Insulin Dependent Diabetes Trust

Report and Accounts

7th October 2000

Registered Company Number 3148360
Registered Charity No 1058284

Trustee's Report

Annual General Meeting
Jenny Hirst welcomed everyone to the meeting with a special welcome to Professor Teuscher from Switzerland, Beatrice Reid from Eire and Carol Baker from Canada.

The Chairman's Report and Annual Accounts for 1999 were presented and accepted by all those present. It was proposed and unanimously accepted that IDDT should donate £2,000 to the islet cell research in Leicester. The election of Trustees took place resulting in the Board of Trustees remaining the same.

Any other business resulted in a lively discussion about the way forward for IDDT. There were suggestions that IDDT should make every effort to expand its membership to reach more people who live with diabetes for the following reasons:

- IDDT is very much a patient/carer centred organisation with an understanding of life with diabetes and the priorities and needs that people with diabetes have.
- many people do not know of the existence of IDDT and would benefit from the information in the Newsletters.
- many people are still not informed that there are alternatives to genetically produced 'human' insulin and that they may be suffering the adverse reactions to it without being aware of the problems some people have.

The Trustees agreed that during 2000, IDDT has been allowed to grow naturally. There has been considerable growth with IDDT being more financially secure and last year there was a need to

employ administrative assistance but further growth would have to be carefully considered, managed and funded. The Trustees also pointed out that they are very committed to IDDT, but they are all volunteers with 'day jobs' and they were already working for IDDT to full capacity, especially since the development of the web site. Expansion means even more work, more work would mean moving to the position of more paid assistance which in turn, would mean a need for more funds. Members also pointed out that they liked the 'personal touch' of being part of IDDT and that this was one of its strengths and attractions. A suggestion from the floor that IDDT goes down the route of fundraising from members was fiercely rejected by the vast majority of people. They said that one of the reasons they enjoyed membership of IDDT was that they were not constantly badgered for money as with many other charities. At the end of the discussion the Trustees agreed to give ways to achieve future growth their serious consideration.

Not so much human story!

The afternoon session started with an account of the history of the 'human' insulin gathered from press cuttings. It began with an announcement in the New York Times in 1981 that Eli Lilly had started limited testing of 'human' insulin in healthy volunteers and had started to build plants in Indianapolis and Liverpool, UK. It ended with an article in Pulse, May 2000, where the Medical Defence Union were advising GPs to warn their patients that 'human' insulin has the potential for lowered hypoglycaemic awareness so that any legal claims in connection with 'human' insulin would be directed at the manufacturers. It reminded us of just how long people with diabetes had been seeking recognition of the adverse effects they had experienced and the clear resistance to this by almost everyone except patients themselves. It also reminded us that there were and still are, doctors who are prepared to question accepted treatments and to believe patients despite apparent pressure to do otherwise and that we are grateful to them.

The full details of these press cuttings will be published at a later date but are available to anyone who would like to see them – contact IDDT, PO Box 294, Northampton NN1 4XS, tel 01604 622837 or e-mailjenny@iddtinternational.org

What works

Forty three years of living with diabetes and my positive experience with the low carbohydrate regime

Ron Raab B.Ec.

Unfortunately Ron Raab could not make the trip from Australia to be with us because of serious illness within his family and this was very disappointing for everyone. He is, however, coming over to our annual meeting in 2001. Nevertheless, Ron had sent us a copy of his talk that was presented to the meeting and it gave rise to a lively and occasionally heated discussion.

About Ron Raab

The internet site http://go.to/insulinforlife relates to his professional work which concerns improving access to diabetes supplies in countries in need. He established Insulin For Life in 1999 after working for 20 years at the International Diabetes Institute in Melbourne, Australia. He plans to create another site, tentatively named http://go.to/diabetes-lowcarbapproach which he hopes will be a responsible source of information as interest in this approach grows.

Recently Ron was elected as Vice-President of the International Diabetes Federation [IDF] and is also a member of their Insulin Task Force.

Below is Ron's presentation that expands on his article published in IDDT's Summer 2000 Newsletter:

Summary

- This article outlines my before and after experience in adopting a low carbohydrate/low insulin/moderate protein approach to the management of my Type 1, insulin dependent diabetes.

- It also outlines the inherent logic of this approach and the contradictions inherent in the high carbohydrate/high insulin approach. It includes reference to the Diabetes Centre in New York which specialises in this approach and which educated me in it. It also includes my local physician's comments on the improvement in my blood sugar control, decrease in hypoglycaemia and other comments and some professional comments on the nutritional aspects.

I was diagnosed with Type 1 diabetes in 1957 at the age of 6, and started on one insulin injection daily, which was the usual method, because doctors tried to minimise the number of injections per day for children. However, my doctor at the time, who also had Type 1 diabetes, felt back then (1959) that good blood glucose control should be the major aim, and my number of injections was increased to two each day. In 1984 I increased it to 3 each day and since 1994 I have been taking 4 each day.

I started self-blood glucose testing in 1980, and of course before that I was testing urine. I now test 4 times each day (using a plasma calibrated meter) and I also regularly moderately exercise 2-3 times per week. I have had some mild background retinopathy, and do have some mild neuropathy, including some delayed stomach emptying. I do not have major diabetes complications that interfere with my life.

In 1998, through the many contacts I had made, I became aware of a new approach - the low carbohydrate, low glycaemic index food plan together with much lower insulin dose and a choice of protein intake. I also visited a diabetes centre in New York that specialises in this. Its Director (Dr. Richard Bernstein) has had Type 1 diabetes for over 50 years. He adopted this food plan many years ago after a lot of experimentation and he reported that his diabetes control very significantly improved. I was also interested in this approach, as I had observed over many years that when my carbohydrate intake was less, my blood sugars were improved. This further encouraged me to try this very different food plan. I was intrigued by reports of normal HbA1c's in Dr. Bernstein's book, news reports and internet site and the many other similar reports.

I did not adopt this approach earlier because the generally accepted and recommended regime was a high carbohydrate food plan and there was not support or encouragement to try this major change. By 1998, the low carbohydrate diet was being discussed a lot in the USA and there was increasing discussion in the diabetes journals and at conferences.

I experimented a lot and since July 1998 have reduced the total amount of daily carbohydrate from about 200 grams to recently 30 grams, which is all of a slowly absorbed type.

Here are some of the results:

- My insulin dose has fallen by over 45%.
- My HbA1c has improved by 24% to 6.3% and continues to decline.
- There is much less variation in daily blood glucose.
- Hypoglycaemia is much less severe.
- Weight has dropped from 84 kg to 74 kg.
- Retinopathy has stabilised (my ophthalmologist made particular note of this new trend in its progression); blood pressure and lipids remain normal.

Very importantly, hunger has decreased (insulin is an appetite stimulant and this regime has resulted in much less insulin). There is much more motivation, less frustration and my subjective quality of life and outlook has improved enormously. There is still some hunger in the evening, however, as I continue to experiment with the food plan and the type and range of meals, particularly in the evening, I am confident that this will also be significantly reduced. I also continue with regular mild exercise. I am very excited about continuing to be able to lower my HbA1c further.

I do not regard this food plan as "radical" or a "fad". It should not be confused with the extreme food plans, which are periodically publicised, especially in America! It does not need to be a " high

protein diet " - rather the level is chosen in part based on what gives a feeling of satiety.

Lowering daily carbohydrate intake makes sense on many levels. Why eat so much of a food type that is at the root of blood glucose instability and which needs (much) more insulin to (try to) take care of, which in turn creates further problems. There is no evidence supporting high carbohydrate intake over lower intake in terms of blood glucose control, yet this is what is being generally advocated and promoted!! Also kidney disease seems to be subsequent to high blood glucose rather than higher protein intake, according to professionals such as Dr Bernstein and his expert colleagues. The general principles apply also to Type 2 diabetes.

The greater the intake of carbohydrate, the more unpredictable is the timing and size of the resultant increase in blood glucose. We also know that insulin absorption (i.e. the size and timing of the effect of insulin in lowering blood glucose) is variable, both between different injection sites and at different times. This variability also increases as the quantity of insulin injected increases. It therefore follows that a high carbohydrate (even of a slowly absorbed type) and a high insulin regime is a formula for more erratic and unpredictable blood glucose profiles, compared to a low carbohydrate and appropriately matched low insulin regime.

The lower the carbohydrate/insulin mix, the less variability and more predictability there is in blood glucose levels. The glucose curve becomes essentially flat. In my experience, things just fall into place when adopting this approach, and what a great feeling it is!

Delayed and variable stomach emptying (gastroparesis), due to impaired vagus nerve function (another form of diabetic nerve disease), further adds to variable and unpredictable blood glucoses. The greater the carbohydrate intake, the greater the size of the additional unpredictable glucose variability due to this cause as well. Delayed stomach emptying is common in most people with "longstanding" diabetes.

Just one example of a satisfying meal that contains 12 grams carbohydrate and 120 grams protein gross:

- garden salad
- medium size steak or fish or vegetable protein
- cooked vegetables (no potatoes or similar)
- coffee with small amount of milk

There is a whole world of satisfying, and indeed delicious, low carbohydrate foods and meals which are readily available or can be easily prepared. This is a simple and practical regime.

Compare this to a meal with say 100 gms carb. With such a meal while also attempting to maintain near normal sugars continually, you have set yourself up for great variation in blood sugars, including the possibility of a major hypo at some stage during the several hours after the meal. Isn't this exactly what is happening with so many patients? Isn't this likely result really self-evident?

I have consulted with the chief of the Metabolic and Obesity Research Laboratory and Professor of Medicine and Biochemistry at Boston Medical Centre, USA. She saw no basis for concern with the proportions and nature of the low carbohydrate, moderate protein, moderate fat regime that underpins this approach.

The major pharmaceutical manufacturer, Bayer, now endorses this approach and includes information about it with meters it sells in America and cites persons with diabetes who use this approach as "living proof of the success of this method".

I was invited to give a talk and slide presentation to a Japanese Diabetes Education Center organised symposium for physicians and educators in April 2000, under the title "The Experience of the Person with Diabetes", on my experiences with this system of blood glucose management. I was invited to make a similar presentation at the Australian Diabetes Society/ Australian Diabetes Educators Association Annual Scientific Meeting in August 2000 at the symposium

"Carbohydrate- More or Less". Following this presentation, my local physician, Dr Richard Arnott, made a number of comments to the participants, including:

"The turn around in Ron's health has been quite dramatic. He previously averaged HbA1c in the mid 8'sand now, over the last 2 years they have averaged 6.3-7.2 and there is also a dramatic redisction in the nuber of hypos, which were a major problem for Ron previously.

His lipids are still within quite acceptable boundaries. There is no dramatic change there. It is an anecdote and I think Ron is in many ways more committed to his diabetes in looking after himself that a lot of people I see, but what he has achieved is quite dramatic and I am ver interested to see more data on this. I think it opens up the question of just how we could improve on things, I think the longer you are in diabetes, the more you realise there is a lot we do not know and we should question some of the accepted dogmas."

I am trying to play a responsible role in discussion and debate about these issues. For me, and many others who now have close to normal blood sugars 24 hours per day, there is no other way to achieve this other than with a low carbohydrate regime.

In summary, smaller amounts of carbohydrate require smaller amounts of insulin and this results in more predictability and much less variation in blood glucose levels.

We now have the tools to maintain near normal blood sugars all the time.

Comments from the delegates!
There was an interesting mixture of responses to the low carbohydrate diet and, indeed, diet generally but one point that was made was that **changes should be made under professional supervision – Ron was trained in this regime**. Nevertheless it made people think and question the dietary advice they had received and the diets they were presently following. It seemed that there were people adopting one of three types of diet with some consideration being given to the glycaemic index:

- **Carbohydrate controlled diet** where the insulin dose is decided and the appropriate amount of carbohydrate then consumed. The point was made that the problems with the carb controlled diet were that all too often the dietician recommended more carbs than the person actually wanted to eat, often more than they ate before they became diabetic. Many people had altered this themselves, ate less and lowered their insulin dose accordingly – perhaps one of the steps along the way to a lowering of carbohydrates in the diet and using a lower dose of insulin.
- **The recommended healthy eating diet** with the amount of carbohydrates not being controlled. The problem expressed with the healthy eating diet was that neither the insulin dose nor the carbs are fixed or stable and this gave rise to many questions: How do newly diagnosed people learn how to balance food and insulin? How do you know what insulin to take if you do not know how much carbohydrate you have eaten? How can 'good' blood sugars results be achieved without constantly adjusting insulin doses and if insulin doses are being constantly adjusted how is balance ever achieved? How do people who do not have the confidence to adjust their own insulin cope under these circumstances? It was also suggested that this 'free' diet meant that people were less aware of food types and their effects because they did not appear to have had as much education on foods and how they work as in the 'old days'. The approach now seemed to be one of "just follow the government recommendations for the general population on healthy eating."
- **Low carbohydrate diet** as described by Ron [although not necessarily as low]. The logic of the low carb diet was accepted by many people – low carb, low glycaemic index foods and would produce less dips and peaks in blood sugars and an appreciably smaller daily intake of insulin. It was also agreed that this would not suit everyone but that it is an option that should be considered in the treatment of people with diabetes but perhaps the way forward is to gradually reduce carbohydrate intake balanced with

a gradual reduction in insulin daily intake. It was recognised that this was radical thinking and not in line with present dietary advice but delegates wondered if dietary advice has just grown like Topsy over the years. On what basis have the dietary recommendations been changed over the years? On the basis of evidence from research and is it possible to have a complete re-think about diet for people with both type 1 and type 2 diabetes?

Any conclusions at the end of the meeting? No! It was clear from the discussion that there were many different attitudes to diet, many different diets being adopted and that the dietary advice from health professionals varied. The meeting did come to the conclusion that there are two very basic questions that need asking and the answers may well point the way forward for future dietary recommendations.

1. What makes blood sugars rise and fall? There is a simple answer - carbohydrates make blood sugars rise and a high carbohydrate diet will make them rise steeply. Insulin injections make them fall. It appears therefore that what we need to do is to stop them rising so steeply and then having to be brought down by large doses of insulin.

2. On what evidence from research are the present dietary recommendations based?

We have all been taught that diet is one of the three cornerstones of the treatment of diabetes. We need to know that the dietary advice we receive is based on evidence from methodologically good research in exactly the same way as we need to know that insulin treatment or tablet treatment we receive is based on evidence from 'good' research.

Summary of the day
Time ran out and Jenny Hirst closed the meeting by pointing out that we would have the opportunity to develop these discussions in 2001 when Ron Raab would be with us to tell us more about his experiences with the low carbohydrate diet. She thanked everyone for attending and for their active participation and reminded everyone that this is what IDDT is all about – people with diabetes sharing their views and experiences with each other and taking an active role in looking at their treatment even if this sometimes means questioning accepted wisdom.

For you diary
The Annual Meeting for 2001 will be held in Birmingham at the Comfort Inn on May 19 and 20th, with an overnight stay to assist people who have to travel a long way. Details will be circulated to members in the coming weeks.

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