Insulin Dependent Diabetes Trust

Report and Accounts
19/20th May 2001

Registered Company Number 3148360
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Trustee's Report

Comfort Inn, Birmingham
This year was the first time that IDDT had held the Annual Meeting with a programme that covered Saturday and Sunday and around 70 people attended. There was an international perspective with speakers from the Australia, America and the UK. The programme was also designed to provide plenty of opportunity for discussions both formally and informally. For some people this was their first opportunity to meet other people with diabetes and their partners, for others it was a welcome opportunity to discuss issues that were important to them. Clearly the overnight stay provided the right atmosphere for people to get to know and learn from each other because there were demands fir this format to continue in the future.

Alone and vulnerable

Jenny Hirst, UK
Jenny opened this session by pointing out that the title was very apt both for individual people who need animal insulin and for IDDT as an organisation. People who suffer the adverse reactions to 'human' insulin are often alone and vulnerable not only because they appear to be the only ones in their locality but also because they are told that they are! IDDT is alone because it is the only organisation that has been truly campaigning for choice of insulins to be available and for the continued availability of animal insulins. As such IDDT is alone and vulnerable and just as people who need animal insulin are criticised and made to feel extreme, neurotic or simply 'trouble causers', IDDT has had all these accusations levelled at it, as have the Trustees.

Jenny then read out a Newspaper cutting dated May 4th 2001. A

mother had found her 16year old son with diabetes dead in his bed one morning - the day after he had been for his routine check for his diabetes and doctors had given him a clean bill of health.

From the press cuttings that IDDT receives, sadly it is clear that this case is by no means isolated with reports of people with diabetes having driving accidents, going missing or wondering off and children rescuing their unconscious parent. We know that the most likely cause of these happenings is hypoglycaemia with loss of warnings.

IDDT is alone and vulnerable but if necessary we will remain so because there are some very pertinent questions that require answers:

- Why had we never heard of the 'dead in bed' syndrome or the expression hypoglycaemic unawareness before the mid 1980s?
- Why did they appear at the same time as the changeover to 'human' insulin? Was it coincidence?

If 'human' insulin is not the cause of these events, then we need to know what is. Fit and healthy young people dying unexpectedly in their beds are avoidable deaths. For some people hypos without warnings may be avoidable by using less aggressive beef or pork insulins. Diabetes organisations, physicians in diabetes, researchers and healthcare professionals around the world should all be asking these very same questions and until they do both IDDT and people with diabetes will remain vulnerable and alone.

Paul Murphy, USA

Paul told us of his life at work with a responsible job as the chief accountant in a large hospital and his hobbies and pleasures. He recounted his experiences of living with diabetes from childhood and reminded us all of the advent of home blood monitoring and how, for the first time, this gave him the sense of both freedom and of being in control not only of his diabetes but of his life. That is until he was faced with the knowledge that the beef/pork insulin that had kept him so fit and healthy all his life was to be discontinued by the manufacturers, Eli Lilly. While disappointed that he had to go through the process of changing the insulin he had used all his life, he approached the change to 'human' insulin with expectations of "everything would be OK after an initial settling in period". Everything was not OK. His blood glucose control was erratic, he was having hypos without warnings, he felt 'phased out' and most of all he felt that he had lost control of his diabetes, and his life. His medical advisers could offer no remedy. He felt alone and vulnerable.

Eventually though he discovered that he could import CP Pharmaceuticals beef insulin from the UK for personal use. He set about doing this and eventually received his CP beef insulin. His diabetes control returned, he felt better again and he was once more in control of his life.

But to be in control, Paul has to pay £30.00, obtain four permits, be able to afford to buy 6 months supply of beef insulin and he has to find a doctor that will sign a form to say that he has to have beef insulin because none of the insulins available in the US are suitable for him. One of these application forms is for the US Dept of Agriculture because the insulin he requires is an animal product! Paul reminded everyone just how vulnerable he and all of us are, to the commercial decisions of the pharmaceutical industry.

He expressed his very sincere gratitude to CP for producing animal insulins. His need was emphasised by the statement that if he and his wife have to come and live in the UK to get the beef insulin he needs, this is what he will do. He reminded us just how alone and vulnerable we all are, because our health and life depends on the unfeeling decisions of some pharmaceutical companies.

Ron Raab, Australia

In this session Ron talked in his capacity as President of 'Insulin for Life', an organisation that helps to supply people in poor countries with insulin and tries to enable them to have access to affordable insulins. The problem is not simply a lack of insulin supplies but a lack of affordable insulin and people are dying as a result.

Insulin for Life collects and sends unopened, in-date insulin and blood testing strips to poor countries and facilitates donations at times of emergency, such as floods or earthquakes.

Ron pointed out that the use of the more expensive 'human' insulin has made this situation worse. He has been arguing the case within the International Diabetes Federation [IDF] that there is a need to discourage the discontinuation of animal insulins because animal insulins are cheaper, more affordable and therefore will save lives. The local production of insulin should also be encouraged to avoid the high costs charged by the large multi-national insulin manufacturers.

The cost of insulin for one person can be 50% of a family's income. He highlighted the case of a young girl with diabetes in the Philippines. The cheaper animal insulin that she was using, has been discontinued and replaced with significantly more expensive 'human' insulin. There are several children in the family so forcing the parents to choose between paying for insulin for one child or feeding all the children. They had no choice but to feed the other children and were forced to let the little girl with diabetes die - all for lack of affordable insulin.

Ron appealed for people in the UK to collect any unopened, in-date insulin and send it to him. The delegates were very disturbed by this situation and agreed that IDDT should help in any way we can. One obvious way is that we would collect any unwanted insulin and send it to Australia for distribution and that we would highlight this need amongst our members and healthcare professionals.

The curently advocated high carbohydrate approach and it's rationale

Norma McGough BSc SRD
Before starting her talk, Norma said that she had for many years worked as a dietitian within the NHS, had been the Head of the Diet division of Diabetes UK and was now working as an independent consultant on diet related issues. In addition to all of this, her husband has diabetes.

There are 1.4 million people diagnosed with diabetes in the UK – 20% are treated with diet only, 50% diet and tablets and 30% with diet and insulin.

Management goals
Dietitians do value individual experiences from patients but they look at the available evidence to support the diabetes management goals. The two main large studies to provide this evidence are the DCCT [Type 1] and the UKPDS [Type 2] and both studies demonstrated that near normal blood glucose levels reduced complications. So the management goals for people with diabetes are to achieve near normal blood glucose levels.

Aims of diet in diabetes

1. Weight management
2. Blood glucose control
3. Blood lipids control [fats]
4. Management of short and long-term complications

History of diet and diabetes

Pre-insulin discovery – green vegetables and no carbohydrates.

Laurence diet 1951 – unlimited vegetables, controlled carbohydrate in exact portions [eventually becoming the 10gm portions], sugars and sugary food were forbidden but meat, eggs and cheese were allowed freely.

In the early 1980s the BDA made its first dietary recommendations which emphasised high carbohydrate diets and the need for fibre. These recommendations were later updated to re-enforce the present recommended diet of high carbohydrate/low fat diet and to include the recommendations about the type of carbohydrate - the introduction of the glycaemic index whereby carbohydrates that were slower acting were ideal for people with diabetes.

Meal Planning
There are 3 basic options for meal planning and the ideal advice is given as a result of the dietitian assessing the needs of the individual. Meals should be regular and the diet should include more fruit and vegetables and less fat.

There are 3 ways to assess carbohydrate values of a meal:

- Plate model – just looking at a plate of food and assessing its content
- Gycaemia index model – assessing the type of carbohydrate
- Carbohydrate exchange model – carbohydrates are restricted to match with the insulin dose and patient's requirements.

In Conclusion
Norma said that any focus by patients on diet will give improved results but that the real challenge is to maintain changes in the long term. In other words the challenge is to be able to make changes to diet and stick to them!

Questions from the delegates
A question about evidence for the recommendations of the high carb/low fat diet, Norma said that it was based on a meta-analysis of research [assessment of studies on diet] that showed that the liberalised carbohydrate/low fat diet resulted in a reduction of complications.

When asked about the low carbohydrate diet, Norma pointed that decreased carbohydrate intake causes the glycogen stores in the liver to be used up. Glycogen retains fluid and the loss of this fluid as a result of the reduced glycogen is the cause of weight loss but fat stores remain.

My experiences with the low carbohydrate diet

Ron Raab B.Ec.
IDDT published Ron's article in the report of the Annual meeting 2000 [available from IDDT] and he reiterated his positive experiences of changing to a low carb diet over the last 4 years. He emphasised that this was very much his personal choice after looking at the evidence and consulting Dr Richard Bernstein in New York, who has diabetes himself.

Ron explained that the management goals for the low carb diet are the same as those described by Norma - to achieve normal blood glucose levels because the evidence shows that normal blood glucose levels reduce the risk of long-term complications.

The explanation of the logic behind the low carb diet is based on the following steps:

- High carbohydrate intake means that the blood glucose levels will rise sharply and therefore larger doses of insulin are necessary to attempt to keep the blood glucose levels normal. So the peaks and troughs in blood glucose levels are greater.
- Greater fluctuations in blood glucose levels result in a greater risk of hypoglycaemia. The DCCT showed in achieving near normal blood sugars, there was a threefold increased risk of severe hypoglycaemia.
- Low carbohydrate diet results in small peaks and troughs in blood glucose levels, less risk of hypoglycaemia and only small doses of insulin giving greater predictability and less variability in blood glucose levels.
- Insulin is an appetite stimulant and therefore with larger doses of insulin the greater is a need to eat more food resulting in weight increase.

There are additional variables with a high carb/high insulin regime:

1. Insulin absorption varies at different injection times and different sites and the greater the dose, the greater is this variability.
2. It has been shown that patient judgements of food values can be 20% inaccurate, so making control even harder.
3. There is increasing evidence that brief increases in blood

glucose levels, such as those after meals, may contribute to the development of complications. With a low carb diet, these post meal levels do not rise as high.

4. Delayed stomach emptying [gastroparesis] is common in people with long-standing diabetes and this adds to variable and unpredictable blood glucose levels especially so with greater carbohydrate intake.

Ron's results:

- His daily insulin dose is about 16 units and his carbohydrate intake has reduced from 200gms per day to 30gms of the slowly absorbed type.
- Reduction in HbA1c by 29% to 5.9 with less variation in blood glucose levels.
- Hypoglycaemia much less severe.
- Weight reduction from 84kg to 73kg, blood pressure and lipids remain normal.
- Stabilisation of retinopathy
- Gastroparesis is no longer a problem.

Ron went on to cover various issues of concern:
Hunger: He said that this was generally not a problem for him although he was hungry in the evenings and therefore was looking to adjustments in his regime to remedy this. He gave an example of a very satisfying meal containing 12gms carbohydrate and 120 gms protein – garden salad, medium sized steak, fish or vegetable protein, cooked vegetables [no potatoes or similar] and coffee with small amount of milk.

Fats: One of the arguments put against the low carb regime is that a reduction in carbohydrate means that people will eat more fats thus increasing the risk of heart disease. But only saturated fats are 'bad' fats – unsaturated have a protective effect against heart disease.

Nutritional value: It is necessary to ensure that the diet is properly balanced and it may be necessary to take some mineral supplements. There is no basis for concern with the proportions and nature of the low carb, moderate protein, moderate fat regime, is a quote from the Professor of Medicine and Biochemistry, Boston Medical Centre, US.

Is it achievable? Ron pointed out that he had come to his present position after long contemplation of his own diabetes where, after 40 years of diabetes, complications were starting to appear. The drive for him was to achieve normal blood glucose levels to prolong his healthy life "to see his grandchildren grow up".

Panel Discussion
Dr Laurence Gerlis chaired this session. When discussing evidence to support either the high or low carb diets, Laurence pointed out that there was no good evidence to support either. This was quite a shock to many people who believed that the dietary recommendations were based on evidence of benefit.

Sue Morris described her regime. When diagnosed, 25 years ago, she was given an amount of carbohydrate to eat at each meal with the appropriate dose of insulin. She soon found that this was far more food than she wanted to eat and more than she had eaten prior to diagnosis and therefore lowered her carbohydrate intake and adjusted her insulin accordingly. She now eats about 70gms of carbohydrate a day and injects about 30 units of insulin. Laurence expressed the view that Sue 'had it right' because she was eating according to her need and injecting the necessary insulin dose to deal with her food intake.

It was clear that there were a variety of diets being adopted by the delegates and considerable differences in total daily doses of insulin and this appeared to vary according to when people were diagnosed. Many still 'counted' carbohydrates and there was a feeling that the removal of this approach had been a retrograde step for patients in understanding dietary needs, food values and in the ability to balance diet and insulin requirements. Some people were already using a low carbohydrate regime. Beatrice Reid, diagnosed over 70 years ago, pointed out that the low carb diet is not new and was advocated by

Dr Lawrence in the 1930s and is one that she has always followed because 'it makes sense'.

The section of the meeting closed with the following thoughts:

- The accepted dietary recommendations of high carbohydrate intake/ high insulin requirements should be addressed. Are these recommendations based on flawed logic? Are they the most appropriate to achieve normal blood glucose results and reduce the long-term complications as well as the daily complication of hypoglycaemia?
- How achievable is the low carbohydrate diet for most people?
- There should be a more open approach to diet and the low carb approach should be considered as an option according to people's individual needs and lifestyles.
- The low carb diet should not be attempted without advice/ information and then it should be adopted gradually.

Many of those using the high carb regime believed that they should go at least part way down the route of lowering their carbohydrate intake gradually. Many people felt that the low carbohydrate diet offers them another option to try to achieve normal blood glucose results and it gave them hope.

For Information

Diabetes Solution – A Complete to Achieving Normal Blood Sugars
Richard K Bernstein, M.D

Publishers Little Brown and Company.
ISBN number is 0316093440

Or visit the website www.diabetes-normalsugars.com
where large sections of the book are available.

Group discussions
What messages would you like to give to other people with diabetes from this meeting and what messages would you like to give all those involved in diabetes care and treatment?

Here are some of the conclusions that were reached:

- IDDT and the Newsletters need to be actively promoted and to reach more people. It needs to promote two basic messages: "Your good health depends on you" and "People with diabetes need information to enable them to make wise choices about all aspects of their treatment".
- Greater patient empowerment is needed through education, information and knowledge.
- Doctors and healthcare professionals need to learn from their patients.
- There must be a break down of the barriers between doctors and patients so that the relationship is one of equality and mutual respect.
- Greater awareness amongst patients and professionals of 'dead in bed syndrome' and the dangers of hypoglycaemia and loss of warnings.
- Continue to lobby for the choice of insulin to be available.
- IDDT should collect unwanted, unopened indate insulins to send to 'Insulin for Life'.

Suggested actions/policies

1. Formal education about diabetes is limited and patchy, so use IDDT Newsletters for education of people with diabetes and healthcare professionals.
2. IDDT must expand to reach more people - local publicity, personal contacts, local groups etc. IDDT should actively seek volunteers to help with this. Encourage patients and their carers to be active rather than passive participants in their treatment – to question accepted wisdom, require evidence for treatment options, 'is there a better way?' Encourage IDDT and patients to have a non-confrontational approach so that doctors and healthcare professionals do not feel threatened.
3. Encourage patients to realise that they have a wealth of experience that should be used to help health professionals to learn about life

with diabetes. Short advice leaflets for doctors from patients eg don't always blame the patient when control is not as good as you expect. Patients to be involved in training sessions for doctors and healthcare professionals.

4. Encourage greater awareness of the dangers of hypoglycaemia and loss of warnings. 'Dead in bed' - target the at risk groups by contact with Student Unions and encourage students to join IDDT by offering free membership. Target school teachers through their training.
5. IDDT must continue to lobby for the continued supply of animal insulins but should consider a less confrontational approach so that this is part of a policy of patients having the basic rights of information and choice.

Chairman's conclusions

The people at this meeting were just a microcosm of the diabetes community and their views may well reflect the needs of many people with diabetes. IDDT's original aims were very focused on the need to inform people of the adverse effects of 'human' insulin and the need for continued availability of animal insulins but many of the issues of concern would mean IDDT fulfilling a somewhat different and much broader role. Indeed IDDT was being asked to be a truly consumer-based organisation for people with diabetes and their families, one that in the past has been fulfilled by other diabetes organisations.

IDDT Annual General Meeting

The members approved the minutes of last years' AGM, the Annual report of the activities of the Trust and the Audited Accounts. Copies of all these are enclosed with the Newsletter. Members requiring the full version of the Accounts including the Auditors notes should contact IDDT for a copy.

Our Treasurer, Sue Morris pointed out that IDDT's financial position had improved considerably throughout the year and this had enabled IDDT to carry out large mailings to health professionals with updated information in line with out objectives of offering help and support to people who need animal insulins. She also pointed out that IDDT was now in a position to consider commissioning small studies into various aspects of diabetes. It was agreed that any IDDT funded research should be into aspects of living with diabetes now and that IDDT should seek the views of its members on the topics that they consider to be important.

Sue also pointed out that IDDT had been forced to increase it's security of the website and computer systems against virus attacks and this had involved increased expenditure.

The Chairman reported that IDDT membership had continued to grow steadily throughout the year with a greater number of people joining through the IDDT website, which had considerably increased in size. IDDT had also built up greater links with other organisations in the UK and abroad.

There being no other nominations the Trustees were re-elected to continue in their present positions.

There being no other business, the AGM was formally closed.

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