



# Insulin Dependent Diabetes Trust

Report and Accounts

31<sup>st</sup> December 2006

Registered Company Number 3148360  
Registered Charity No 1058284



## Trustee's Report

### 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, an organisation investigating ways that patients and clinicians can identify gaps in research that are important to both.

**Year 2006** was another active year for IDDT with the focus remaining on reaching people with diabetes and parents and children living with diabetes. IDDT has also tried to reach greater numbers of health professionals involved in diabetes to try to ensure that they are aware that the choice of pork insulin will continue to be available after the discontinuation of Novo Nordisk pork insulin at the end of 2007.

In October 2006 IDDT held its Annual Conference, *'Make Your Voice Count'* with a maximum attendance. It was particularly pleasing that delegates included non-members of IDDT, people from countries outside the UK and healthcare professionals. It was very noticeable that there was a great demand for more and better education,

especially on the relationship between insulin and diet.

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

There were shortages of supplies of Wockhardt animal insulins during the early part of 2006. This delayed IDDT's planned advertising campaign in local newspapers to inform people of the possible adverse effects of synthetic insulins and of their choice of insulin treatment.

Throughout 2006 there was sustained advertising of IDDT's aims and the continued availability of animal insulins to primary care nurses and to GPs through their professional journals. This significantly increased the numbers of practice nurses expressing a wish to receive information and publications from the Trust to 1800 by the end of the year. Many nurses request multiple copies of IDDT leaflets for their patients and several thousand leaflets were sent out in addition to the quarterly Newsletters.

### **Nursing in Practice Conference**

In 2006 IDDT had stands at the Nursing in Practice conferences in Birmingham and in Manchester. These were a great success and the decision has been taken to attend these conferences in Birmingham, Manchester and London in 2007.

### **Reaching Teachers**

The Information Packs developed in 2005 for teachers and for parents of children with diabetes have been very popular. A children's department has been set up and a quarterly Parents' Bulletin is produced by Beverley Freeman to acknowledge the particular needs of families living with diabetes.

### **Staff levels**

During 2006 IDDT employed two full time members of staff to handle the increasing membership and work load. By the end of 2006, it became clear that it would be advisable to have additional clerical assistance when necessary, if IDDT is to continue to grow and build on the increased membership and activities of the Trust. This decision was carried out in early 2007 and has enabled the Trust to be more

efficient and effective.

### **IDDT-International Website**

The IDDT-International website has continued to be updated and developed and is the largest source of new members.

**ePolitix** is a website used extensively as an information source by politicians and civil servants. IDDT has continued to maintain a microsite with ePolitix to support the lobbying campaign and raise awareness amongst politicians of the issues that affect people with diabetes, especially those requiring animal insulin.

### **International affiliates**

IDDT has strengthened the international links with people and groups in countries around the world. IDDT Canada has successfully campaigned with the Society of Diabetics Rights and in April 2006, Health Canada approved the use of Hypurin pork insulins following the discontinuation of Lilly pork insulin in the same month. Lobbying continues in Canada to try to ensure that all the Provinces help to cover the cost which is the equivalent of £50 a vial, much higher than the UK and unaffordable for many people.

During 2006 Novo Nordisk discontinued pork insulins in all other countries except the UK and the Trust has offered support and information to people in these countries. Associates from Germany are successfully importing pork insulin from Argentina and it works well for them.

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

In January 2006 Novo Nordisk announced the discontinuation of pork insulin in the UK by the end of 2007. During 2006 IDDT continued to lobby government about the vulnerable position of people needing animal insulin once Wockhardt UK becomes sole supplier of pork insulin, especially as their ability to supply during 2004 to 2006 was unreliable. IDDT also expressed concerns about what steps were being taken to ensure that patients received the correct information - that animal insulins would continue to be available. As a result in

May 2006 a meeting was held with the Department of Health, Novo Nordisk, Wockhardt and Diabetes UK. Wockhardt assured the meeting that they had expanded their production facilities and Novo Nordisk gave assurances that their literature would not imply that their discontinuation meant that there was not an alternative supplier of pork insulin. IDDT expressed concerns that people would be effectively 'forced' to use insulin analogues. Sadly despite best efforts, many people are receiving misinformation and a further meeting is to take place in 2007.

The Trust continues to deplore the decision chosen by Novo Nordisk to reduce the choice of insulins to insulin analogues and has serious concerns about the lack of evidence of the long-term safety of insulin analogues and their potential for carcinogenic effects.

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

This Supplement by Professor Ernst Chantelau and Jenny Hirst published by IDDT in 2005 questions the therapeutic benefits of insulin analogues against their potential carcinogenicity. In order to try to ensure that people needing insulin have a truly informed choice of insulin and are aware of the potential risks, the Supplement is circulated to all who contact IDDT.

### **Lobbying and Campaigning**

The lobbying campaign that started in 2003 continued through 2006. The main thrust of the campaign remained the same:

- 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.

Following Novo Nordisk's statement of their intention to discontinue all pork insulins and eventually all 'human' insulins in favour of insulin

analogues, the campaign also focussed on:

- the need for evidence of safety of insulin analogues,
- evidence of their benefit,
- the cost effectiveness to the NHS
- the lack of choice for people unable to tolerate them.

Our members have worked tirelessly to seek the help of their MPs. This resulted in over 30 Parliamentary Questions being asked throughout 2006, many letters from MPs to Ministers and a presentation to a meeting with the All Party Parliamentary Group for Diabetes [APPG]. The APPG agreed to support our campaign and wrote to Andy Burnham MP, then Minister of Health, requesting that the National Institute for Clinical Excellence [NICE] assesses all insulins and issues guidance on their use. In December 2006, the Minister agreed to support this but subsequently reneged upon this agreement requiring increased pressure from IDDT in 2007.

The Trustees would like to thank lobbyists, Ranelagh International, for their help and advice in raising IDDT's profile in the political arena and achieving meetings with the APPG and the Dept of Health. The Trustees also wish to express thanks to the many MPs and Members of the House of Lords who have been extremely supportive throughout the year. Above all, the Trustees express their sincere gratitude to members of the Trust for their unfailing support and the time and effort they are spending on the campaign.

The Trustees thank Wockhardt UK / CP Pharmaceuticals for their commitment to the ongoing supply of bovine and porcine insulin in vials and cartridges and 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.

2006 saw a continued 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 and is concerned that people are not given the fully informed choice of insulin treatment, to which they are entitled. Through the website, IDDT-International enables 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 distributed to members, to diabetes specialist nurses and practice nurses with a special interest in diabetes.

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. They are also produced in large print. 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 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 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 2006, the Trust approved:

- on the basis of a report of the initial work the grant was extended to investigate whether insulin analogues have mitogenic activity ie increased cell multiplication.
- evaluation of the diagnosis, treatment and follow up by healthcare providers in Ramallah.

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

Collection of in-date, unwanted insulin - in 2006 the Trust collected over 20,000mls of unwanted, in-date insulin for people unable to afford it - a massive 2.0 million units of insulin! We also collected blood glucose test strips, new blood glucose meters and thousands of syringes and lancets. The supplies were sent to Africa and India. 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 number of people supporting this scheme to help with the insulin and medical costs of children at Dream Trust in India has grown so that members are now supporting the medical needs of 30 children with diabetes. 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. 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.

### **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 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 editorial 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 £259,596 and net realised incoming of a capital nature of £485,968 making net overall realised outgoing resources of £226,372. The total reserves at the year end after reserving for unrealised losses of nil stand at £2,213,977.

### **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.

### **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 2006 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 10 August 2007

Mrs S Morris  
Director and Trustee

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