



Insulin Dependent Diabetes Trust

Report and Accounts

31st December 2002

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 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 which 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 2002 was a significant and very active year for IDDT. In July 2002, the Cochrane Review of animal and 'human' insulin was published. In August 2002, the Daily Mail published a major article about the adverse effects that can be caused by 'human' insulin and in October 2002, Novo Nordisk announced a reversal in their strategy and that they would continue to supply pork insulin in the UK. There was a sharp rise in membership following the Daily Mail article and a continued rise in people joining from the IDDT website. The Trust also saw a steady rise in income, especially legacies and donations for research.

High quality scientific evidence - the Cochrane review.

In July 2002, the Cochrane Review comparing animal and 'human' insulin was published and it clearly demonstrated that there is no evidence that 'human' insulin is superior to animal insulin. Of equal importance, the Review also showed that the vast majority of the research was methodologically poor and little or no research had ever been carried out to compare mortality, complications or quality of life issues.

The review not only strengthened IDDT's position for the need for animal insulins to continue to be available but provided patients with the much needed evidence to empower them to request, or even demand, a change to natural animal insulin. IDDT sent copies of the abstract version of the Review to every member and it is included in all information packs to enquirers.

The Trustees would like to thank Sir Iain Chalmers, the retired head of the UK Cochrane Centre, for his encouragement that IDDT should become involved in Cochrane. His support enabled the Trust to recognise the need for high quality evidence to inform healthcare decisions by patients and their doctors. It also provided the Trust with the understanding that first line treatment with synthetic insulin is not, and never has been, based on evidence of benefit.

Mailing of GPs.

In the light of the Cochrane Review and the continuation of Novo Nordisk pork insulin, members at the Annual General Meeting 2002, expressed the wish that the Trust should inform all GPs of the findings of the Cochrane Review, the adverse reactions that some people on synthetic GM insulin and the availability of all animal insulins. A mailing was prepared during the latter part of 2002 and 35,000 GPs were mailed in the early part of 2003.

The Daily Mail, August 29 2002 published an article entitled "The GM Injection" which described the history of the development of synthetic insulin and the adverse effects that many people experienced, including the 'dead in bed syndrome'. This resulted in several hundreds of telephone calls and letters mainly from people who recognised the symptoms the article described and wanted information about the availability of animal insulin. There were also calls from people who were already using animal insulin and wanted to support the work of IDDT to ensure that animal insulin continue to be available.

IDDT sent information packs to everyone that made enquiries and helped and supported people who wished to change to animal insulin. This resulted in a sharp increase in membership and the effects of the Daily Mail article were felt for many months after its publication.

Novo Nordisk reversed their decision to discontinue pork insulin on the UK. Following a meeting with directors of NovoNordisk UK and further correspondence, in October 2002 Novo Nordisk informed IDDT that in view of the fact that 20,000 people in the UK use their pork insulin they had reversed their decision and would continue to supply pork insulin in the UK. 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. At the same time, the Trustees are acutely aware that people in most other countries are not so fortunate. However, it has to be noted that Eli Lilly the suppliers of pork insulin in the US and Canada now state that pork insulin will continue to be available and their published discontinuation dates appear to have been removed.

The Trustees wish to express their gratitude to CP Pharmaceuticals for their commitment to the supply of bovine and porcine insulin in vials and cartridges and for the work they do to help people to import the animal insulins they need through the personal importation procedures in various countries.

IDDT - International continues to develop greater communication and mutual support between the IDDT groups in the different countries. 2002 also saw an increase in the number of people contacting IDDT and from an increased number of countries around the world. Many of these people want help, support and information on the many issues relating to diabetes, its complications and the difficulties of living with it. But sadly, many of the people contacting IDDT are desperate to find a source of natural animal insulin because the animal insulin they have relied on, has been discontinued in their own country. Of great concern to the Trust, is the increasing numbers of people who contact the Trust from America and Canada having been misinformed by healthcare professionals and told that pork insulin is no longer available in their countries. The Trust continues to deplore that incorrect information is provided by such sources that patients should be able to trust.

The increase in communications and reports of the difficulties people are encountering convinces the Trust of the continued need for the choice of natural animal insulins to be available to everyone with diabetes. The Trust also believes that it is essential that people have a truly informed choice of treatment. The formation of IDDT-International was an important and significant step for this group of people.

IDDT-International has helped people to realise that the adverse effects they experience are shared by many other people. It has enabled the events of 2002 described earlier, to be transmitted to people in other countries to encourage and empower them to campaign for recognition of the problems that synthetic insulins can cause and to campaign for easily accessible and affordable natural animal insulins.

Lobbying and Campaigning

During 2002, the Trust developed a database of members who are prepared to be active on such issues. The immediate need for lobbying was removed by Novo Nordisk's change in strategy and IDDT's major role for the foreseeable future must be an awareness campaign:

- To inform people requiring insulin treatment of the availability of animal insulin and their right to informed choice of treatment.
- To inform them of the findings of the Cochrane Review.
- To inform them of the adverse effects that GM insulin causes some people.

To this end a publicity pack has been prepared distributed to members who wish to be active in this way at local level.

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.

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.

The decision in 2001 to produce information leaflets has proved successful and we are now supplying them to people living with diabetes and also to healthcare professionals.

We continue to provide the Newsletter in large print for people 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.

IDDT activities for people in developing countries

Collection of in-date, unwanted insulin - this has continued to grow and the Trust now sends weekly supplies of insulin and other diabetes related essentials to the Dream Trust in India. This is a diabetes clinic for children and young adults whose families cannot afford the necessary insulin and other supplies to keep them alive.

Sponsor a child at the Dream Trust This initiative was started towards the end of 2002. IDDT members have been asked to contribute £2.00 a month to help sponsor the treatment of a child at the Dream Trust. The Trustees thank everyone that has helped these initiatives to help needy people.

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 2002

Co Chairman

Jenny Hirst

Dr Matthew Kiln

Treasurer

Sue Morris

Medical Adviser

Dr Laurence Gerlis

Trustees

Carol Baker

Larrane Ingram

Veronica Readman

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