



Insulin Dependent Diabetes Trust

Report and Accounts

31st December 2004

Registered Company Number 3148360
Registered Charity No 1058284



Trustee's Report

Organisation

A board of 8 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.

Year 2004 was the 10year anniversary of the formation of IDDT and was another active year for IDDT with the focus on reaching the wider population of people with diabetes and the healthcare professionals treating them.

In October 2004 IDDT celebrated the 10year anniversary with a well-attended conference 'The Voice for Choice'.

Widening IDDT's message

IDDT began a planned advertising campaign in local newspapers to inform people of the possible adverse effects of GM insulins and to inform them of their choice of insulin treatment. There was an excellent response from people with diabetes, as a result of which IDDT membership increased by a third so demonstrating the value of greater publicity of the adverse effects experienced by some people when using synthetic insulin.

The advertising ceased in September due to shortages of supplies of animal insulins manufactured by CP/Wockhardt UK but IDDT plans to continue when stocks return to normal.

With the increasing tendency for diabetes to be managed in primary care, the Trust also increased the number of articles and advertisements in professional journals, especially those concerned with primary care. As a result of this over 500 practice nurses expressed a wish to receive information and publications from the Trust.

Increasing the office facilities

The increase in membership and the increase in activities of the Trust resulted in an office expansion and improved office equipment during 2004. This has enabled the Trust to be more efficient and effective.

Website Revision

A complete revision of the IDDT-International website took place and this was launched in June 2004. There has been an increase in visits to the website and in people wishing to join IDDT..

The Threat of Discontinuation of Pork Insulin by Novo Nordisk UK

In 2003 Novo Nordisk stated their intention to make a final decision about continued availability of their pork insulin before the summer of 2004 but this did not take place. They then stated that they would make the decision by mid 2005 but this has still not been made. IDDT continues to lobby against Novo Nordisk's discontinuation as it would leave people in the UK with Wockhardt UK as the sole supplier of pork insulin and their supplies have unreliable during 2004 and 2005.

However in September 2004, Novo Nordisk did announce 18months notice of the discontinuation of some of their GM 'human' insulin product range. The company recommends that people using these GM insulins should change to insulin analogues but the Trust has serious concerns about this as the long-term safety of insulin analogues is unknown and they have the potential for carcinogenic effects. The Trust deplores Novo Nordisk's decision as it yet again ignores the needs of people with diabetes, it reduces patients' choice and causes

an unnecessary change of insulin for many people, for little or no clinical benefit.

Cochrane Review of Short-acting insulin analogues

In 2004 a Cochrane Review of short-acting insulin analogues was published which showed minimal clinical benefit for patients but warned that a cautious approach to the use of insulin analogues should be adopted due to the lack of evidence of their long-term safety and their potential for carcinogenic effects.

Once again the Trust expresses its thanks to the Cochrane Collaboration for providing people with diabetes with high quality evidence on which to make their treatment choices.

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 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, both now and in the future, who cannot tolerate GM insulins.

Our members have worked tirelessly to seek the help of their MPs and MEPs. This resulted in over 40 Parliamentary Questions, a meeting in May 2004 with civil servants from the Dept of Health and in December a meeting with the Health Minister, Rosie Winterton. The campaign has continued into 2005 and will continue as long as necessary. The Trust is totally committed to safeguarding the health and wellbeing of the 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.

At the AGM in 2003 IDDT members agreed to employ the services of a parliamentary lobbyist. Mr James Pawsey was appointed to this role

and the Trust is extremely grateful to him for his energetic commitment to our cause and without whom we would not have raised our profile in the political arena or achieved meetings with the Minister of Health.

The Trustees wish to express thanks to the many MPs and MEPs who have been extremely supportive. They also express their sincere gratitude to the members 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. We again reiterate that the campaign to maintain Novo Nordisk pork insulins is not a reflection on CP's commitment or the quality of their animal insulins. It is based on the belief that for the UK to be left with 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. During 2004 animal insulins were discontinued in most EU countries.

2004 saw an increase in the number of people contacting IDDT from other countries with many searching for information about personal importation from the UK of the animal insulins they need.

The Trust continues to deplore the discontinuation of animal insulins in countries around the world as it denies people the treatment they need. 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 realise that the adverse effects they experience with synthetic insulin 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 problems that GM insulins can cause and to campaign for easily accessible and affordable natural animal insulins.

In addition to its campaign for continued availability of animal insulins, the Trust has also written to the Minister of Health about the lack or reduction in supplies of blood glucose reagent strips in some areas of the country. This continues to be of concern.

Increasing awareness among politicians and organisations through ePolitix microsite

ePolitix is a website used extensively as an information source by politicians and civil servants. In 2002 IDDT launched a microsite on the forum of ePolitix to raise awareness amongst politicians of the issues that affect people with diabetes and in particular the need for patients/consumers to be involved in every aspect of their healthcare and decision making. The Trustees decided to continue with this microsite for 2004 as a source of information to support the lobbying campaign.

IDDT publications

The Trust continues to publish a quarterly Newsletter and this is sent to members, to 400 diabetes specialist nurses throughout the UK and 550 practice nurses with a special interest in diabetes. During 2004 IDDT has continued to develop a database of people who contact IDDT for information and these people are sent an Information Pack and the next two issues of the Newsletter and then asked if they would like to be members. This system has resulted in an increase in membership.

The Trust has increased the number of leaflets that are available on various aspects of diabetes. The demand for information leaflets has increased and we are now supplying them to people living with diabetes and to healthcare professionals.

IDDT continues to provide the Newsletter in large print and on tape for visually impaired and blind people. The Trustees 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 is hoped that IDDT will be able to continue to make small research grants up to £10,000 available. Many of the applications received are not in line with the Trust's policy and therefore have not been accepted.

In 2004, the Trust awarded three grants in the following areas:

- Young people and insulin pumps
- People with chronic ischaemia and diabetic neuropathy.
- The subjective beliefs about the health and illness in women with Type 2 diabetes.

IDDT activities for people in developing countries

Collection of in-date, unwanted insulin - this continues to grow and in 2004 the Trust collected 52,000mls of insulin for people unable to afford insulin. So regular supplies of insulin and other diabetes related supplies are sent 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 - IDDT members continue to contribute £2.00 or more a month to help sponsor the insulin and medical needs of children at the Dream Trust. Members donate

£180.00 per month and the regular reports about the children demonstrate how much 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. This provides encouragement to continue with the aims and objectives. It also reflects the needs of people with diabetes and their families to be represented by a patient/carer based charity that understands these 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.

Reserves policy

The Trustees regularly assess the activities of the charity in relation to its financial position in order to conform with its rolling forward plan. The Trustees have ensured that there are sufficient free reserves to cover planned activities.

Trustees' responsibilities

The Trustees are responsible for the preparation of the financial statements for each year that give a true and fair view of the state of affairs of the charity at the end of the financial year and of the surplus

deficit for that year. In preparing the financial statements, they are required to:

- Select suitable accounting policies and apply these consistently;
- Make judgements and estimates that are reasonable and prudent;
- Prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue in business.
- The Trustees are responsible for keeping proper records which disclose with reasonable accuracy at any time the financial position of the charity and enables them to ensure that the financial statements comply with the Companies Act 1985. The Trustees are responsible for taking any reasonable steps for the prevention and detection of fraud and any other irregularities.

By order of the Trustees.

Mrs J Hirst (Joint Chairperson)

The Trustees of IDDT 2004

Co Chairman

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