



# Insulin Dependent Diabetes Trust

## Report and Accounts

31<sup>st</sup> December 2005

Registered Company Number 3148360  
Registered Charity No 1058284



## Trustee's Report

The Trustees present their annual report and accounts for the year ended 31st December 2005.

The Board of Trustees is satisfied with the performance of the charity during the year and the position at 31st December 2005 and consider that the charity is in a strong position to continue its activities during the coming year, and the charity's assets are adequate to fulfil its obligations.

The particular ways in which objectives have been achieved are described below.

The Objectives of the Charity and how it is attempting to achieve

the objectives

The charity is constituted as a company limited by guarantee and is therefore governed by a memorandum and articles of association. The directors of the company are also the Trustees of the charity.

The restrictions in the charity's activities imposed by its memorandum and articles are restricted funds which can only be used in furtherance of the charity objectives.

The charity's objectives and principle activities continue to be that of making the day to day life of people with diabetes easier.

The particular way in which these objectives are achieved are detailed below:

- the need to maintain a choice of insulin treatment
- raising awareness of the adverse effects that some people experience when using GM synthetic insulins
- maintaining supplies of animal insulins indefinitely for people, both now and in the future, who cannot tolerate GM insulins.

### **Organisation**

A board of 7 trustees administer the charity, covering policy, membership and finance.

### **Investment powers**

Under the memoranda and articles of the Trust, the charity has the power to make any investment that the Trustees see fit.

### **Related Parties**

The charity has no financial links with any other charities or organisations. IDDT 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, a new organisation investigating ways that patients and clinicians can identify gaps in research that are important to both.

Year 2005 was another active year for IDDT with the focus on reaching the wider population of people with diabetes, the healthcare professionals treating them and parents and children of people with diabetes.

In October 2005 IDDT held its Annual Conference, 'Your Voice Counts' with a maximum attendance. It was particularly pleasing that delegates included non-members of IDDT, people from countries outside the UK and healthcare professionals.

### **Widening IDDT's message**

IDDT intended to continue the planned advertising campaign in local newspapers to inform people of the possible adverse effects of GM,

synthetic insulins and of their choice of insulin treatment. However, the shortages of supplies of animal insulins manufactured by CP/Wockhardt UK continued throughout 2005, therefore IDDT had no alternative but to delay this form of advertising until Wockhardt stocks returned to normal.

As diabetes is increasingly being managed in primary care, the decision was taken to try to put forward the IDDT aims and concerns to primary care nurses and to GPs and so increased the advertising to these health professionals through their professional journals. This increased the numbers of practice nurses expressing a wish to receive information and publications from the Trust to 900 by the end of the year. Many nurses have requested and continue to request multiple copies of IDDT leaflets for their patients.

### **Nursing in Practice Conference**

In 2005 for the first time and encouraged by the response the advertising campaign from nurses, IDDT had a stand at the Nursing in Practice conference at the NEC in Birmingham. This was a great success and the decision has been taken to attend these conference in both Birmingham and Manchester in 2006.

### **Reaching Teachers**

In 2005 IDDT developed an Information Pack for teachers and also one for parents of children with diabetes. The Trust worked with Rapor to produce a pull-out supplement for a teacher's magazine that goes to 26,000 primary schools. The supplement provided basic facts about childhood diabetes and mainly concentrated on recognition of hypoglycaemia in children with diabetes in the classroom and how to deal with it. The supplement was very well received by schools and teachers with many requests for the Information Packs.

### **Increasing the staff**

During 2004 it became clear that if IDDT was to continue to grow and build on the increase in membership and activities of the Trust, then the level of staff would have to be increase to a second full time member of staff. This decision was carried out in early 2006 and has

enabled the Trust to be more efficient and effective.

### **IDDT-International Website**

The revision of the IDDT-International website in June 2004. There has been an increase in visits to the website and in people wishing to join IDDT.

**ePolitix** is a website used extensively as an information source by politicians and civil servants. In 2002 IDDT launched a microsite on the site to raise awareness amongst politicians of the issues that affect people with diabetes and in particular the need for patients to be involved in every aspect of their healthcare and decision making. The Trustees decided to continue with this microsite for 2005 as a source of information to support the lobbying campaign.

### **International activities**

IDDT has continued to expand the international links with people and groups in countries around the world. This became particularly important in the USA and Canada when Eli Lilly, the only supplier of pork insulin in these countries, announced their discontinuation in December 2005 and April 2006 respectively. For people in the USA who are unable to tolerate the only alternative of GM human or analogue insulins, the Trust has worked hard to try to disseminate information about the system for personal importation of both pork and beef insulin from the UK. The IDDT Trustee in Canada, Carol Baker, has worked with others to have Wockhardt pork insulin licensed in Canada. This was achieved in 2006, although at a very worrying high price of the equivalent of £50 a vial.

During 2005 Novo Nordisk also announced discontinuation of pork insulins in all other countries except the UK and the Trust has offered support and information to people in these countries.

### **The Threat and Discontinuation of Pork Insulin by Novo Nordisk**

The final decision by Novo Nordisk about the discontinuation of their pork insulins did not take place in 2005 as promised. In fact, the decision was made in January 2006. So during 2005 IDDT continued

to lobby against Novo Nordisk's discontinuation as it would leave people in the UK in the very vulnerable position of Wockhardt UK being the sole supplier of pork insulin, especially worrying as their supplies were unreliable during 2004 and 2005.

However, during 2005 Novo Nordisk did discontinue some of their GM human insulin product range and recommended people to change to insulin analogues. The Trust deplores this decision by Novo Nordisk and has serious concerns about this unnecessary change of insulin for many people and this further reduction in the choice of insulins, especially as the long-term safety of insulin analogues is unknown and they have the potential for carcinogenic effects.

### **The Safety of Analogue insulins - Should Patients be concerned?**

This is the title of a Supplement published by IDDT and widely circulated to patients, patient organisations and health departments in various countries. The Supplement contains an article by Professor Ernst Chantelau and Jenny Hirst questioning the therapeutic benefits of insulin analogues against their potential carcinogenicity. The article is in two versions - one for non-medical readers and one for medical readers. The purpose of the Supplement is to provide patients with a more informed choice of treatment and to give greater publicity to the concerns about insulin analogues and their unknown long-term safety.

### **Lobbying and Campaigning**

The lobbying campaign that started in 2003 has continued throughout 2004 and 2005. The campaign centres on:

- the need to maintain a choice of all insulin treatment
- raising awareness of the adverse effects that some people suffer when using GM 'human' insulins
- maintaining supplies of animal insulins indefinitely for people who cannot tolerate GM insulins
- the vulnerability of people who need animal insulin if there is only one supplier in the UK.

Our members have worked tirelessly to seek the help of their MPs and MEPs. This resulted in over 30 Parliamentary Questions being asked throughout 2005 and a meeting with the then Health Minister, Jane Kennedy. Following this meeting Jane Kennedy made a statement confirming that the Dept of Health fully accepts that some people need animal insulin and that it should continue to be available. This was a major step forward in the campaign and IDDT has built on this in the following campaign activities. The Trust is totally committed to safeguarding the health and wellbeing of the estimated 30,000 people in the UK, and the many others in countries outside the UK, who are unable to tolerate GM insulins. It is equally committed to maintaining the choice of insulin treatment to suit the varying needs of everyone with insulin requiring diabetes.

In August 2005 IDDT's parliamentary lobbyist, Mr James Pawsey retired and Ranelagh International was appointed to this role. The Trustees would like to thank both Mr Pawsey and Ranelagh for their commitment to our cause and without whom we would not have raised our profile in the political arena or achieved meetings with the Ministers of Health.

The Trustees wish also to express thanks to the many MPs and Members of the House of Lords who have been extremely supportive throughout the year. They also express their sincere gratitude to members of the Trust for their unfailing support and the time and effort they are spending on this campaign. The Trustees also wish to thank Wockhardt UK / CP Pharmaceuticals for their commitment to the ongoing supply of bovine and porcine insulin in vials and cartridges. The Trustees also wish to reiterate that campaign for a second supplier in the UK is not a reflection on the quality of Wockhardt insulins but is based on the belief that one supplier of animal insulin is an unsafe and vulnerable position for the 30,000 people who need it.

**IDDT - International** continues to develop greater communication and mutual support between the IDDT groups and individual people with diabetes in different countries. This has increased with the continued systematic discontinuation of animal insulins in countries around

the world.

2005 saw an increase in the number of people contacting IDDT from other countries many of whom were desperately searching for sources of pork insulin and information about personal importation from the UK.

The Trust continues to deplore the discontinuation of animal insulins in countries around the world as it denies people the treatment they need at an affordable price. The Trust also continues to be concerned that people are not given the fully informed choice of insulin treatment, to which they are entitled. This convinces the Trustees of the continued necessity for IDDT-International to provide factually correct information to people with diabetes.

IDDT-International continues to enable people to recognise that the adverse effects they experience with synthetic insulins are shared by many other people. 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 and for easily accessible and affordable natural animal insulins.

### **IDDT publications**

The Trust continues to publish a quarterly Newsletter which is distributed to members, to over 400 diabetes specialist nurses and 900 practice nurses with a special interest in diabetes. During 2005 IDDT continued to develop a database of people who contact IDDT for information that has resulted in a continued increase in membership.

The Trust has increased the number of leaflets that are available on various aspects of diabetes and redesigned them into small booklets for easier display in GP and hospital waiting rooms. The demand for IDDT leaflets from people with diabetes, their relatives and from health professionals has markedly increased throughout the year.

IDDT continues to provide the Newsletter in large print and on tape for

visually impaired and blind people. The Trustees again wish to thank to Eileen and Richard Probyn-Skinner for being the readers for the tape version.

### **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 - to studies that look into ways of making the day to day life with diabetes easier for people.

Legacy income is variable but it was agreed at the AGM 2005 that the amount available for each grant should be increased from £10,000 to up to £30,000. Many of the applications received are not in line with the Trust's policy and therefore have not been accepted.

In 2005, the Trust approved grants in the following areas:

- whether insulin analogues have mitogenic activity ie increased cell multiplication.
- Evaluation of the diagnosis, treatment and follow up by healthcare providers in Ramallah where there are very few poorly equipped and staffed diabetic clinics.
- The relationship between the maternal blood glucose, their constituents of colostrum and the baby's source of energy in women with and without diabetes.
- An extension of the grant to evaluate the NSF for diabetes in primary care.

### **IDDT activities for people in developing countries**

Collection of in-date, unwanted insulin - in 2005 the Trust collected over 25,000mls of unwanted insulin for people unable to afford insulin - a massive 2.5 million units of insulin! We responded quickly to tsunami appeal followed by regular supplies of insulin to help children and adults with diabetes in India, Tanzania and Turkey. The Trust thanks all those who send unwanted insulin and especially the diabetes clinics around the UK who are very supportive of this initiative.

Sponsor a child at the Dream Trust - the numbers of people supporting

this scheme to help with the insulin and medical costs of children at Dream Trust in India has grown so that £300 per month is now being sent. The sponsors, who donate at least £2.00 per month, receive regular reports about the progress of the children and these show how they benefit from this help. IDDT and Dr Pendsey at Dream Trust express their gratitude to IDDT members who support needy families.

### **Financial Affairs**

IDDT is 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.

### **In conclusion**

The Trustees would like to express their thanks for the continuing support and help of IDDT members and their families which provides encouragement to Trustees to continue with the aims and objectives of IDDT. It also 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.

### **The organisational structure and how decisions are made**

The organisational structure of IDDT is a Board of Trustees who are involved in the decision making for the charity. There are two paid members of staff who carry out the decisions the decisions of the Trustees. Minor day to day decisions are taken by the Co-Chairs in consultation with the Treasurer, 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.

### **Method of election of members of the Board of Trustees**

This is carried out at the AGM in accordance with the Memorandum and Articles of the charity. The whole membership is invited to nominate members for election to the Board of Trustees. There is a rotation system 3 yearly and if there has been an absence of new nominations, the AGM has proposed and approved that the Board be re-elected.

#### **Relationships with other groups, charities and individuals**

The Trust is a totally independent organisation.

#### **Details of related parties and transactions with related parties**

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

#### **Transactions and Financial position**

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 £296,772 and net realised incoming of a capital nature of £568,341, making net overall realised outgoing resources of £271,565. The total reserves at the year end after reserving for unrealised losses of nil stand at £2,027,677.

#### **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 fulfil its obligations.

#### **Policies on reserves, investment policies and investment performance**

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 which 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.

#### **Share Capital**

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

#### **Effectiveness of fundraising policies**

The charity relies on grant aid from the donors identified in the accounts and whose support is valued. There are no other fundraising activities.

#### **The major risks to which the charity is exposed and reviews and systems mitigate**

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.

#### **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.

#### **The members of the Board of Trustees of the Charity during the year ended 31st December 2005 were:**

##### **Co- Chairman**

Jenny Hirst

Dr Matthew Kiln

**Treasurer**

Sue Morris

**Medical Adviser**

Dr Laurence Gerlis

**Trustees**

Carol Baker

Larrane Ingram

Veronica Readman

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.

The members of the Board of Trustees of the Charity at the date the report and accounts were approved were:

**Co- Chairman**

Jenny Hirst

Dr Matthew Kiln

**Treasurer**

Sue Morris

**Medical Adviser**

Dr Laurence Gerlis

**Trustees**

Carol Baker

Larrane Ingram

Veronica Readman

**Bankers**

Barclays Bank plc

Leicester

LE87 2BB

**Auditors**

Paul Slater & Co

Chartered Accountants

1 Washington Street

Kingsthorpe

Northampton

Northants

NN2 6NL

**Statement of Directors' and Trustees' Responsibilities**

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 judgements 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 25 July 2006

Mrs S Morris

Director and Trustee

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