



Insulin Dependent Diabetes Trust

Report and Accounts

31st December 2008

Registered Company Number 3148360
Registered Charity No 1058284



Trustee's Report

The report follows the order set out in the SORP with paragraph headings highlighting each disclosure required, including Trustee induction and training. The report includes a risk management statement, which also refers to compliance with applicable national standards. The charity's objectives, aims, strategies and major activities undertaken are summarized in the objectives and activities section. The achievements and performance section provides detailed information about the nature of the activities undertaken, including performance information, for each of the main areas of charitable activity.

Structure, Governance and Management

Governing Document

The organisation is a charitable company limited by guarantee, incorporated on 10 December 1995 and registered as a charity in January 1994. The company was established under a Memorandum of Association, which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the company being wound up members are required to contribute an amount not exceeding £1.00.

Recruitment and Appointment of Board of Trustees

The directors of the company are also charitable trustees for the purposes of charity law and under the company's Articles are known as members of the Board of Trustees. Under the requirements of the Memorandum and Articles of Association, the members of the Board of Trustees are elected to serve for a period of three years, after which they must be re-elected at the next Annual Meeting. Due to the nature

of the work of the charity and the importance of understanding the needs of and representing people with diabetes and their families, at no time shall the number of trustees who are medically qualified or are allied health professionals exceed twenty five percent of the total number of trustees. The charity records the particular skills of the trustees in order to maintain a broad mix of skills and expertise.

Trustee Training

The trustees are familiar with the practical work of the charity. New trustees are encouraged to take short training sessions to familiarise themselves with:

- The responsibilities of trustees.
- The documents, memorandum, and Articles of Association for the operations of the charity.
- The current financial position and sources of funding of the charity.
- The objectives and forward plans for the charity.

Risk Management

The Trustees cannot find any major risks to which the charity is exposed each financial year when preparing and updating the strategic plan, in particular those relating to the operations and finances of the charity.

A risk register has been established. Procedures are in place to ensure compliance with health and safety of staff and visitors to the offices. Internal control risks are minimised by the implementation of procedures for authorisation of all transactions and projects.

Organizational Structure

A board of eight trustees administer the charity, covering policy, membership and finance. The Co-Chairs in consultation with the Treasurer take minor day-to-day decisions, where necessary. Modern technology enables consultations to be made quickly and easily. Major decisions on future policies are taken to the AGM for approval of members. During 2008, there was a staff of three full time people with a management structure in place. Training of the staff and updating

their skills takes place as and when required to ensure their skills and knowledge remain relevant and up to date.

Related Parties

The charity has no financial links with any other charities or organisations. The charity does not accept any financial assistance or sponsorship from pharmaceutical companies. There are groups in other countries with similar objectives that are affiliated to the Trust. IDDT is an affiliate of the James Lind Alliance, an organisation investigating ways that patients and clinicians can identify gaps in research that are important to both parties.

Objectives and Activities

The charity's main objectives remain unchanged:

- To offer care, support and information to people with diabetes and their families.
- To ensure that those people who are dependent on insulin for the treatment of their diabetes have a fully informed choice of insulin.
- To try to ensure that animal insulin continues to remain available for those who require it.
- To fund research aimed at improving the lives of people with diabetes now.

The main objectives of the charity for the year continued to focus on the need to:

- Reach more people with diabetes to offer information and support.
- Reach health professionals treating people with diabetes so that they are aware of the availability of animal insulins, and
- Help children with diabetes and their parents with the provision of information to them and to teachers so that they had better understand the needs of children with diabetes in schools.
- To produce a booklet to clarify the differences between Type 1 and Type 2 diabetes and create a better understanding of the basic facts about both conditions.

To achieve these objectives include the following:

- Increasing the promotion of the help the charity can offer through local press advertising.
- To continue to develop and update information leaflets on the many aspects of diabetes.
- To target health professionals so that they receive regular information from the charity and free information leaflets for their patients.
- To further develop the Children's Department of the charity to address the needs of children and young people with diabetes.

Achievements and Performance

Increase in membership

By the end of 2008, the charity's membership had increased by over 2000 to a total of 12,082, with the increases in membership being primarily from specific advertising campaigns about adverse effects of synthetic insulins and treatment choices, availability of IDDT information leaflets as well as from the attendance at professional conferences.

Information provision and listening service

The charity continues to publish a quarterly Newsletter distributed to members, diabetes specialist nurses and practice nurses with a special interest in diabetes. The number of information leaflets on various aspects of diabetes has been increased and all of them are now in the form of small booklets for easier display in GP and hospital waiting rooms.

The charity supplied over 45,000 information leaflets requested directly by people with diabetes or by health professionals. The quarterly Newsletter continues to be the main source of regular contact with membership and health professionals. The Newsletter and leaflets are produced in large print. The Newsletter is also produced on tape for people with visual impairment and the Trustees again thank the

readers for their unfailing help with this. A Parents' Bulletin is published quarterly and in 2008 IDDT introduced a Goodie Bag for children with diabetes and their siblings as a result the parent membership rose sharply and continues to grow.

The website is regularly updated and continues to grow and is a regular source of new members.

In October 2008 the charity held its Annual Conference, which was well attended but highlighted the continued need for information about carbohydrate counting and for more and better education especially on the relationship between insulin, diet and exercise.

Health professionals

The charity has held a sustained advertising campaign in nursing journals and had stands at Nursing in Practice conferences in Birmingham, Manchester and Cardiff. These were a great success and the decision has been taken to attend these conferences in Birmingham, Manchester and Cardiff in 2009.

Teachers

The Information Packs developed in 2005 for teachers and for parents of children with diabetes have been very popular indicating teachers' need for information and in 2008, the fact sheets were updated. The charity had a stand at the National Education Conference in 2008 and plans to attend again in 2009 in addition to continuing with advertising in education magazines and journals.

International activities

IDDT – International has strengthened the international links with people and groups in countries around the world. 2008 saw a continued increase in the number of people contacting IDDT from the UK but also from other countries especially the United States where many people are desperately searching for affordable sources of pork insulin and information about personal importation from the UK.

Following Novo Nordisk's discontinuation of pork insulins in all countries, the UK is the only country with easily accessible pork and beef insulins, so the charity has offered support and information to

people in other countries. Associates from Germany are successfully importing pork insulin from Argentina and IDDT- Canada has successfully campaigned with the Society of Diabetics Rights for the approval by Health Canada of Hypurin pork insulins, although at a very high cost. Providing information and support wherever people live continues to be a major role and IDDT encourages and supports them to campaign for recognition of the adverse effects that some people experience when using human or analogue insulins and for easily accessible and affordable natural animal insulins.

The Trust continues to deplore the decision chosen by the pharmaceutical industry to reduce the choice of insulins and has serious concerns about the lack of evidence of the long-term safety of insulin analogues and their potential for carcinogenic effects. The Trustees thank Wockhardt UK for their commitment to the ongoing supply of bovine and porcine insulin in vials and cartridges but believe that having only one supplier of animal insulin is an unsafe and vulnerable position for the significant numbers of people who need it.

Support for people in developing countries

In 2008 the charity again collected and donated over 26,000mls of unwanted, in-date insulin for people in developing countries unable to afford insulin and the treatment they need. Over 8,000 blood glucose test strips, new meters and thousands of syringes and lancets were also donated to Africa and India. The Trustees thank all those who send unwanted supplies especially the diabetes clinics around the UK who are very supportive of this initiative.

The number of people supporting the charity's 'sponsor a child scheme' to help with the insulin and medical costs of children at Dream Trust in India continues and the medical needs of 30 children with diabetes are being supported by members. The charity and Dr Pendsey at Dream Trust express their gratitude to IDDT members who support needy families.

The Safety of Analogue Insulins - Should Patients be concerned? The

Supplement by Professor Ernst Chantelau and Jenny Hirst published by the charity in 2005, which questions the therapeutic benefits of insulin analogues against their potential carcinogenicity, continues to be sent to people who contact the charity to try to ensure that people needing insulin have a truly informed choice of insulin and are aware of the potential risks.

In October 2008, the charity helped to fund the second International Workshop on insulin and Cancer held in Germany. One trustee attended the workshop.

IDDT Research Grants

The Trust has continued to advertise the availability of research grants to be awarded in line with the aims of the charity and increased the maximum grants to £30,000 as a result of the decision taken at the last AGM.

Many of the applications received are not in line with the Trust's policy and therefore have not been accepted. In 2008, the Trust funded:

- A study investigating whether honey from Fiji is more effective at healing foot ulcers than standard therapy and if there are any adverse effects. A qualitative study relating to insulin initiation and treatment in a multi-ethnic population.
- A study entitled "Discovering the myths, barriers and facilitators to the initiation of insulin in disease prone UK South Asian populations and to make recommendations following consultation with service users and service providers."
- A study entitled "Generation and characteristics of insulin-synthesizing pseudo-islets from adult stem cell cultures derived from human pancreas" which aims to look for sources of beta cells for transplantation.
- A study entitled "Patient Choice in the Treatment of Diabetes – the role of information provision". As government policy is based on patients' right to choose treatment and to information on which to base this choice, this study is investigating whether people with diabetes do have a choice, whether they want choice, if so, to

they want more information in order to make that choice and what barriers to treatment choice exist.

Financial Review

The financial accounts are set out on the profit and loss balance sheet and the notes to the accounts. The financial statements have been prepared implementing the Statement of Recommended Practice for Accounting and Reporting by Charities by the Charity Commission for England and Wales [effective October 2000] and in accordance with the Financial reporting Standard for Smaller Entities [effective June 2002]. The Trustees consider the financial performance by the charity during the year has been satisfactory.

The Statement of Financial Activities show net outgoing resources for the year of a revenue nature of £427,088 and net realised incoming of a capital nature of £709,506 making net overall realised movement of resources of £282,418. The total reserves at the year end stand at £2,485,564.

Principle funding sources

The principle sources of income are from legacies and voluntary donations. The Trustees are aware of the need to generate greater regular income and are investigating possible ways of achieving this.

Investment Policy

Under the Memoranda and Articles of the charity, the charity has the power to make any investment that the Trustees see fit.

Reserves Policy

The Trustees have resolved to establish reserves to provide for future activities, and the Trustees have wide powers of investment.

Within those powers, a statement of investment principles has been set out as below. The policy on reserves is that existing assets are retained to produce income, income that is wholly utilised to support existing activities. There is no intention in the long term to either increase or reduce the capital held. The policy is justified in that it

is necessary to preserve income at the present levels in order to maintain the activities of the charity.

Details of related parties and transactions with related parties

Apart from monthly editorial fees paid to the Co-Chairman, as agreed with the Charity Commission, the Trustees receive only out of pocket expenses.

Specific changes in fixed assets of each of the funds

The Board of Trustees is satisfied that the charity's assets are available and adequate to fulfill its obligations.

Share Capital

The company is limited by guarantee and therefore has no share capital.

In Conclusion

The Trustees are very grateful for the continued generosity of the members in making donations and especially to the increasing number of people who make regular donations through their bank. The Trustees also wish to record their gratitude to the donors of legacies and donations in memory of loved ones. Their kindness in helping other people with diabetes is very much appreciated.

The Trustees would also like to express their thanks for the continuing support and help of members and their families, which provides encouragement to Trustees to continue with the aims and objectives of IDDT. This support reflects the needs of people living with diabetes to be represented by a patient/carer based charity that understands their needs and remains independent and uninfluenced by outside financial influences.

The Trustees reaffirm their commitment and determination to try to ensure that people with diabetes and their families have the informed choices of treatment and the access to them that they deserve and need.

Legal Status

The charity is an incorporated charity governed by memorandum and articles. There are no restrictions in the governing document on the operation of the charity or on its investment powers, other than those imposed by general charity law.

By order of the Trustees

Mrs J Hirst (Joint Chairperson)

The members of the Board of Trustees of the Charity during the year ended 31st December 2008 were:

Co- Chairman

Jenny Hirst
Dr Matthew Kiln

Treasurer
Jenny Hirst

Medical Adviser

Dr Laurence Gerlis

Trustees

Carol Baker
John Birbeck
Larrane Ingram
Veronica Readman
Dr Rob Rijckborst

Directors responsibilities

All the directors of the company are also Trustees of the charity, and their responsibilities include all the responsibilities under the Companies Act and of trustees under the Charities Act.

Charity Law and the Companies Act require the Board to prepare financial statements for each financial year which give a true and fair view of affairs of the charity as at the end of the financial years and of surplus or deficit of the charity. In preparing those financial statements the Board is required to:

- select suitable accounting policies and then apply them consistently,
- make judgments and estimates that are reasonable and prudent,
- prepare financial statements on the ongoing concern basis unless it is inappropriate to presume that the charity will continue in business,
- state where applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements.

The Trustees are also responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which are sufficient to show and explain the charity's transactions and enable them to ensure that the financial statements comply with the Companies Act 1985. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

This report was approved by the Board of Trustees on

Jenny Hirst
Director and Trustee

Insulin Dependent Diabetes Trust

PO Box 294
Northampton
NN1 4XS

tel: 01604 622837

fax: 01604 622838

e-mail: support@iddtinternational.org

website: www.iddtinternational.org