



Insulin Dependent Diabetes Trust

Report and Accounts

31st December 2003

Registered Company Number 3148360
Registered Charity No 1058284



Trustee's Report

The Aims Of The Trust

- To offer care and support to people with diabetes and their family carers, especially those experiencing difficulty with synthetic 'human' insulin.
- To influence appropriate bodies to ensure that all insulin users have a continued supply of their chosen insulin.
- To ensure that all patients and family carers are properly informed of the alternative treatments available to them.
- To collect information and experiences from those with diabetes and their carers, to use the results of this to help others in the same situation and to pass it to health professionals to create a greater understanding of 'life with diabetes'.

- To inform our members and others through a quarterly Newsletter
- In the longer term to promote research and surveys into 'human' insulin and its effects.

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 2003 was an active year for IDDT and one in which the Trust focused on reaching the wider population of people with diabetes and the healthcare professionals treating them. The publication of the Daily Mail article about the adverse effects of synthetic GM insulin in August 2002 had effects into 2003 resulting in increased numbers of people contacting IDDT. This demonstrated the value of greater publicity of the adverse effects experienced by some people when using synthetic insulin and during 2003 IDDT took every opportunity to reach people through the media and membership of IDDT has shown steady growth during 2003.

The publication of the Cochrane Review of animal and 'human' insulin [July 2002, updated May 2003] provided the much needed evidence that synthetic 'human' insulin is not superior to animal insulin. In turn, this enabled Trust to provide people with high quality evidence to support their wishes to change to animal insulin so enabling them to have more meaningful discussions with their doctors. The Trust now includes the abstract of the Cochrane Review in all their Information Packs to inquirers and new members.

Following the publication of the Cochrane Review and in line with the wishes of the members at the Annual General Meeting 2002, the Trust prepared a poster for GPs. It provided information on the findings of the Cochrane Review, the adverse reactions that some people on synthetic GM insulin and the availability of all animal insulins. The mailing was sent to 35,000 GPs in the early part of 2003.

The Trustees would again like to thank all those involved in developing and preparing this Cochrane Review. It has provided the Trust and, more importantly people with diabetes, with the high quality evidence necessary to inform their treatment decisions and those of their doctors.

During 2003, the preparations for a total revision of IDDT-International's website took place and this was launched in June 2004.

The Trust continues to receive a steady rise in income and is very grateful for all the donations and legacies received during 2003.

The Threat of Discontinuation of Pork Insulin by Novo Nordisk UK

In October 2002, IDDT was delighted to announce that Novo Nordisk UK had agreed to continue production of pork insulin. This decision was greeted with great relief and gratitude by the many members who rely on pork insulin to maintain their health and quality of life. However this was short lived and in 2003, IDDT learned that Novo Nordisk had decided to make a final decision about continued availability of their pork insulin before the summer of 2004.

Lobbying and Campaigning

As a result of this information from Novo Nordisk, in 2003 the Trustees decided that the campaign for the continued availability of animal insulin had to be stepped up in order to safeguard the health and wellbeing of the 30,000 people unable to tolerate synthetic GM insulins. It was agreed that IDDT should employ the services of a parliamentary lobbyist. This was carried out and in October 2003, the first of many meetings with MPs of all Parties took place. This has continued in 2004 with the addition of a simultaneous lobbying campaign by IDDT members through their local MPs and MEPs.

The Trustees wish to express their sincere gratitude to the members for their support and the time and effort they are spending on this campaign. They also wish to express their gratitude to CP Pharmaceuticals for their commitment to the supply of bovine and porcine insulin in vials and cartridges. 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 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.

As a result of the diagnosis of one cow in Canada with BSE in late 2003, the Australian government immediately banned all imports of beef insulin. Thanks to the equally immediate actions of IDDT-Australia and communications between IDDT-Canada and the UK this decision was reversed within days.

2003 saw an increase in the number of people contacting IDDT in the United States where the availability of pork insulin became difficult as a result of Eli Lilly discontinuing one of their pork insulins, Pork Lente insulin. Sadly many people were wrongly informed, usually by health professionals and pharmacists, that all pork insulins had been discontinued and this resulted in many desperate calls to IDDT-US and a subsequent increase in IDDT-US membership. This situation was mirrored in Canada.

The Trust continues to deplore the provision of incorrect information about the availability of animal insulins by healthcare professionals to people with diabetes in countries around the world, the United Kingdom being no exception.

The Trust also continues to deplore the fact 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.

2003 saw the preparations for IDDT-India and the Trust is pleased to report that these came to fruition in 2004 with the launch of IDDT-India and the addition of its new website. IDDT's Newsletter continues to be distributed to physicians with an interest in diabetes throughout India.

IDDT-International continues to help people to realise that the adverse effects they experience with synthetic insulin are shared by many other people. Providing information and support for people in this

situation wherever they live continues to be a major role and IDDT encourages and supports them to campaign for recognition of the problems that synthetic 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 2003 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 and to 400 diabetes specialist nurses throughout the UK. During 2003 IDDT developed 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. However, in 2003 the Trustees made an exception and agreed to jointly fund with Harvard University a 3year study looking into the way that insulin works in the body. They considered that this may help to provide a better understanding of why synthetic GM insulins are not tolerated by some people.

IDDT activities for people in developing countries

Collection of in-date, unwanted insulin - this has grown considerably and the Trust continues to send weekly supplies of insulin and other diabetes related essentials for children and young people with diabetes at the Dream Trust in 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 - IDDT members continue to contribute £2.00 or more a month to help sponsor the treatment of a child at the Dream Trust. The Trustees thank everyone who has supported these initiatives to help 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 ensure that people with diabetes and their families have the informed choices of treatment and 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 2003

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