarial expenses	3,011	6,024	-	9,035	9,975
Printing and stationery	2,502	2,502	-	5,004	5,218
Postage	919	2,756	-	3,675	3,834
Web Site	321	963	321	1,605	910
Consultancy	3,915	_	-	3,915	_
Other administration	1,771	3,542	591	5,904	2,284
	21,479	17,295	1,665	40,439	31,177

The trustees receive no remuneration but are reimbursed for expenses incurred

THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM NOTES TO THE ACCOUNTS YEAR ENDED 31 DECEMBER 2009 Continued

5	Grants Payable in Furtherance of Charitable Activities		
		2009 £	2008 £
	Support for delegates to attend symposium	6,813	11,408
		6,813	11,408
	All grants have been paid to individuals		
6	Governance Costs		
		2009 £	2008 £
	Audit and Accountancy	6,633	5,082
	Secretarial Expenses	3,011	3,325
	Council Expenditure	3,767	-
	Other Administration	15	
		13,426	8,407
7	Investments		
		2009	2008
	Unlisted investments:	£	£
	Cost		
	At 31 December	400,000	250,000

Unlisted investments comprise National Savings Bank income bonds. Accordingly, they are included at cost which represents the capital value of the bonds to the charity. Investments are held to provide an investment return

8 Debtors

	2009 £	2008 £
Other debtors	-	101,566
Prepayments	4,875	
	4,875	101,566

THE SOCIETY FOR THE STUDY OF INBORN ERRORS OF METABOLISM NOTES TO THE ACCOUNTS YEAR ENDED 31 DECEMBER 2009 Continued

9 Creditors: amounts due within one year

2009 £	2008 £
36,409	28,559
-	120
6,000	10,134
42,409	38,813
	£ 36,409 - 6,000

10 Statement of funds

	Unrestricted accumulated fund		
	2009 £	2008 £	
At 1 January 2009	599,389	490,339	
Net incoming/ (outgoing) resources for the year	(49,261)	109,050	
At 31 December 2009	550,128	599,389	

11 Related party transactions

Certain trustees are also members of the Society During the year they have paid membership fees on an arm's length basis