# DIABETES
# IRELAND

SINCE 1967, DIABETES IRELAND HAS BEEN DEDICATED TO HELPING PEOPLE WITH DIABETES

# Diabetes Ireland

Produced for the 50th anniversary
of Diabetes Ireland

April 2017

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# Foreword

**We are delighted to welcome you to this publication, produced to commemorate 50 years of Diabetes Ireland. In November 2016 we held our 50th annual general meeting in Dublin, which marked the beginning of our year-long celebrations.**

The seeds of Diabetes Ireland were sown in 1957 when efforts were made to get a diabetes charity off the ground. However, it wasn't until 1967 that the momentum was established for an organisation to become a reality. Some 750 people attended the first public meeting of the Irish Diabetic Association in Dublin. One of its first major successes was to obtain free medication for people with diabetes.

Since then each year our organisation has gone from strength to strength as we identify and achieve annual goals. This publication charts the development of Diabetes Ireland over the past 50 years.

We have grown to become a strong and unified voice in advocating for better services for those with diabetes and influencing health policy in this area. The purchase of a state-of-the-art headquarters in Santry in 2013 considerably broadened our scope, enabling us to offer services directly to thousands of people with diabetes. The opening of another care centre in Cork was one of the highlights of 2016.

With our comprehensive support and education services, our meetings, activities and regional services nationwide, our website and quarterly magazine, we constantly strive to provide what our members need to optimally manage their diabetes.

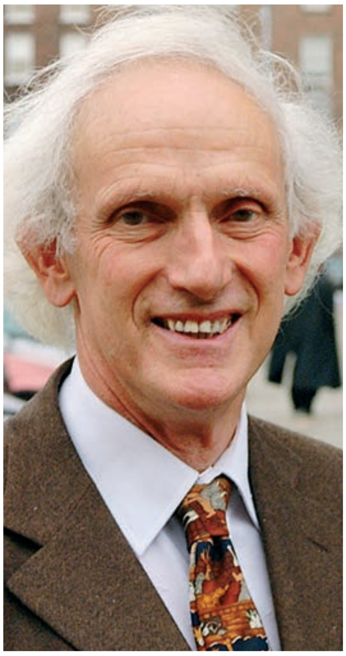
We would like to take this opportunity to thank everyone who has given their time, commitment and enthusiasm – in paid roles and as volunteers – over the past 50 years. We look forward to many more advances as Diabetes Ireland continues to grow.

**Hilary Hoey, Chairperson**
**Gerald Tomkin, President**

# Contents

# From a single room to a state-of-the-art **Diabetes Care Centre**

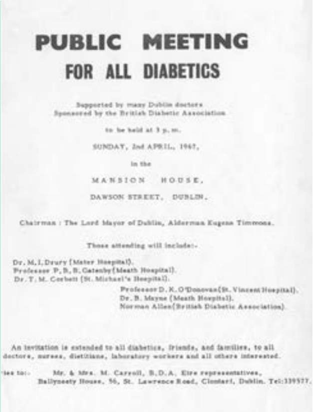
Diabetes Ireland has had a major impact on awareness of diabetes and the development of diabetes services in Ireland, Prof Gerald Tomkin tells Sheila O'Kelly



Prof Gerald Tomkin

1967
First public meeting

1999
Four Peaks Challenge



PUBLIC MEETING
FOR ALL DIABETICS

Supported by many Dublin doctors
Sponsored by the British Diabetic Association

to be held at 3 p.m.

SUNDAY, 2nd APRIL, 1967,

in the

MANSION HOUSE,

DAWSON STREET, DUBLIN.

Chairman : The Lord Mayor of Dublin, Alderman Eugene Timmons.

Those attending will include:-

Dr. M.I. Drury (Mater Hospital).
Professor P.B.B. Gatenby (Meath Hospital).
Dr. T. M. Corbett (St. Michael's Hospital).
Professor D. K. O'Donovan (St. Vincent Hospital).
Dr. B. Mayne (Meath Hospital).
Norman Allen (British Diabetic Association).

An invitation is extended to all diabetics, friends, and families, to all doctors, nurses, dietitians, laboratory workers and all others interested.

ies to:- Mr. & Mrs. M. Carroll, B.D.A. Eire representatives,
Ballyneety House, 56, St. Lawrence Road, Clontarf, Dublin. Tel:339577.

**In 1975 Prof Gerald Tomkin embarked on what was to become a long-term involvement with the Irish Diabetic Association, subsequently the Diabetes Federation of Ireland and now Diabetes Ireland. This had been set up in 1967 by Patricia and Michael Carroll, who had tirelessly run the fledgling organisation from a room in their home in Clontarf, Dublin.**

Their first major achievement had been in relation to medication for Type 1. "The Carrolls were successful in working to get free insulin for everyone with Type 1 diabetes. At that time the health services were not well organised for the lesser well off and insulin had very significant cost implications for many," Prof Tomkin recalls.

While this was a real milestone for people with diabetes, there was a lot more to be done. Prof Tomkin believed that the appointment of a strong CEO was warranted to spearhead efforts at advocating for people with diabetes and growing the organisation.

Ian Morrison, former director of the Bank of Ireland and chairman of the Adelaide Hospital Board, became president of the Irish Diabetic Association. In addition, Paul Mooney, from the pharmaceutical company NovoNordisk, then came on board and added some extra energy to the organisation.

Between 1995 and 1997 the organisation received a two-year grant of £50,000 for educational literature from the Department of Health through the National Lottery.

Around this time it also received a £25,000 grant from Servier Laboratories to conduct a pilot scheme through general practitioners to identify people newly diagnosed with Type 2 diabetes.

In addition, the Four Peaks Challenge in the 1990s attracted attention. Shown on RTE it raised a lot of money.

"It was important because it showed the public that diabetes was compatible with the highest achievements," said Prof Tomkin.

In 1998, Kieran O'Leary joined the Diabetes Federation of Ireland. One of his early fundraising successes was to organise the Kilimanjaro trek. In 2000, the first National Exercise Day was held with the aim of developing public awareness that exercise had

a role in preventing type 2 diabetes and heart disease.

"The organisation has gone from strength to strength since then. Kieran has excellent communications skills and powers of persuasion, particularly with the Department of Health. He has been an outstanding CEO ," said Prof Tomkin.

Another key appointment was that of Anna Clarke, clinical nurse specialist, who has since received a doctorate and has grown her role into the important area of Health Promotion and Research Manager. "Between these two appointments Diabetes Ireland now has a very powerful voice", said Prof Tomkin.

Underlying the growth and success of the organisation, is the fact that Diabetes Ireland has doggedly knocked on doors and continuously makes noise about diabetes care.

"Diabetes Ireland has had an enormous effect on awareness of diabetes and the growth in services. There was no other voice. It has been a huge advocate for patients and provides the necessary support. We know that the appointments of many of our consultant endocrinologists wouldn't have happened around the country without Diabetes Ireland. It has also boosted services hugely, especially in terms of diabetes nurse specialists, dietitians and podiatrists," said Prof Tomkin. These services are continuing to expand.

Times have changed in terms of how diabetes is perceived as a public health issue. Around 2000 the National Cardiovascular Health Strategy published by the Department of Health and Children, barely mentioned diabetes. However, following discussions with the Diabetes Federation, by 2001 the Department had started to rethink this. Up until then there was little awareness about how important vascular disease was in relation to diabetes.

"Only microvascular disease – blindness, kidney failure and neuropathy – had been considered relevant. No one talked about large vessel disease – hypertension and dyslipidaemia (cholesterol levels) as being important aspects to managing people with diabetes. So it has changed dramatically over the years," said Prof Tomkin.

Other major developments have been in relation to paediatric diabetes.

"Children really had a very hard time when I first started practising. Things have improved dramatically for paediatric diabetes care," said Prof Tomkin.

There were very few paediatricians with specialised diabetes knowledge in the 1970s. Now there are several in the country with more appointments being planned.

"There is much more awareness regarding care of children with diabetes. Improved access to insulin pump therapy has been very helpful," he said.

He points in particular to the support from Diabetes Ireland children's camps and activities, and the role of parent support groups.

For years Diabetes Ireland campaigned for free annual eye screening for people with diabetes. Finally, in 2013, the national Diabetic RetinaScreen programme began. It offers free eye screening for everyone with diabetes over the age of 12 and has been a great success, said Prof Tomkin.

The move by Diabetes Ireland from Gardiner Street to state-of-the-art premises in Santry in 2013 moved the organisation up another gear. Prof Tomkin feels that the timing was perfect for this major expansion.

"That was completely due to Kieran O'Leary's foresight. He saw the opportunity when property prices were so low. It is wonderful to see the Care Centre thriving. They have used the space in Santry to make it an active rather than a passive sort of place."

When Prof Tomkin came back to Ireland from working abroad in 1975, there was very little diabetes expertise in the country.

"Most physicians looking after diabetes had very little knowledge of diabetes apart from in one or two units. However, when I trained I worked with a specialist called Robert H Micks in Sir Patrick Dun's who was professor of therapeutics. Prof Micks was exceptional because during the war he promoted a new machine for measuring potassium. The significance of that was that ketoacidosis can cause potassium to fall to dangerously low levels".

Diabetic ketoacidosis (DKA) is a dangerous

Number
27655

4399365

**Certificate of Incorporation**
on change of name

I hereby certify that
**THE IRISH DIABETIC ASSOCIATION**

having, by a Special Resolution of the Company, and with the approval of the Minister for Enterprise, Trade and Employment, changed its name, is now incorporated as a limited company under the name

**THE DIABETES FEDERATION OF IRELAND**

and I have entered such name on the Register accordingly.

Given under my hand at Dublin, this
**Wednesday, the 8th day of March, 2000**

for Registrar of Companies

RP

The official opening of the new Diabetes Care Centre in 2013 by Roisin Shortall

2013
New state-of-the-art premises

2013

Diabetic RetinaScreen Programme

2000

First national exercise day

> The first significant change in diabetes care during Prof Tomkin's professional career was the recognition that diabetes was also associated with large vessel disease, which could lead to heart attacks and strokes

condition upsetting the delicate balance of the body's chemistry. Prof Micks popularised the use of potassium all over Europe.

"In the US people were dying of ketoacidosis a few days after hospital admission, because their potassium went right down. Now more people die from hypoglycaemia than they do of ketoacidosis," said Prof Tomkin.

"He is considered one of the founding fathers of saving lives from ketoacidosis. It was this work in particular that promoted my interest in diabetes," he added.

"In the Mater Hospital, Dr Ivo Drury made a big impact and developed a diabetes centre. He was quite extraordinary because he looked after diabetes patients in the three maternity hospitals. He had a very unusual way of treating people with diabetes by giving them huge doses of long-acting insulin. He was a very good clinician," he said.

From the 1970s, physicians such as Dr John O'Sullivan in Cork, Dr John O'Donnell in Galway and Dr Jim Devlin in Beaumont began to specialise in diabetes.

Endocrinology was developing as a specialist field in the UK. When Prof Tomkin returned to the Adelaide Hospital, the concept of specialising in diabetes was not commonly accepted. "I had to work very hard to specialise in the area," said Prof Tomkin.

The first significant change in diabetes care during Prof Tomkin's professional career was the recognition that diabetes was also associated with large vessel disease, which could lead to heart attacks and strokes.

"This awareness came at a time when we could do something about it. Up to about 20 years ago we had very poor medication for blood pressure and no treatment for cholesterol. Then suddenly we could address these.

"People were also beginning to realise that good diabetes control really did stop retinopathy," he said, adding that these changes had taken a long time.

Prof Tomkin does not consider therapeutic developments or the insulins as the answer to everything in diabetes management.

His view is that metformin and sulphonylureas have been the mainstay of treatment for Type 2 diabetes for more than 20 years, and still are.

He said people are living longer because of the improvements in cholesterol lowering and blood pressure medications. The understanding that high blood sugar damages the eyes has also reduced the levels of diabetic retinopathy.

But what has made the biggest difference in treating eye disease is laser therapy and the new anti-VEGF injections for treating macular degeneration. "These treatments are incredibly successful in stopping blindness," said Prof Tomkin.

This means that people are living very successfully with diabetes and they are living longer. They don't go blind and they don't lose their kidney function due to high blood pressure.

Despite all the improvements in care, the incidence of both Type 1 and Type 2 diabetes is increasing. Prof Tomkin believes that the higher levels of obesity do not necessarily tell the full story, particularly as increasing Type 1 diabetes levels are unrelated to obesity.

"The beta cell transplants have been disappointing. The pancreas transplant is now very successful, but it really is such a huge operation and there are not enough pancreases to go around. There is also the related problem of serious immunosuppression," said Prof Tomkin.

"The new generation of islet cells or beta cells that can be manufactured and put in under the skin are exciting. If these fail you can repeat the process. That is very exciting for the future of Type 1 diabetes therapy. Diabetes care facilities are much better now. Our main problem is getting people to take control of their own diabetes," said Prof Tomkin.

"We often see both young and old people who just disappear from the clinics. They feel well and don't think about the future or they may be scared. This is a major concern and we haven't anywhere near a proper understanding yet about how to help these people," said Prof Tomkin.

# **Three pioneering women** who helped get Diabetes Ireland on its feet

## Phil Vizzard

**Phil Vizzard was the first person to be employed by the then Irish Diabetic Association, with which she worked from 1982 until shortly before her untimely death in 1994. She joined the Irish Diabetic Association when her youngest child started school. At the time the organisation was run from the front room of the two founders, Michael and Patricia Carroll.**

The family involvement has continued in latter years with Phil's daughter, Nicola Vizzard, now a diabetes nurse specialist and a former director of Diabetes Ireland. "Phil was always chatting to patients. She loved her job, absolutely loved it," recalls Nicola.

In October 1989, Phil attended the key St Vincent meeting in Italy on behalf of the Irish Diabetic Association. The small Italian town of St Vincent hosted a meeting organised by the World Health Organization and the International Diabetes Federation. At this meeting, representatives of diabetes associations, including the then Irish Diabetic Association, and government health departments from all over Europe unanimously agreed what became a landmark document known as the St Vincent Declaration.

Nicola also remembers her mother being very much involved when the European Association for the Study of Diabetes (EASD) held its conference in the RDS, Dublin in the early 1990s.

Another highlight was when the renowned pianist, Ruth Slenczynska, played on behalf of the organisation in March 1992, at the National Concert Hall, Dublin. It was a fundraiser and part of the 25th anniversary celebrations.

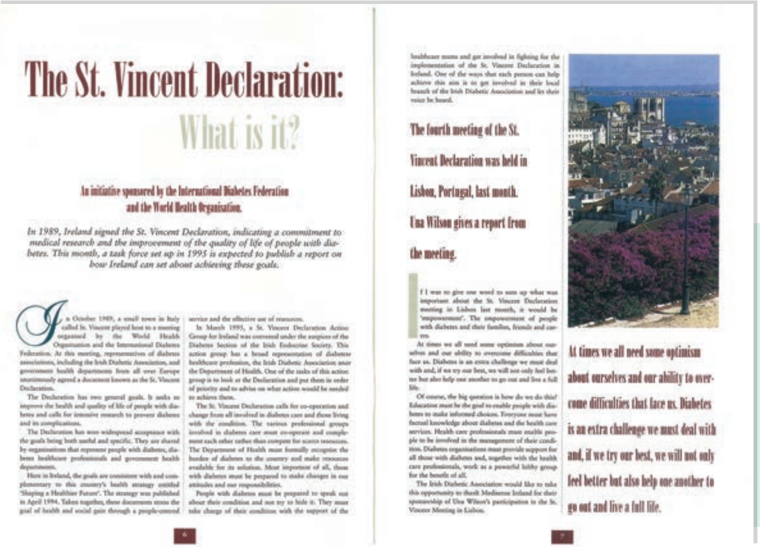
One important contribution Phil made was to introduce computerisation to the organisation.

"She had to learn computers herself to do so," recalls Nicola. "Diabetes Ireland has gone from strength to strength and it is great to see it. It went from an organisation with one part-time employee (Phil); then Úna Wilson joined to make it one and a half people and now to see what they have. My father would say that 'if mammy was alive today and she saw how great the organisation was, she would be so happy," said Nicola.

The Phil Vizzard Research Fellowship Grant was set up in Phil's memory after she died in 1994.

Nicola has been working for some time as a diabetes nurse specialist, and explains that this came about purely by accident.

"I trained in the Mater in 1997. For the last year of my training I did a lot of work on St John's diabetes ward in the Mater. I really enjoyed it. Then I went to Holles Street Hospital for two years. In 1995, I filled a maternity cover vacancy in the Diabetes Day Centre – all by pure accident – and I ended up staying in that clinic until I moved to the Mater Private Hospital last year," said Nicola.



The St. Vincent Declaration:

What is it?

An initiative sponsored by the International Diabetes Federation and the World Health Organisation.

*In 1989, Ireland signed the St. Vincent Declaration, indicating a commitment to medical research and the improvement of the quality of life of people with diabetes. This month, a task force set up in 1995 is expected to publish a report on how Ireland can set about achieving these goals.*

The fourth meeting of the St. Vincent Declaration was held in Lisbon, Portugal, last month. Una Wilson gives a report from the meeting.

At times we all need some optimism about ourselves and our ability to overcome difficulties that face us. Diabetes is an extra challenge we must deal with and, if we try our best, we will not only feel better but also help one another to go out and live a full life.

1989

St Vincent Declaration

1994
Phil Vizzard Research Fellowship Grant

“In the old days of Diabetes Ireland, even before I was qualified, we were always fundraising. We’d be shaking boxes outside football matches, raising sponsorship or collecting money in pubs. Of course the money they had then was nothing like what they have now. There were months in the old days when there was not enough money in the pot to pay the staff salaries. They have come on so much now,” said Nicola.

“I think Diabetes Ireland is a huge support for people with diabetes. If anyone is looking for general information, I will always refer them to the Diabetes Ireland website. All the information they will get there is free, accurate and up to date. It is a great network of patients and the new centre in Santry is fabulous with wonderful services,” said Nicola.

Nicola was a director of the Diabetes Federation of Ireland for some years. She was very involved with the family activity camps and fundraisers like the trip to Kilimanjaro.

“I learnt more on those weekends away with the young adolescents than any text book would ever have taught me. You see them living with diabetes and coping or not coping with it. It meant that when people came into the clinic and asked me if their children should go on one of the camps, I could say, yes definitely. The children pick up so much information from each other.

“People are now more aware of diabetes than they were years ago. Information is everywhere. When I qualified, Type 2 diabetes was for the middle-aged overweight person – over 50. Now we are seeing them in their 30s and 40s. And sometimes in their 20s,” said Nicola.

## Úna Wilson

**Another key woman in the history of Diabetes Ireland was Úna Wilson. She was diagnosed with Type 1 diabetes in 1982 and a few months later her 12-year-old daughter, Orla, was also diagnosed. After their diagnoses, Úna joined the Irish Diabetic Association and started attending all its meetings. More recently, Úna’s grandchild (Orla’s daughter) has been diagnosed with Type 1.**

About 1989, Úna decided to go back to work. She was doing a course and needed to do six weeks’ work experience.

1990
European diabetes meeting Dublin

1990
‘Live Life to the Full’ information pack launched

“I said if I was going to work for free, I would work for someone who needed help and I went to the Association,” said Úna. At the end of the six weeks Úna was offered a part-time job and she joined Phil Vizzard as the second member of staff.

“The two of us got on like a house on fire. The following year we produced our first large information pack. It was called ‘Live Life to the Full’ and there was about 10 sheets in it dealing with the different aspects of diabetes,” said Úna.

In 1990, there was a major European diabetes meeting in Dublin and President Mary Robinson launched the information pack at that conference.

“We sent out one of these packs to every member of the Association and to all the diabetes clinics, which was really big for us.

“At that stage we opened a few more branches around the country – Kilkenny, Carlow, Portlaoise. We used to go to branch meetings and talk about the Association and I used to talk about living with diabetes.

“We were really trying to educate people about the condition. People were being diagnosed and weren’t getting a huge amount of education at that time,” said Úna.

A few years later the Diabetes Federation of Ireland launched an information booklet for schools.

“I went to schools talking to the teachers about

> “We were trying to empower people to find out about their diabetes. People can be told what to do but really you have to be out there helping yourself. Nobody can do it for you”

having a child in the school with diabetes. It wasn't as common then as it is now.

"At that stage we used to bring family and friends into the office when there was a mailshot going out. They all stuffed envelopes. My and Phil's kids did it and various other people who had an interest in helping. That was always a great social occasion," said Úna.

Sadly Phil Vizzard died in 1994 and Úna then ran the office single-handedly.

"Peggy Gunning was a friend of mine. I knew she was interested in going back to work and I asked her if she would come to work with me and she did," said Úna.

As the organisation began to grow more rapidly around the mid-1990s, there was increasing emphasis placed on the whole idea of self management.

"We were trying to empower people to find out about their diabetes. People can be told what to do but really you have to be out there helping yourself. Nobody can do it for you.

"Attitudes towards diabetes have changed over the years. People are becoming more aware of what it is all about.

"Back in the 1990s, we used to be fighting with insurance companies about mortgages and motor insurance for people with diabetes. And even about jobs. That has all changed. People have become aware that they can live a normal life once they look after the condition," said Úna.

"I got a great grounding from my doctor, Dr Ivo Drury. By golly you were educated about your diabetes. I was in hospital for 12 days – really to learn all about diabetes. Now they hardly keep people in hospital at all when they are diagnosed.

"These days I am on four injections a day, including one at night. But my daughter and her daughter in the US are both on insulin pumps and they use continuous glucose monitoring. I'll stick with the injections at this stage," said Úna.

Úna finished working at the Diabetes Federation of Ireland in 1998, the year Kieran O'Leary joined the charity. In the meantime, there have been significant developments in the services provided by Diabetes Ireland.

1998

Kieran O'Leary joined

"There was a great need for the new Diabetes Ireland Care Centre. That was the kind of thing we were talking about 20-30 years ago, but it was up in the air then. The chances of anything like that happening then were slim. We used to be delighted if we got a few hundred euro from some of the pharmaceutical companies to help us on our way," said Úna.

## Peggy Gunning

**Peggy Gunning joined the Diabetes Federation of Ireland shortly after the untimely death of Phil Vizzard in 1994 and continued working for the Federation until 2006.**

At first Peggy did the accounts, but later moved into working on the helpline. She saw the organisation grow from a small, relatively little-known body, to a large, busy one, with regional offices and support branches throughout the country.

Working on the helpline, Peggy dealt with all basic enquiries. This included telling people about the supports available in their area, sending out information packs and explaining how to handle the diagnosis.

And Peggy knew plenty about handling the condition. Ironically while working in the Federation, she developed Type 2 diabetes herself. "I wasn't surprised as my brother and sister have it too," she said.

As she was so aware of the symptoms, "I latched onto it immediately," said Peggy.

"I lost a bit of weight and I was thirsty and tired. These are three of the main symptoms, so immediately I had myself checked out," she said.

As Peggy sought medical advice so quickly, the condition was detected in the early stages and she was able to control her diabetes through diet alone for three years, before having to start taking medication as well.

NEWS

Thirty years of the Irish Diabetic Association

The newly designed 'Sweet Pea' logo of the recently renamed Diabetes Federation of Ireland.

Farewell

For the first few years that Peggy worked with the Federation, Prof Gerald Tomkin, was a regular visitor to the office. GP, Dr Tony O'Sullivan who has Type 1 diabetes himself got involved around that time too.

"I enjoyed working there so much – all the people in and out. They would come in to pay their membership and have a chat," said Peggy.

# 1967 2016 The first 50 years

**1967**
- First public meeting of people with diabetes
- Free insulin scheme announced
- First committee of the Irish Diabetic Association formed

**1968**
- Irish Diabetic Association incorporated

**1971**
- Mr & Mrs Carroll and the committee obtain free diabetes medications for all under the Long Term Illness scheme

**1980**
- First Irish Diabetes Nurse employed in the Mater Hospital

**1985**
- Phil Vizzard becomes first staff member

**1989**
- Landmark St Vincent Declaration on diabetes. Phil Vizzard attends meeting in Italy on behalf of the Irish Diabetic Association
- Úna Wilson joins the organisation's staff

**1990**
- EASD (European Association for the Study of Diabetes) meeting held in Dublin. An Educating the Educators programme was agreed at this meeting paving the way for the growth of the Diabetes Nurse Specialist role
- Úna and Phil produce first information pack 'Live life to the full' which is launched by President Mary Robinson at the EASD meeting held in Dublin
- First Children's Adventure Camp held in Donegal

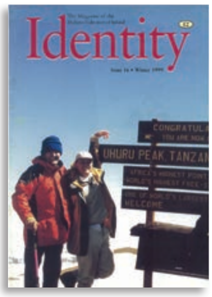
**1992**
- Peggy Gunning joins the staff, eventually running the Helpline

**1993**
- Church gate collection launched by the Donegal Branch

**1994**
- Launch of first Diabetes Information Pack for Schools

**1995**
- Phil Vizzard Research Fellowship Grant established in memory of Phil
- Children's Tadpole Club set up, later becoming Sweetpea Kidz Club

**1996**
- 'Identity' magazine launched



**1997**
- Young Adults Type 1 Diabetes Four Peaks Challenge

**1998**
- Name changed to Diabetes Federation of Ireland
- Kieran O'Leary joins Diabetes Federation of Ireland
- First diabetes nurse specialists appointed to Tallaght Hospital
- First diabetes family weekend held

**1999**
- First overseas fundraising trip to Kilimanjaro
- First National Children's Adventure Camp
- National Parents Support Network formed
- Insurance industry agrees Specified Illness & Whole of Life Cover life cover scheme for Diabetes Federation of Ireland members & their families

**2000**
- 'New beginning' five-year strategy published
- Travel insurance scheme launched for Diabetes Federation of Ireland members & their families
- First Diabetes School Educational video launched
- National Exercise Day launched to highlight role of prevention

**2001**
- St Vincent Group highlights disparities in Irish diabetes services
- Clinical Nurse Specialist, Anne Clarke joins Diabetes Federation of Ireland
- First conference for young people with diabetes in Delphi, Co Mayo
- South Counties Diabetes Association integrated into Diabetes Federation of Ireland
- Lo-call Diabetes Helpline launched
- New interactive community website for people with diabetes in Ireland launched
- First Diabetes Young Adult weekend held
- Diabetes Federation of Ireland wins IDF (Europe) Patient Association of the Year Award
- Diabetes Service Development Group (DSDG) set up

**2002**
- Southern Regional Office opened followed by Western Regional Office
- Diabetes Ireland Professional Services Section set up
- DSDG Report "Securing the Future" launched
- Diabetes Federation of Ireland successfully advocated for High Cholesterol & Hypertensive medications for people with diabetes

to be included on the Long Term Illness scheme
- Received an Irish Pharmaceutical Commendation Award for an improving patient care initiative

**2003**
- First “Diabetes Health Awareness Exhibition” held
- Conference specifically for parents of children with diabetes held
- “Volunteer of the Year” initiative launched
- Launch of *Diabetes Ireland*, the new official journal of Diabetes Federation of Ireland

**2004**
- Initiative launched to train qualified counsellors to support people with diabetes
- Won the 2004 Irish Pharmaceutical Award for best public awareness initiative for its ‘Life Under 7’ campaign

**2006**
- Diabetes Federation invited to become a member of HSE Diabetes Expert Advisory Group (DEAG)
- Launch of ‘The way forward 2006-2010’
- Health Promotion team set up
- Motor industry stops discriminatory practices in car insurance for people with diabetes
- Former Chairperson Dr Tony O’Sullivan becomes President of IDF (Europe)

**2007**
- CODE Structured Education Programme launched
- IDF (Europe) ‘Together We Are Stronger’ meeting held in Dublin for first time

**2008**
- DEAG produces its first report

**2009**
- Diabetes Ireland Research Alliance (DIRA) established
- First “National Teen Activity Day” event held
- DIRA partners with Juvenile Diabetes Research Foundation to promote high quality diabetes research in Ireland

**2010**
- First HSE podiatrists employed to provide footcare service
- First “30Km Night Hike” held in Dublin

**2011**
- Look to the Future 2011-2015 strategy launched
- First podiatrists employed by Diabetes Ireland to provide footcare service
- HSE Paediatric Diabetes Working group set up
- First charity group to meet the new President at Aras an Uachtarain
- First Annual Paediatric Healthcare Professional Study Day held
- Diabetes Federation joins with other support groups to produce new resource pack ‘Managing chronic health conditions at school’

WORLD DIABETES DAY

President marks World Diabetes Day

**2012**
- Republic of Ireland Diabetes Junior Team participated in International Diabetes Junior Cup

**2013**
- Diabetes Ireland moves to state-of-the-art premises in Santry, Dublin
- Free annual diabetes RetinaScreen programme introduced

**2014**
- First Diabetes Ireland Care Centre opens in Santry
- First National Junior Diabetes Cup event

**2015**
- HSE launches paediatric model of diabetes care
- Diabetes ‘Cycle of Care’ launched in primary care

**2016**
- “Changing Lives 2016-2020” strategy launched
- Cork Diabetes Ireland Care Centre opens
- Online interactive education module for diabetes patients launched
- Commemorative medals presented to those living with diabetes for over 50 years to celebrate 50th birthday of the charity

# What it said in the papers 1957-1979

**Nov '57**

## Association for diabetics?

There are about 4,000 diabetics in the Republic and it is expected that an Irish association for diabetics will be formed next week in Dublin. One of its foremost aims will be to get the Government to introduce a system under which medicine and special foods essential to diabetics will be available more cheaply.

A reporter learned officially yesterday from the Department of Heal… that no special scheme for diab… contemplated so far. … that spo… org… ad…

**Jan '58**

## Diabetic association to be formed

A meeting of the provisional committee of the Irish Diabetic ssociation has considered suggested articles of association and passed them for final drafting, after which a general meeting will be held.

Those interested are invited to … the … addresses only …

**Jan '58**

## Diabetic body's draft articles

Suggested articles of association for the proposed Irish Diabetic Association have been passed for final drafting by the provisional committee in Dublin.

Those interested are asked to communicate with the Ho… Sec., Irish Diabetics Associ… tion, Abbey Buildings, Midd… Abb… Dubli…

**May '61**

## DIABETICS: THEIR CASE FOR STATE AID

Irish Times Reporter

THOUSANDS of diabetics feel that the State should help them to maintain their health by subsidising insulin and the foods which form their restricted diet.

It is unlikely, however, that the Government will make any move in this direction, because the acceptance of such a principle would mean that it would have to be extended to sufferers from other diseases and the national health bill would rise consequently.

It has been calculated that there are from 4,000 to 6,000 known diabetics in the Republic, and a number of arguments have been put forward for the subsidisation of insulin and special foods for them.

One diabetic said: "The State gives free treatment to the tuberculosis patient, and to those affected by other infectious diseases, but apparently it draws the line in the case of the non-communicable disease.

"If the State helps the T.B. case and the disabled, there is an obligation on it to contribute to the diabetic, because, by keeping himself in health with insulin, he is saving the State expense and in his everyday work is playing his part in national production."

### LIFE-LONG TREATMENT

Many doctors a… sympathetic with this viewpoint; … say that assistance shou… the special … to middle… in the use i… to lives… obt… ca…

… was setting a principle for subsidising other medicines," one doctor said. "The diabetic must continue to take insulin to keep alive and it is, therefore, a continuing expense; with other medicines this is not the case, as the complaint is generally cleared up."

### STRICT DIET

The cost of insulin varied according to the severity of the diabetes. Two doctors agreed that on average the cost would not be more than 5/- to 7/- a week, but the strict diet with which the diabetic has to content himself can mean additional cost on the household. Special types of flour and bread can work out at 8/- to 10/- a week, while suitable chocolate, jams and tinned fruit can also add to the cost.

Diabetic chocolate is exempt from Customs duty and package tax. Other sweets for diabetics may be imported duty-free under licence in certain circumstances.

"On a rough calculation I would say that it costs the diabetic about 25/- a week to keep up his treatment," a doctor said. "… here is certainly a case for St… help for the middle-income di… but I cannot see it com… the health legislation … br… ened."

**April '67**

## FORMING DIABETIC ASSOCIATION

A public meeting will be held in the Mansion House, Dublin, at 3 p.m. tomorrow to form a Diabetic Association. All known diabetics in the region and those interested in the disease—especially parents of diabetic children—have been invited to attend.

The meeting, which is being supported by many Dublin doctors, is sponsored by the Britis… Diabetic Association. A branch … recently in Cork and ef… be made to found simi… throughout the country.

The Lord Mayor … Alderman Eugene Ti… preside a… orrow's …

**Nov '67**

## Diabetics to organise in Galway

THE IRISH DIABETIC Association plans organising a new branch in Galway early next year, said Mr. Michael J. Carroll, chairman, at a meeting of the Association in the Mansion House, Dublin, yesterday.

He said they also hoped to organise holiday camps for children suffering from diabetics and to get employment for diabetics.

Mr. Basil Payne, secretary of the Voluntary Health Insurance Board, told the 120 diabetics at the meeting that about 300.000 people had insured themselves with the Board since it was set up in 1957. He said tha… a total of 435 people had be… …lined. Only seven o… …etics, and th… admis…

**Jan '67**

## ORGANISATION FOR DIABETICS FORMED

A meeting in Cork on Saturday unanimously approved of the formation of an organisation—the Southern D… Association—

… m, secretary … and General … said that … ould include … wor… to …

**June '67**

## DIABETIC ASSOCIATION

A public meeting, sponsored by the Irish Diabetic Association, will be held in St. Mary's Hall, Hig… street, Kilkenn… …rrow at … p.m. to form a … branch … the associa… …es the sou… and … cia…

**June '67**

## Self-support by diabetics important

Far more important than economic betterment of the diabetic was the idea of self-support, through help of other diabetics. This was stated yesterday by Dr. M. J. Drury, Mater Hospital, Dublin, at a meeting in Kilkenny at which a regional branch of Irish Diabetic Association was formed.

Dr. V. Barry, said he looked forward to the time when, as a result of research, diabetes would be not only curable but could b… prevented.

Dr. H. J. Roche stressed th… need of having diabetics labelled under the medicalert system.

Mr. Norman Allen, British Diabetic Association, said he hoped … bet… …and British … th… toge…

**May '67**

## FREE DRUGS OFFERED TO DIABETICS

INSULIN will be given free to sufferers from diabetes in the 26 Counties. This was announced last night by the Minister for Health, Mr. Flanagan. The drug costs most of the diabetics who use it about £2 a week.

Mr. Flanagan spoke at a Dublin Lions Club reception to introduce "Medic-Alert," a medical identification scheme.

Mr. Flanagan said the free insulin scheme … into effect immedi… only condit… hav… re…

… the appropriate treatment would be.

The "Medic-Aler…" syst… was st… ed in the Un… …go and qu… Now … e a…

Sept '68

LEGAL NOTICES

APPLICATION FOR A LICENCE OF THE MINISTER FOR INDUSTRY AND COMMERCE

NOTICE is hereby given that in pursuance of Section 24 of the Companies Act, 1963 application has been made for a licence of the Minister for Industry and Commerce directing a company about to be formed under the name The Irish Diabetic Association to be registered with limited liability without the addition of the word "Limited" to its name.

The main objects for which the company is proposed to be established are:

(a) To provide an organisation for the benefit and service of diabetics.

(b) To promote study of the causes and treatment thereof and the diffusion of information concerning the same.

(c) To act as an authoritativ and advisory body to safegu social and economic i of diabetics.

(d) To promote lectures, sions and corresponder diabetes and associate for the information and of diabetics and the generally.

The other objects of the c are set out in extenso in the andum of Association, a c which may be inspected at the of Hayes and Sons, Solicitors, Stephen's Green, Dublin.

NOTICE is hereby further g any person, company or cor objecting to the application lodge notice of objection with retary, Department of Indu Commerce, Dublin, on or be 10th day of October, 1968.

Dated this 17th day of Se 1968.

HAYES & SONS,
15 St. Stephen's
Dublin, 2.

Oct '67

Diabetics aim to contribute to research

THE NEWLY-FORMED Irish Diabetic Association (Dublin Region), plans to contribute to research with the hope that a cure for the disease will be found eventually.

This was announced by the Association's chairman, Mr. Michael arroll, when he ut 400 members in House, Dublin, yesvere attending the of lectur

Nov '68

Irish Diabetic Association

A BRANCH of the Irish Diabetic Association will be formed in Limerick on Sunday, 10th November, at 3 30 p m at the Social Service Centre, Henry St, when a Limerick diabetic specialist will be speaking. It will be a public meeting, and all diabetics and those with an interest in the disease, especially parents of diabetic children, are invited to attend.

The aims of the association are to help diabetics, particularly new ones, to understand their disease and treatment; to visit and help those diabetics who may be disabled or ill; to represent the interests of the diabetic community in the district and provide a meeting place for betics in the locality, to money for the support of branch and

ly covered by of the (Green Card) plus travel expen certain cases. Through generosity of various throughout the country Association has limited available which will be u offset the balance of £ cases of genuine hardship. ment forms for the h may be obtained from Honorary Secretary, The Diabetic Association, at St. Law

Aug '71

Lessons in living on holiday course

HAPPY, smiling children filed up to get their self-service meal in the sunny diningroom of College, yesterday children on

age and we realise that they have problems—just as we have.

"We al have the same advan disadvantages and we lot about the arn that we d as long as xchange it— eat icecream, ut down on

Sept '71

WIDE SCOPE OF FREE TREATMENT SCHEME

By Our Medical Correspondent

AS MANY readers will have learned from the advertisements which appeared in the national press yesterday, the Minis for Health has announced the list of chronic diseases wh free treatment or medications have been promised si the last Budget. The new concessions will become on October 1st.

Free hospital out-patient all chil ovided for inco of family

who wishes to avail him scheme should contact board in his area and a im with the n form. Thos already receiving rough their hea ut new f

June '70

Holiday for diabetic children

Sir — The Irish Diabetic Association (Ballyneety House, 56 St. Lawrence Road, Clontarf, Dublin 3) is organising a holiday for young diabetics (aged approx. 9-14 years) at Gormanston College, Co. Meath, from Sunday, August 2-16 inclusive. It will be a medically-supervised holiday with resident doctors, nurses and dietitians. The aim is to give the children a holiday; to ncourage th be as inble withi

April '71

Diabetics urged to obtain identity

ONLY a small number of the 30,000 diabetics in Ireland wear the medic alert bracelet or necklet which might save their lives.

Mr. M. J. Carroll, chairman of the Irish Diabetic Association yesterday appealed to sufferers to apply for the device.

He said diabetics have often been mistake for drunks when they go i oma or become

is to apply at 56 St. Clontarf, or

April '72

DIABETIC GROUP TO FORM CORK BRANCH

It is proposed to form a Cork Branch of the Irish Diabetic Association (Ballyneety House, St. Lawrence Road, Clontarf, Dublin 3) in addition to those already functioning in Athlone, merick, Galway and Ti ublic meeting h Fath

Nov '72

Diabetic body sets up national council

A National Council for the Irish Diabetic Associati was s a meeting in Thu The council's obj nate the activitie branches through

Officers elec Carrol

April '71

Treatment free for diabetics

The Minister for Health, M Childers, announced last nig that diabetes sufferers here a eligible for a free comprehensi range of appliances and dru for the treatment of the disea

The Minister's statement v made in conjunction with launching by the World Hea Organisation of a mass publicity programme designed make the public more conscious of diabetes and its treatment.

The statement said that since the scheme started in 1967 approximately 7,500 diabetes sufferers were receiving assistance. This figure did not include medical card holders who receive comprehensive medical care free of charge.

The Minister added that in

Sept '71

ATHLONE BRANCH OF DIABETIC ASSOCIATION

A branch of the Irish Diabetic Association (affiliated to the British Diabetic Association) will be formed in the Royal Hotel, Athlone, on Sunday, October 3rd, at 3 p.m. Acco statement, it will be a pu and doctors from A will be those with of diabecti betic c nd.

Oct '75

DIABETICS FORM DUBLIN BRANCH

Mr. John Vallance-Owen, Professor of Medicine at Queen's University, Belfast, will speak at a meeting in Dublin on Sunday to mark the inauguration of the Dublin Branch of the Irish Diabetic Association.

The branch has been established speci look after the

April '79

Irish for diabetic congress

THE Irish Diabetic Assoc will be represented by two de gates at the 10th world congress of the International Diabetes Federation in Vienna in September; 2,500 scientists will attend to hear the results of the latest research and treatment.

The Irish association is a full member of the federation. Ireland will be considered as the host country for the 1982 world congress.

Between 2% and 4% of the population have diabetes. In most cases it affects persons of mature years as a consequence of overweight. Young diabetics must observe a strict diet and get insulin injections daily.

A statement from the Irish association said it was of decisive that diabet

May '73

Irish diabetic group joins federation

THE IRISH Diabetic Association has now become an associate member of the International Diabetes Federation, an organisation embracing some 40 countries, according to a statement from the association issued yesterday.

The association will be represen at the federation's July meetin Brussels by Mr. P. O'Keeffe. ork.

Clippings from material accessed in the Irish Newspaper Archives and *Irish Times* digital archive courtesy of the library at the University of Limerick. We are grateful to Dr Ned Barrett for compiling this valuable archive for Diabetes Ireland

# Diabetes Ireland grows from fragmented voices to unified force for change

Kieran O'Leary

Since joining in 1998, Kieran O'Leary set about strategically expanding the services provided by Diabetes Ireland and ensuring the needs of people with diabetes in Ireland were fully met. Interview by Sheila O'Kelly

**1999**
Website developed

**2000**
Five-year development strategy

**Diabetes Ireland CEO Kieran O'Leary joined the Diabetes Federation of Ireland in June 1998. He became the third member of staff working alongside Úna Wilson and Peggy Gunning. This was the start of a period of significant development, moving the organisation centre-stage in improving diabetes awareness and education and advocating for better services. The achievements up to the present day speak for themselves.**

At the time, relationships with healthcare professionals needed to be developed. "Some nurses were involved with the local branches, but there was no cohesion, direction or relationship between us as a patient organisation and the healthcare professionals. That was one of the first things we needed to address," Kieran recalls.

"Our focus was on promoting awareness. The only problem was that we had no money. So I spent about 12 months travelling around meeting all the branches, healthcare professionals and consultants. I was also trying to engage with the HSE to secure funding," said Kieran.

When Kieran joined the Federation, Prof Gerald Tomkin, the current President of Diabetes Ireland, had recently set up an executive committee to manage the organisation. There was also a national council with about 28 members that met six times a year.

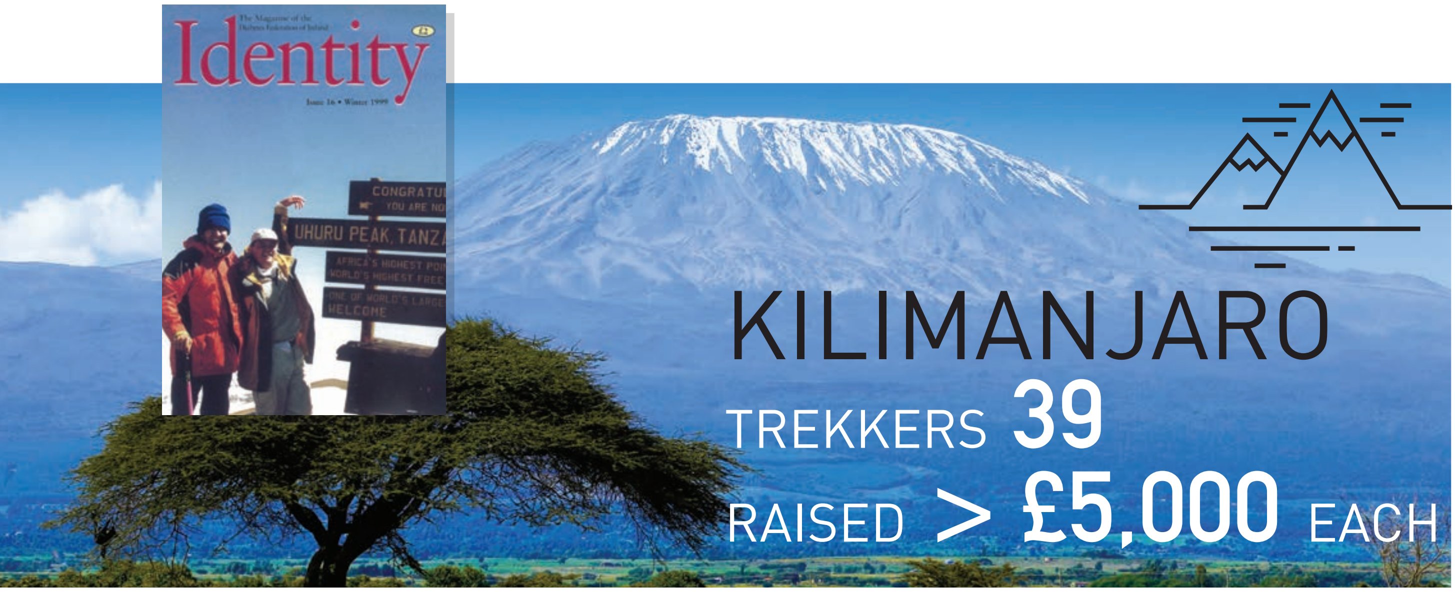
Prof Tomkin had recognised that the problem of diabetes as a health issue in Ireland was growing rapidly and that there was a huge lack of awareness among the general population.

In order to promote its message, the organisation launched its first website in 1999, under the guidance of Mary Frances McKenna who was working as editor of the organisation's patient journal *Identity*.

A few months after Kieran joined, colleague Úna Wilson retired. There was no funding for full-time staff so staff were hired through a FÁS employment scheme that was in place at the time. And then he began fundraising in earnest. The first port of call was to organise a fundraising trek.

"We decided to organise a trip to Kilimanjaro, promote it and try and make it a good fundraising initiative. That really worked. I had to do the rounds and persuade doctors and nurses to come along as part of the medical team. We had a total group of about 39. It raised a profit of over £50,000. We were the first diabetes group ever to go up Kilimanjaro and achieved public recognition for this," Kieran recalls.

These funds gave the organisation the impetus to



recruit staff. In addition, we approached the Health Promotion Unit of the Department of Health, to request funding to hire a nurse. This was successful and Dr Anna Clarke, clinical nurse specialist and now Diabetes Ireland Health Promotion and Research Manager, joined the organisation.

Over the subsequent years there were many successes in terms of achieving equitable treatment for people with diabetes in terms of insurance. In 1999, following lengthy negotiations, Irish Life Insurance agreed terms for a group specified-illness and life-cover plan for members of the Diabetes Federation. Notably this made this type of insurance available to people who might otherwise have been turned down.

In October 2000, the organisation put in place a travel insurance scheme that for the first time offered full cover for its members. Members could avail of this scheme without having a medical report.

In 2006, following serious campaigning, the motor insurance industry removed discrimination against people with diabetes in relation to car insurance. The organisation argued successfully that since the law already required all motorists to disclose any illness (including diabetes) before getting a licence, that if the Driver and Vehicle Licensing Agency (DVLA) felt someone was fit to drive, so too should the motor insurance industry.

"We made the case for getting rid of blanket discrimination. Just because you have diabetes doesn't mean you are a higher risk. In fact if you have diabetes you usually have a more structured planning of day-to-day driving. That was a huge win for the diabetes community," Kieran recalls.

Kieran and Anna invested a lot of time travelling around the country to talk to people with diabetes as well as health professionals. It was clear that the organisation would have more strength if it had one united voice.

"Once we had toured the country, it became apparent that from an advocacy point of view, diabetes was not on the radar. It was not a priority of the Department of Health whose focus was on the cardiovascular strategy and smoking cessation," Kieran said.

This led to the roll-out of the Diabetes Federation of Ireland's first five-year plan, put together helped by the funds raised from the Kilimanjaro event.

*'A New Beginning'* was published in 2000. The main aims of this five-year development strategy were to expand the services provided by the Diabetes Federation of Ireland and to work in partnership with all those interested in ensuring that the needs of people with diabetes in Ireland were fully met.

During Micheál Martin's time as Minister for Health from 2000-2004, the charity successfully campaigned to have cholesterol and blood pressure medication added to the long-term illness medications list. This meant that people with diabetes could get these essential medicines free.

The Federation's five-year plan, *A New Beginning'* was very well received and led to a closer relationship with the Department of Health. Funding from the department helped to establish the telephone diabetes helpline.

One of Anna's priorities was to set up a professional services section to help cement relations with medical professionals. The next stop was the 'Decision Makers' conference', which went on to become the annual health professionals study day – a key event in the Federation's annual calendar. In addition, in recent years Diabetes Ireland has been working in conjunction with MedMedia on the quarterly journal, *Professional Diabetes and Cardiology Review* for health professionals working in the area of diabetes and cardiology care.

An active support group for parents had developed by the early 2000s. This group produced a diabetes education video for schools, which was the first of its kind. We secured funding so that a copy of this video could be distributed to every school in the country.

In October 2001, the first Irish conference for

> "Once we had toured the country, it quickly became apparent that from an advocacy point of view, diabetes was not on the radar"

young people with diabetes took place in the Delphi Adventure Centre, Co Mayo. Some 60 young adults with diabetes from all over Ireland gathered to meet people their own age who also had the condition.

The first conference specifically for parents of children and adolescents with diabetes was held in 2003. The conference focused on the needs of parents and siblings as well as the child with diabetes.

Later in 2011 a paediatric advocacy group was set up to lobby the HSE. In November 2015, the HSE finally launched the 'Paediatric model of diabetes care'.

In 2011, the Diabetes Federation of Ireland, Asthma Society of Ireland, Brainwave the Irish Epilepsy Association and Anaphylaxis Ireland came together to produce a resource pack *'Managing chronic health conditions at school'.* The pack helps teachers and parents to work together to provide a safe and enjoyable school environment for students with any one of these conditions.

"The teacher has a duty of care to have an overview of the child. But there is not a specific duty of care on them to give injections. Understandably many schools had issues or were hesitant," said Kieran.

With multi-dose insulin injection regimes, children nowadays often need injections during the school day. Thus, the organisation continues to press for support from special needs assistants (SNAs).

## FIRST GOALS

- **Set up a telephone helpline**
- **Open seven new regional offices**
- **Improve detection and prevention of diabetes**
- **Promote diabetes research**
- **Improve public awareness**
- **Train and develop Diabetes Ireland staff**

"It is in the child's long-term health interests to be on a multi-dose regime. During 2016, we were working with schools. We think that up to the age of eight in particular, children with diabetes should have SNA support. Over 12, there should be an SNA in the school who knows a child has diabetes and whom the child can go to if they have any problems," said Kieran.

In the area of paediatric care, the organisation has been successful in substantially increasing the numbers of consultant paediatric endocrinologists and paediatric diabetes nurse specialists. Areas to benefit have included Sligo, Drogheda, Donegal, Galway, Limerick, Cork and Waterford.

### Diabetes Service Development Report

By the early 2000s the organisation had in the region of 30 branches. In 2001, the Irish St Vincent Group *(see panel)* highlighted the striking disparities in diabetes services around Ireland.

The Diabetes Service Development Group (DSDG) was initiated by the Diabetes Federation of Ireland in 2001 to bring together people from across the diabetes community. This group worked intensively over many months to draw up the report.

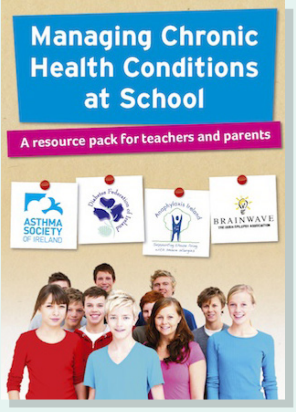
"We had met the Department of Health, but we were getting nowhere. Then we decided to produce our own strategy. We invited in representatives from the various healthcare professional bodies that were involved in diabetes. We had an independent chair and Anna Clarke was the secretary. We met the first Saturday morning of every month for six months."

The launch of Diabetes Service Development Report achieved a lot of national attention helping to increase the profile of diabetes as a health issue.

The DSDG designed a framework with costings, for putting in place comprehensive diabetes care in Ireland for everyone with diabetes, regardless of their age or location, over four-years.

Following the DSDG report, Diabetes Federation of Ireland lobbied the Department of Health to write a policy paper prioritising diabetes based on the information in the DSDG report. This paper focused on:

**2001 –
Diabetes Service
Development Report**



**2011 –
Managing chronic health
conditions at school**

**2016 –
Diabetes Ireland
five-year plan**

- The cost-benefits of preventing diabetes complications
- The expanding number of people with diabetes
- Future prevalence rates

### Diabetes Expert Advisory Group

By 2006 the Diabetes Federation of Ireland was a member of the Expert Advisory Groups set up by the HSE. It was the only disease-specific grouping to be part of the Expert Advisory Groups. The other three groups focused on older people, children and mental health.

"We were invited to take part because we had been highlighting that the need was there. The DSDG report was also very influential. Diabetes was becoming such a huge issue in terms of numbers trying to access health services. It was the first time the HSE prioritised diabetes," said Kieran.

The aim of the Diabetes Expert Advisory Group (DEAG) was to help those providing services including doctors, consultants and nurses, and those receiving services – people with diabetes and carers, to become involved in influencing how services were planned and developed.

The DEAG produced its first report in 2008, but by then the Celtic Tiger was in the past and budgets were decimated.

"We had to prioritise and based on feedback from people all over the country, we focused on stopping blindness and reducing the number of amputations," said Kieran.

After many years of campaigning by Diabetes Ireland, free annual diabetes screening was finally introduced in 2013.

In the meantime, the branches were becoming more active. In the early 2000s, the Southern Counties Diabetes Association became incorporated into the Diabetes Federation. Cork and Sligo offices were opened to offer a regional presence.

The children's Tadpole Club, set up in 1995, was renamed as the Sweetpea Kidz Club in the early 2000s. Diabetes Ireland ran children's holiday camps which were very popular and allowed children, sometimes for the first time, to get to know other children with diabetes.

The organisation was keen to meet the needs of each age group so it also began to hold public information meetings for people with Type 1 diabetes, Type 2 diabetes and special events for teenagers. These attracted significant numbers.

"In 2001, Cork and Kerry still had the Southern Counties Diabetes Association. But we needed to be an all-country Republic of Ireland association. We successfully held negotiations to bring them on board.

"We opened the Cork office in 2002, and an office in Sligo. That meant we had a national presence and we could negotiate as the voice of the diabetes community in terms of advocacy. That was the goal," said Kieran. Later the organisation was restructured into four regions similar to the HSE.

Another major step forward was in 2004 when the charity initiated a scheme to support accredited counsellors around the country to provide counselling services for people with diabetes by running diabetes training programmes. Counselling is just one of the services available at the Diabetes Ireland Care Centre in Santry.

In 2006, the Federation launched *'The Way Forward 2006-2010'*. Dr Tony O'Sullivan, outgoing president of the Federation, highlighted its focus on supporting people with diabetes and their families, raising awareness of diabetes and fostering early detection.

Also in that year the HSE invited the Federation to set up a structured education programme for people with Type 2 diabetes. The result was the Diabetes Ireland CODE (Community Oriented Diabetes Education) training courses for people with Type 2 diabetes. The evidence is strong that people who participate in structured diabetes education will manage their condition better. The HSE provided some funding to deliver CODE programmes around the country, this was matched by the charity.

2004

Counselling services set up

2000s

Sweetpea Kidz Club

Diabetes Ireland employed four healthcare professionals to help deliver the programme and they also enabled Diabetes Ireland to increase its role in promoting improved diabetes care and awareness, and holding more diabetes screening events.

However, while CODE courses are available all around the country, there are still not enough places available for the people who need them. Evaluations show that people who attend enjoy long-term improvements to their health and

Teachers at one of the annual teacher-training days

lifestyle. To help deal with this shortfall, in 2016 Diabetes Ireland developed an online education module for people with diabetes.

"We are still only supporting 2,000-2,500 people a year and there are 200,000 out there. This module will just help us fill some of the gap," said Kieran.

In 2009, the Diabetes Ireland Research Alliance (DIRA) was set up to develop and fund diabetes research in Ireland. DIRA's aim is to encourage people internationally to see Ireland as a place where world-class research can take place. The Diabetes Ireland Research Alliance is a partner of the Juvenile Diabetes Research Foundation (JDRF), the leading charitable funder of Type 1 diabetes research worldwide.

**Services at the Dublin Care Centre include:**
- Podiatry
- Dietetics
- Hearing tests
- Eye screening
- Counselling.

**In June 2016, the Cork Diabetes Ireland Care Centre opened with services including:**
- Podiatry
- Footwear
- Dietetics
- Eye screening

A landmark for the organisation was its move in 2013 from Gardiner Street, Dublin, where it had limited space, to new premises in Santry, Dublin, which now houses a state-of-the-art diabetes care centre. This move was made possible by a bequest of a house left to the charity some years before, and the fact that office space was not as expensive during the downturn in the economy.

Diabetes Ireland now employs 30 staff, with 75% healthcare professionals.

The organisation has a current five-year plan from 2016. "With this five-year plan one of the main priorities is to raise awareness of pre-diabetes, that is people who are at high risk of developing diabetes and who need to change their lifestyle. We also want to make it clear that Type 1 and Type 2 diabetes are different," said Kieran.

Diabetes Ireland is also working with GPs to ensure that children with diabetes are diagnosed more promptly.

Diabetes Ireland continues to run at least three events a week, including:
- Public information meetings
- Diabetes screening events
- Workplace awareness days
- CODE (Community Oriented Diabetes Education) training courses.

The Diabetes Working Group set up by the HSE has meant major developments in services and structure, including the Diabetes Cycle of Care strategy.

"We hope that in addition to free diabetes-related medications, under the recent Cycle of Care, everyone with Type 2 diabetes will get at least three annual reviews a year from their GP. In recent years around the country we have seen huge improvements in the level of resources being provided for people with diabetes and new technologies like the insulin pump. We will keep pushing to make sure that all the developments people with diabetes need are put in place," said Kieran.

"We want everyone with diabetes to have the support and confidence to live a long and healthy life. That is our vision," said Kieran.

In the late 1990s, the charity's annual income was about £65,000 a year. Now it is €2 million. Most of this is used to fund professional healthcare staff who deliver services directly to patients.

"The more money we have, the more services we can provide. Our services are labour intensive and to provide them we need nurses, dietitians and podiatrists," said Kieran.

It costs around €25 to become a member of Diabetes Ireland. If every person with diabetes became a member, 200,000 multiplied by an average of €25 – that would come to €5 million per annum. Imagine what we could do with that!

The charity will be working to attract as many members as possible with a view to expanding its services for people with diabetes in the future.

> "We will keep pushing to make sure that all the developments people with diabetes need are put in place"

# Diabetes: **Yesterday, today and tomorrow**

**Prof Richard Firth** looks at the diagnosis and treatment of diabetes from ancient times when the prescription was to avoid sex and wine, to today's more modern treatments

**In June 2016, it was my privilege and pleasure to present a group of individuals, who were attending the opening of a new Diabetes Day Centre in one of Ireland's peripheral hospitals, with Diabetes Ireland '50-Year Medals', which acknowledge that the individuals have had diabetes for 50 years.**

This is a remarkable achievement, and fortunately it is a frequently increasing occurrence. I for one have known well over 100 such outstanding individuals. They will almost without exception have, with their healthcare professionals, looked after their diabetes very well over the years. So, how have we reached this stage of increasing numbers of people with diabetes improving their prognosis and quality of life?

We have come a long way since the first reference to diabetes in the *'Ebers Papyrus',* written around 1500BC, which described a condition of "too great emptying of the urine".

Around 2300BC, Apollonius in Greece for the first time used the term diabetes, which means 'to pass through' (*dia* - through, *betes* - to go). Aretaeus of Cappadcoia was a Greek Physician who described diabetes as "a dreadful affliction not very frequent among man, being a melting down of the flesh and limbs into urine."

Two very astute Indian physicians, Sushruta and Charaka, in the fifth century AD, were the first to differentiate between the two types of diabetes mellitus. They observed that thin individuals with diabetes developed diabetes at a younger age in contrast to heavier individuals with diabetes who had a later onset and lived longer periods of time after the diagnosis.

Some 200 years later, Li-Hsuan in China, noted that patients with diabetes were prone to infections and he prescribed avoidance of sex and wine as treatment for diabetes – a treatment that may not go down too well these days!

A Swiss physician with a five-barrelled name but also known as Paracelcus, in the early 16th century, allowed the urine of patients with diabetes to evaporate and observed a white residue. However, he incorrectly felt that this was salt and not glucose.

In 1670, Thomas Willis in Oxford noticed a sweet taste from the urine of patients with diabetes. *Mellitus* means honey sweet.

However, no great advances were seen until the late 19th and early 20th centuries. Minkowski and Von Mering working in Strasbourg in 1889, observed that removing the pancreas from dogs caused them to develop severe thirst, excessive urination and weight loss with increased appetite.

Minkowski was convinced that this was due to the dogs developing diabetes and indeed found glucose in the urine. Following this, a number of researchers around the world made significant contributions by 'curing' such animals by injecting pancreatic extracts or by regrafting a pancreas back into each of these diabetic dogs.

Nicolas Constantin Paulesco, in the early 20th century working in Bucharest, Romania before Banting and Best, injected pancreatic extracts into dogs who had their pancreases removed. This resulted in the death of the animal with symptoms of hypoglycaemia (dangerously low blood glucose). The dogs' blood glucose fell from 7.8mmol to 1.4mmol per litre.

However, because of World War 1, Paulesco did not publish the report of his experiments until 1921. As a result, many people in Romania feel that Paulesco and not Banting and Best was the true father of insulin.

Frederick Grant Banting was a young and not very successful orthopaedic surgeon who developed an interest in diabetes. At the University of Western Ontario in Canada, he isolated a very crude extract of insulin from the pancreases of foetal calves. He injected 'a thick brown' substance into the buttocks of Leonard Thompson, a 14-year-old boy being treated for diabetes at Toronto General Hospital. Leonard Thompson became acutely ill, developing abscesses at the injection sites. However, a second injection using a much improved preparation, made by the biochemist James Collip, caused Leonard's blood glucose to fall from the equivalent of 29mmol per litre down to 6.7mmol per litre and the ketones disappeared from his urine. Leonard Thompson received ongoing therapy and lived for another 13 years but died of pneumonia at the age of 27.

> "We have come a long way since what could be described as the first diagnostic test for diabetes following observations in India 3,000 years ago that the urine of people with diabetes attracted ants and flies"

There was universal acclaim for these achievements. In 1923, the Nobel Prize in Physiology or Medicine was awarded to Banting and John JR MacLeod, in whose laboratory the work was carried out. Both Banting and MacLeod acknowledged the contributions of Charles Best, a physiology student who worked with Banting, and of Collip – indeed the two Nobel Laureates shared their prize with Best and Collip.

While Leonard Thompson did not survive for very many years, Ted Ryder, one of the first four children to receive insulin in 1922 in Toronto, lived until the age of 76, dying in 1993.

After Fredrick Sanger and Dorothy Hodgkin separately won Nobel Prizes for discovering the exact building blocks of insulin and the shape of the insulin molecule respectively, the drive to synthesise new insulins began to accelerate.

Thus the insulins traditionally used, which had been extracted from the pancreases of calves and subsequently pigs, and that occasionally caused allergic reactions, began to be replaced with insulins that were identical to human insulin but were made by bacteria into which the insulin gene had been inserted.

Subsequently, the pharmaceutical industry championed the development of human insulin, in which the structure was changed to either accelerate or slow down the absorption of injected insulin. This meant they could replicate the pattern of background insulin levels along with a rapid rise in meal-time insulin seen in people without diabetes who have a normally functioning pancreas.

This concept was progressed further starting in the 1970s with the insulin pump. These are worn externally and administer rapidly acting insulin under the skin through a tiny plastic cannula (tube). The insulin is released in successive tiny droplets to supply a background or 'basal' insulin, supplemented by a 'bolus' given with meals to mimic the normal pancreas.

At first, these insulin pumps were too big to be of practical use, but they have progressively become miniature. Now they are virtual mini-computers that can be pre-programmed for different infusion rates. They can also store and display large amounts of information on a visual screen. The body absorbs insulin from these pumps in a much more predictable way and usually results in an improvement in diabetes control and reduction in hypoglycaemic events (when blood glucose levels fall dangerously low).

It is now well established that Type I diabetes is partially genetic and that, together with some environmental trigger, it causes an autoimmune destruction of the beta cells and ultimately depletes the body of insulin. For many years it was known that people who developed Type 1 diabetes were generally found to be young and slim, and developed diabetic ketoacidosis (DKA) if they were insulin deficient. They also had little if any detectable insulin when their blood was tested.

Diabetic ketoacidosis is caused when too many ketones are produced too quickly. The ketones can upset the delicate balance of the body's chemistry leading to serious problems.

In contrast another type of diabetes, now known as Type 2 diabetes, was found to affect older, more overweight people who did not appear to develop ketosis. Such people did retain measurable, but reduced levels of insulin, and did not succumb to the disease quite so rapidly. Unfortunately, this led to the mistaken belief that Type 2 diabetes was not as dangerous as Type 1 diabetes.

Sir Harry Himsworth injected insulin into people with diabetes and found that there was one group who were sensitive to insulin (we now know these are people with Type 1 diabetes) and another group in whom the insulin did not reduce blood glucose levels very much (Type 2).

Diet, exercise and lifestyle are of vital importance in the treatment of diabetes. Prior to insulin, the Frederick Allen diet in the US in the early 20th century was a restricted 400-calorie diet with reduced carbohydrates for those with diabetes.

At the time most people diagnosed with diabetes had Type 1 and while the lack of carbohydrates restricted the rise in their glucose levels, they gradually lost weight and eventually when their insulin stores ran out, they succumbed to ketosis.

Prof Richard Firth presents Diabetes Ireland '50-Year Medals' to individuals who have had diabetes for 50 years. Pictured (l-r) at the opening of the Dundalk County Hospital Diabetes Care Centre were: Jenny Thompson, Diabetes Nurse Specialist; Paul Finegan and Owen Garvey, who received 50-Year Medals; Prof Richard Firth (back); Bridget Kavanagh, 50-Year Medal recipient; Pauline O'Hanlon, Diabetes Nurse Specialist; and Mary Connolly, 50-Year Medal recipient

2016
'50-year Medals'
awarded

For the remainder of that century a low-carbohydrate diet was recommended, but in the 1980s and 1990s carbohydrate allowances were liberalised with restrictions on proteins and fats.

While the ideal composition of the 'diabetic diet' has again become quite controversial, with many people advocating a reduced carbohydrate diet, there is little doubt that the basic principles of achieving an ideal body weight and improving insulin sensitivity with exercise is a universal goal.

Glucoses meters today derive from those using colorimetric strips in the 1970s in large and bulky meters. However, these were the first machines to allow people to measure their blood glucose levels at home.

We have come a long way since what could be described as the first diagnostic test for diabetes following observations in India 3,000 years ago that the urine of people with diabetes attracted ants and flies. This caused them to name the condition *'madhumeha'* or 'honey urine'. Von Fehling developed a quantitative test for glucose in the urine in 1848 and this became the standard diagnostic test for diabetes.

Our glucose meters for testing capillary blood from a finger prick are becoming smaller and more sophisticated with the ability to analyse patterns and store large amounts of information. However, the process remains tedious and painful for some, resulting in many discontinuing blood testing.

The past 10 years have seen an increasing use in continuous blood glucose monitoring by a probe under the skin which can continuously measure and record blood glucose levels in the extracellular fluid. Of course, a huge amount of research is ongoing trying to link this monitoring system to an automated insulin pump, which would result in one of the holy grails of diabetes research – the artificial pancreas.

Another massive advance has been the description of 'glycosylated haemoglobin' or HbA1c. Glucose attaches to haemoglobin, the oxygen carrying protein in the red blood cell. The HbA1c is the percentage of the total haemoglobin in the blood that has been glycosylated. The higher the level of glucose (that is, the worse the control of the diabetes), the more glucose adheres to the haemoglobin and the higher the HbA1c.

The red blood cell which contains the haemoglobin has an average life of 120 days and the HbA1c therefore gives an indication of diabetes control over the preceding four to six weeks. All the outcome measures of diabetes trials now use the HbA1c as the index of diabetes control.

The classic microvascular (small blood vessels) complications of diabetes such as those affecting the eyes, the kidneys and the nerves to the lower limbs were unequivocally shown to be dependent on the level of glycaemic control by certain landmark studies in diabetes. For Type 1 diabetes this was the Diabetes Control and Complications Trial (DCCT), published in 1993 and for Type 2 diabetes the United Kingdom Prospective Diabetes Study (UKPDS), completed in 1998. Thus glycaemic control is very important.

However, historically, 80% of people with diabetes died prematurely from heart disease. This is especially true of people with high cholesterol levels, high blood pressure and those who smoke.

Many studies have shown a massive impact on mortality when there is good control of diabetes, blood pressure and cholesterol.

Many medications now exist to help control glucose levels in Type 2 diabetes and these other risk factors. Patient education and awareness are

# History of Diabetes

## A Timeline

| | |
|---|---|
| 1500 BC | First reference to diabetes in Ebers Papyrus |
| 2300 BC | Term diabetes is first used |
| 5th C AD | Differentiation between Type 1 and Type 2 diabetes is first made |
| 1848 | Quantitative test for glucose in urine developed |
| 1889 | Discovery of the pancreatic origin of diabetes |
| 1921 | Discovery of insulin |
| 1922 | Leonard Thompson is the first person with diabetes chosen to receive insulin |
| 1923 | Frederick Banting and John MacLeod win the Nobel Prize in Physiology or Medicine for their role in the discovery of insulin |
| 1923 | Pharmaceutical industry champions the development of human insulin |
| 1970 | First glucose meter introduced |
| 1976 | First insulin pumps invented |
| 1977 | First islet transplant performed at the University of Minnesota |
| 1978 | First living donor pancreas transplant |
| 1993 | Diabetes Control and Complications Trial highlights importance of glycaemic control in reducing risks of other complications in Type 1 diabetes |
| 1998 | United Kingdom Prospective Diabetes Study proves the importance of glycaemic control in reducing risks of other complications in Type 2 diabetes |
| 1999 | First lasting islet cell transplant perfected in Edmonton, Canada |

the bedrock of diabetes care and I would urge all patients to be aware of the targets for these deadly risk factors and be aware of their own levels.

Obesity surgery in Type 2 diabetes (partial gastrectomies and gastric bypasses) have been performed on tens of thousands of overweight patients with spectacular results. Cure rates of diabetes and hypertension of 80% in such individuals are being noted.

Patient education and awareness are also crucially dependent on the multidisciplinary team now charged with the care of those with diabetes. Quite apart from the doctors, the diabetes team consists of any or all of the following:

- Specialist nurses
- Dietitians
- Podiatrists
- Psychologists
- Administrative and secretarial staff.

This educational and supportive environment is also a major advance in diabetes care.

### Attempts to cure diabetes

The first living donor pancreas transplant was performed in 1978.

The first islet transplant was performed at the University of Minnesota in 1977. However, the first lasting islet cell transplant technique was perfected in 1999 in Edmonton, Alberta, Canada. Islet cell transplants extracted from the pancreases of people who had died, gave people with Type 1 diabetes 15 months without needing insulin. The islets did not last indefinitely and required further top-up ‘infusions’. However, hypoglycaemia was abolished completely in these individuals. The chief limitation is a shortage of available donors.

Research is also active in the use of islet cells that will not be rejected by the host. Attempts are also being made to create islet cells from human pancreatic duct cells, foetal pancreatic stem cells and embryonic stem cells.

### So where are we now?

We have come a long way, and have the tools that allow us to go on and live a long and healthy life. However, one could argue that since the discovery of insulin, advances have not really been revolutionary, merely a process of gradual refinement. There is still a great deal that needs to be done – tedious involvement in measuring this and injecting that, which also requires a great deal of motivation. This motivation isn’t always present, leading to poor self-care, often with disastrous consequences.

Nowadays, one cannot but be optimistic that major advances, be it an artificial pancreas, islet or stem cells, or the obesity pill for Type 2 diabetes is just around the corner.

# From boiled up needles to insulin pumps: **a trip through time with diabetes**

Dr Tony O'Sullivan

Having lived with diabetes for 40 years, **Dr Tony O'Sullivan** has experienced great strides forward in the management of his condition and has been an active advocate for others living with diabetes, both with Diabetes Ireland and internationally

1970s
Diagnosed at age 14

**I'm coming up to 40 years living with Type 1 diabetes, and I'm expecting a medal! I feel like a survivor, not only of the condition but of the treatment, and I am certainly lucky to have stayed reasonably intact until now. I'm in my early 50s, and if you believe as I do that life begins at 70, then I've got to keep working at it for many years to come.**

I was diagnosed in the 1970s, when I was 14. The usual story, peeing all the time and wasting away. I was in a boarding school, so why should anyone have noticed? In hospital my diabetes education consisted of being given a medical text in which I read "people with diabetes do not usually survive beyond the age of 40"(I don't think Type 2 diabetes existed at all back then).

My treatment was a mixture of insulin extracted from cow pancreas, given using a glass syringe which I kept in methylated spirits. I had to boil up the needle once a week and could start with a new one every two months or so. Testing was a tablet dropped into a urine sample, followed by a volcanic reaction which always came out a disappointing yellow (high glucose). In my boarding school going to the loo to do the test meant running into the smokers, so diabetes started me smoking as well (I've given up since).

I never had a problem about injecting in public, even though the process was quite long. I opened my travel pack, took out my syringe and squirted meths out of it until the alcohol dried out; then I shook my insulin bottles and carefully drew it all up before injecting. I remember doing this on a ferry on the Irish Sea once, and when I looked up after injecting it seemed as if the whole ship was staring, I think they thought I was a teenage drug addict.

Progress finally started to impact on my life: first came disposable needles, then a disposable insulin syringe with needle just like we have now. I found it hard to throw them away at first. Before leaving school I was given an actual glucose meter. It was a little bit fiddly, but great. The only problem was, because I was on a mixture, I was never told

> “Progress finally started to impact on my life: first came disposable needles, then a disposable insulin syringe with needle just like we have now. I found it hard to throw them away at first”

how to adjust my insulin. The finger pricker was designed by a specialist in the art of torture – a big swinging guillotine which whacked a needle deep into my finger, drawing great quantities of blood – maybe that’s why I did so little testing in college.

In 1980, I went to study medicine in Dublin, and discovered there was life beyond diabetes. I attended the Mater Diabetes Clinic where we all sat around making up some blood results, passing around different coloured pens and even blood-staining the pages to add realism. Of course I was kidding nobody but myself. However, at this clinic I came across the most significant technological leap forward in all diabetes care – the diabetes nurse. In my case the wonderful Deirdre Cregan, who gave me the first sense of hope and optimism in my struggle with diabetes.

Being a doctor with diabetes doesn’t make you a better doctor, nor any better at managing diabetes, but it has its moments. On my first day as a medical student on the wards, we were introduced to a patient, a young man who told us about his symptoms of thirst and going to the loo a lot. The tutor asked if any of us had an idea what might be the problem with this man – needless to say I was top of the class that day.

My training hospital was the Adelaide, where I met Prof Gerald Tomkin, who was of course one of the foremost diabetes specialists in Ireland, and still is. He brought the artificial pancreas machine to Ireland in 1987, and while it was huge and cumbersome, it gave us all some optimism about the future. I spoke at some Diabetes Federation events around the country about the machine, and the positive reaction to this technology had a big impact on me, driving me into involvement with the Diabetes Federation of Ireland, and eventually with the International Diabetes Federation.

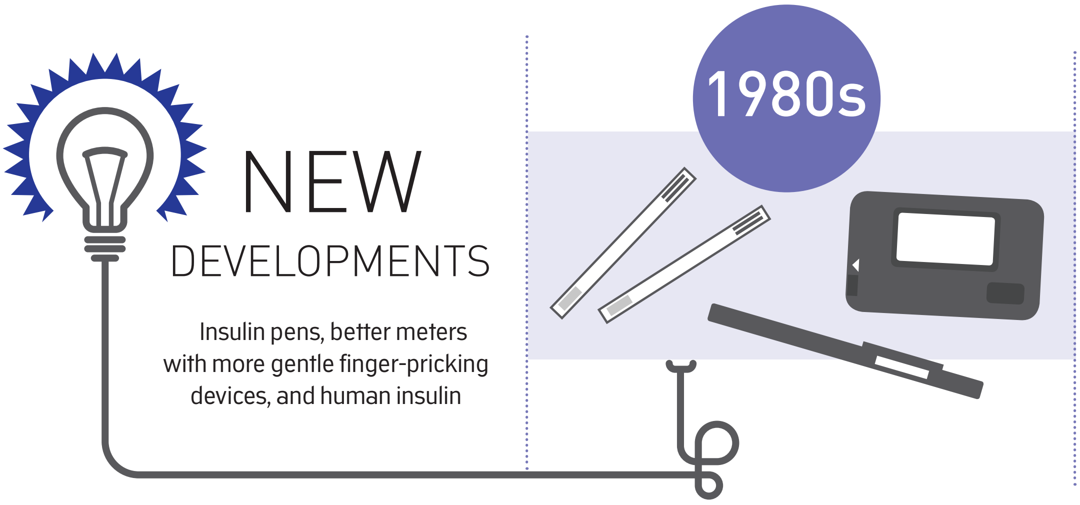
New developments came thick and fast in the 1980s: insulin pens, better meters with more gentle finger-pricking devices, and human insulin. I remember breathing several sighs of relief as these innovations arrived. One of the best was the MediSense meter which used an electronic strip for the first time. It was lightning fast and I thought it looked so cool.

I moved to Cambridge in 1988 to train as a GP. Caitriona and I were married in 1990 and the first of our three children was born in 1992. We moved back to West Cork in 1993 and to Dublin in 1994. I met Prof Tomkin again then and at his suggestion I joined the committee of the Diabetes Federation of Ireland, starting a 13-year involvement with diabetes politics.

I was always impressed with the energy of people with diabetes and their efforts to support one another. Over the following years I realised the true extent of this, including meeting people with a lifelong involvement in volunteering.

It is great to see Diabetes Ireland continuing to flourish and develop new services.

Meanwhile, the diabetes clock kept ticking. Analogue insulins arrived, adding further improvement to control in Type 1. In 1999, I attended the American Diabetes Association medical conference. I met many people with



NEW
DEVELOPMENTS

Insulin pens, better meters with more gentle finger-pricking devices, and human insulin

## “When I meet a young person with Type 1 diabetes, I am optimistic that they will be able to enjoy a very full life”

Type 1 there, all of whom were using insulin pumps. When asked if they would return to injections, they all said they would not. I came home and set about starting pump therapy, and was using a pump myself by June 2000.

My glucose levels were suddenly fantastic, a sign of the greater efficiency of fast-acting insulin, but I also started gaining weight, a downside of this efficiency. I had to start being more careful about food for the first time, but the flexibility of the pump, the lower overall insulin dose, the ability to use a higher basal rate in the early morning or to take a 0.5-unit dose with a tiny snack, all make pumping the optimum way to use insulin.

During this time I also became involved in the International Diabetes Federation European Region. This is a group of diabetes associations from 60 countries including the huge area of Eastern Europe and Central Asia. This involved a huge amount of travel, which eventually I had to give up as I was also running a single-handed general practice at the time.

Meanwhile, I was lucky to visit most European countries as well as Kazakhstan, Belarus and others. We set up an association development course and hired a development officer to support fledgling associations, which were often run from somebody’s kitchen.

We also spent a lot of time working with the European Parliament to establish diabetes as a health priority. We had a lot of support from the Irish EU Presidency and from Irish MEPs.

The IDF European Annual Congress was held in Dublin to coincide with the 40th Anniversary of Diabetes Ireland. The event was opened by President Mary McAleese, who offered a warm Irish welcome to the diverse group of delegates. Our eastern colleagues were especially impressed to be able to chat with the President personally. As her sister was working in Belarus as a nurse at the time, President McAleese had a genuine understanding of their particular difficulties.

In 2007, I had to end my involvement with IDF due to work pressures. I continued to push for greater GP involvement in diabetes care, and ran a course for some years with the Irish College of General Practitioners, helping GPs and practice nurses to keep up to date with the rapidly changing field of Type 2 diabetes.

Recently, the Diabetes Cycle of Care has commenced, where GPs manage uncomplicated Type 2 diabetes in their surgeries. This is good for everyone with diabetes, because the expensive resource of hospital diabetes care will now be more accessible for people with complex Type 2 diabetes, and those with Type 1 diabetes who need that expertise.

Over the past few years I’ve continued trying to improve my diabetes numbers, which have never been fantastic. I’ve learned about carb counting, obtained a sensor pump, used ratios, I’ve even tried healthy eating!

My A1c is still stuck around 60 (about 7.7 in old numbers – everyone’s using the new numbers now, right?). This year, after 40 years of diabetes, I attended a pump DAFNE course in Loughlinstown, and still learned a lot of new stuff from the experts there – both the professionals and the other people with diabetes. Like me, they struggle through each day and have to be good about forgiving themselves – an important skill in living with diabetes.

The sensor pump is an annoying friend who keeps telling you what you’re doing wrong. I was over-reacting to it, and hence swinging from highs to lows several times a day. After the course I’ve backed off a bit and the swings have improved. I’m also using the wizard more, and temporary basals (steady trickle of insulin), which are brilliant when exercising. So I think I’ll be around for a while longer.

Of course, no diabetes story would be complete without acknowledging the support of friends and colleagues, but especially my family – from my wife Caitriona who keeps a steady supply of orange juice cartons everywhere, to my kids Aisling, Maeve and Niall, who chased me around with a glucagon dart when I delusionally tried to go to work at 3am. They share the life and are affected by diabetes as much as I am.

What about the future? As with Ireland, the best days for diabetes are still ahead. I’ve seen so many incredible changes that have liberated people with Type 1 and Type 2, and if anything the pace of change is accelerating, not slowing down.

There are new insulins available this year, and a new rapid-acting one to come. The FreeStyle Libre wearable meter will be a real game-changer for Type 1 when it gets GMS approval, hopefully soon.

That is why, when I meet a young person with Type 1 diabetes, I am very optimistic that they will be able to enjoy a full life, not restricted by inflexible treatments as it once was.

We have an incredible range of resources right now, to help us stay in good condition while we wait for a virtual or actual cure. We just have to use them. Remember, patience isn’t just the wait, it’s how we look after ourselves on the way.

**Some highlights of the period during which I was involved with Diabetes Ireland included:**

- Appointments of Kieran O’Leary and Anna Clarke
- Establishment of regional offices in Cork and Sligo
- Agreement with the HSE to fund diabetes education
- The partnership with Medmedia as publishers of *Identity* now *Diabetes Ireland* of course

# **50 years** of diabetes care for children in Ireland

Prof Hilary Hoey

Prof Hilary Hoey, Chairperson of Diabetes Ireland, writes about the major advances in the care of children with Type 1 diabetes

**The lives of children with diabetes and their families have improved considerably during the past 50 years. While in the early 20th century the average life expectancy of a 10-year-old child with newly diagnosed diabetes was approximately one year, today children with good diabetes control can expect to live a full life with a normal life span.**

There are now greatly improved insulins, technologies and easier access to health information than ever before. The healthcare professionals treating children with diabetes know more about the complexity of the condition and which treatments work best. Diabetes Ireland has worked continuously since its foundation to provide support for children with diabetes and their families, and to promote and lobby for services and resources needed.

Traditionally children with diabetes were looked after by general paediatricians and adult endocrinologists until the 1980s, when we saw the appointment of paediatric endocrinologists Dr John McKiernan in Cork, Dr John Gleeson in Sligo, Dr Colm Costigan in Crumlin and myself in the National Children's Hospital.

The first diabetes nurse specialists Adrienne Brennan and Ann Corby were appointed in the National Children's Hospital, Harcourt Street, which transferred to Tallaght in 1998. Ms Brennan subsequently qualified as the first paediatric diabetes advanced nurse practitioner in Ireland.

Today paediatric diabetes is recognised as a specialty and Dr Stephen O'Riordan was appointed the first National Clinical Lead for Paediatric Diabetes in 2011; followed by Prof Nuala Murphy in 2015.

A national 'Model of Care' has been developed for children and young people with diabetes in Ireland by the HSE Paediatric Working Group in collaboration with the Faculty of Paediatrics along with patient input from Diabetes Ireland. In addition guidelines for the transition of care from paediatric to adult health are services are available.

The *'Model of Care for Children and Young People with Type 1 Diabetes'* was launched by then Minister for Health Leo Varadkar in December 2015. Excellent paediatric diabetes physicians and multidisciplinary paediatric health professionals including diabetes nurse specialists, dietitians, psychologists and other allied health professionals trained in paediatric diabetes have been appointed during the past 10 years. However, there is an urgent need to expand the paediatric diabetes staff and resources throughout the country in keeping with this Model of Care.

Diabetes is a common chronic condition in childhood and is due primarily to insulin deficiency known as Type 1 diabetes. This is different to Type 2 diabetes which occurs mainly in adults. The cause of Type 1 diabetes is not yet clear and current research shows that genetic, autoimmune and environmental factors are associated.

The incidence of diabetes in childhood has been increasing at a rate of 3% throughout the world during the past 50 years. A prospective

COVER STORY

Welcoming the paediatric Type 1 model of care

The new model of care is putting children and their families at the centre of their care plans, writes Sheila O'Kelly

diabetes ireland

Child focus

Improving services for children?

Campaign secures children's nurse

Fitting diabetes into family life

Summer fun for fundraisers

DAWN study sheds light on diabetes challenges

Diabetes Ireland

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Diabetes Helpline Lo-call 1850 909 909

Services for children with diabetes have improved immensely in recent years, including the development of a national *Model of Care for Children and Young People with Type 1 Diabetes*

National Diabetes Register for children with diabetes was established by Prof Edna Roche in 2008. This register shows that Ireland has a high and increasing incidence of childhood diabetes. There are currently 27.5 children with diabetes per 100,000 children under the age of 16, which amounts to approximately 3% of children.

In collaboration with other international registries and the Eurodiab network, the register aids further insight into the cause of diabetes in childhood. Monitoring the occurrence of diabetes in populations also allows improved healthcare planning and appropriate resource allocation. This results in enhanced patient care.

When a child is first diagnosed with diabetes, the presentation of symptoms is substantially more rapid than in adults. However, diabetes may be difficult to diagnose particularly in young children.

Recent evidence has shown that those who present with late symptoms and signs of diabetes are more likely to suffer from diabetic ketoacidosis (DKA) and require more intensive treatment initially. They also tend to have more difficulty obtaining good metabolic control.

A major study led by Prof Edna Roche and supported by Diabetes Ireland and the National Children's Hospital Foundation is currently being undertaken. Its purpose is to develop a programme to promote early detection and reduce the incidence of DKA in young children when they present with symptoms to healthcare professionals. It is also designed to raise awareness among the general population about Type 1 diabetes signs and symptoms. This will also help reduce the risk of diabetes-related complications in later life.

The management of diabetes in childhood has greatly improved during the past 50 years

## KEY ISSUES
### FOR CLINICAL PRACTICE

- **Empowerment:** Empowering the child and family by education, motivation and support is the cornerstone of good control
- **Psychosocial:** Psychosocial factors play a very important role in the management of childhood diabetes
- **Individual needs:** The diabetes management regimen should be tailored to the individual needs of the family and provided by a multidisciplinary team trained in paediatric diabetes care
- **Wide involvement:** Siblings, the extended family, the school and the community should also be involved in the process
- **Cohesive approach from healthcare team:** The healthcare team should have a cohesive approach and target optimal glycaemic control. Continued parent involvement is important, with the promotion of independent, responsible self management appropriate to the child's level of maturity and understanding. It is also necessary to develop strategies to manage the transition to both adolescent and adult services
- **Easily accessible ongoing care:** Adherence to treatment over a long period of time presents many difficulties for children and their families. Easily accessible ongoing care and support are required
- **Extra resources for vulnerable groups:** Children from single parent families and ethnic minority groups have poorer metabolic control and lower quality of life (QOL). It is therefore very important that additional resources are provided to meet the needs of this particularly vulnerable group
- **Positive and effective care:** The challenge for the paediatric diabetes care team is to provide an enthusiastic, positive and comprehensive approach; and to lay the foundation for each child and family to cope positively and effectively with a lifetime of diabetes

> "We are determined to see a high-quality national diabetes service available for everyone"

with improved insulins, technologies and easier information access. However, the management is complex and it has been clearly shown in recent years that good diabetes control not only reduces diabetes complications, but is also associated with a better quality of life for children and their parents.

Structured self-management education is the keystone of successful diabetes care. It requires a patient- and family-centred empowering educational programme that includes a curriculum, a trained educator and quality assurance, together with regular audit.

## School

Children and young people spend most of their day in school or college. Problems for glucose management, insulin and meals have come about due to changes in care that enhance diabetes care. They include:

- Recent developments of improved insulins
- Recommendations for more frequent insulin administration
- The insulin pump
- Glucose monitoring.

School personnel must be educated about diabetes management including:

- Blood glucose monitoring
- Insulin administration
- Hypoglycaemic events.

This will allow them to support and help the young person participate fully in all the available work, sport and leisure activities. A school resource pack was developed by Diabetes Ireland with the support of the Irish National Teachers' Organisation in 2011.

Diabetes Ireland has played a major role in the provision of education and advocacy. It has also provided invaluable support for children and their families since its foundation 50 years ago.

As a result, services available include:

- Eye screening for over 12s as part of the HSE national retina screening programme
- Children's activity clubs including the Tadpole Club which in 2001 became the Sweetpea Kidz Club
- Teen days organised nationally and regionally for teenagers with diabetes
- The National Diabetes Cup 5-a-side soccer tournament has been running for three years
- Events for the child and whole family include weekend fun and educational activities for families whose children with Type 1 diabetes are aged five to 14.

For children with Type 1 diabetes and their families, the misconception and lack of understanding of the differences between Type 1 and Type 2 diabetes is frustrating. Diabetes Ireland intends to play its part in reversing these trends by developing new campaigns to understand the significant differences between Type 1 and Type 2 diabetes. Diabetes Ireland is developing partnerships and collaborations with other groups and organisations to develop these messages and reach as many people as possible.

## Research

Paediatric diabetes research has increased in recent years. Ireland has been to the forefront of international research on the management of paediatric diabetes and quality of life of children and their families. This includes membership of the steering committee of the Hvidoere International Study Group on Childhood Diabetes, of which I am a member.

## Link with JDRF

JDRF IMPROVING LIVES. CURING TYPE 1 DIABETES.

Diabetes Ireland has promoted and supported high quality Irish-based and global paediatric diabetes research with international organisations such as the JDRF (Juvenile Diabetes Research Foundation). This organisation is committed to the cure, treatment and prevention of Type 1 diabetes and its complications.

Major ongoing international research and developments include:

- The prevention of diabetes
- Detection of triggers
- Genetics predictors
- Targeting of treatment
- Immune modulation
- Restoration of beta cells, including islet-cell transplantation
- Fully automated closed loop insulin pumps.

Diabetes Ireland will continue to campaign to make sure the resources are in place to follow the blueprint outlined in the Model of Care. The organisation is determined to see a high quality national diabetes service available for everyone. We will continue to hold Government and state agencies to account and to work with policy makers to maintain diabetes as a public policy priority and to improve diabetes services.

Living with diabetes is not easy. However, with the right help, advice and support, there is no reason why Irish people with diabetes cannot live life to the full. This is our goal and each year through our patient education and information services we provide that support to thousands of Irish people with diabetes and their families when needed most.

# Junior & teen **highlights**

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Kicking diabetes into shape

World Champion kickboxer Catherine Brady tells us how

What is hunger?
Type 1 and 2 complications
Weight loss surgery
Pregnancy and A1c

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Teen activity day
Healthy food for school
Beating diabetes blues
Dublin lunar walk

Thumbs up!

New pack to help schools manage kids with diabetes

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SWEETPEA KIDZ CLUB

SweetPea Picnic!

37

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Kids first

Paediatric advocacy campaign

Artificial pancreas
Research news
Dublin Lunar walk
Spring meeting

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# **Diabetes Ireland** changes focus to **patient empowerment**

**Dr Anna Clarke**, Health Promotion and Research Manager with Diabetes Ireland, welcomes the shift from 'doctor knows all' to people with diabetes taking control

**Life has changed a lot in the past 50 years and also in the diabetes world. There have been changes to the faces, the way diabetes is managed and the daily lives of people living with diabetes. When the Irish Diabetic Association was set up in 1967, support and funding research was the goal, but over the years it has had to evolve to fulfil its original mission.**

During the 50 years there have been phenomenal advances in medicine and changes in the delivery of healthcare services. The daily management of chronic conditions and particularly diabetes have led many changes and continue to make an important contribution to this evolutionary process.

## Insulin improvements

In 1967, the only option for the treatment of Type 1 diabetes was to inject animal insulin, which came from cows or pigs. It sometimes resulted in adverse reactions and, over time, insulin resistance. Syringes were glass, which needed to be boiled to sterilise and then to be stored in methylated spirits. Needles were similarly cleaned and reused for months.

Today, human insulin is produced by micro-organisms and is used without fear of running out of it. Insulin can now be given as injection or continuously by pump, using disposable needles.

## Glucose testing

The way glucose levels are tested has also changed dramatically. The only way to assess glycaemic control (blood glucose control) outside a laboratory up until the 1980s was by testing urine for the presence of glucose.

Today there are numerous, far more accurate portable kits to test blood glucose levels by a simple finger prick. This includes HbA1c, the test that measures a person's average blood glucose level over the past two to three months.

## Advances in technology

The advances in technology meant that the Irish Diabetic Association evolved with support from the pharmaceutical companies. It focused on public meetings and general education on diabetes-related issues with dietetic information always a key focus.

Dietary advice has changed, but the basic principles remain the same – be aware of the carbohydrate content and tailor to suit your insulin. In the 1960s, carbohydrates were restricted to 'exchanges' which were interchangeable but prescriptive in quantity. Now for Type 1 diabetes, it is all dose-adjusted insulin for normal eating; and for Type 2 diabetes the focus is on carbohydrate content and portion size.

## Still a long way to go

Yet there is still a long way to go both for the organisation and for diabetes management. It was in 1967 that it was first speculated that Type 1 diabetes had an autoimmune basis, whereas now that is the first line in every explanation.

Researchers have learned how diabetes develops, how to prevent or delay Type 2 diabetes, and how it affects all of the body. All of this was virtually unknown in the 1960s. There has been a lot of change and advancement in the management and outcomes, but what people really want is a cure and we don't have that yet.

## Diabetes Ireland Research Alliance (DIRA)

Diabetes Ireland has always supported Irish research. Initially this was with small supplementary grants, but we now have a dedicated research stream – Diabetes Ireland Research Alliance (DIRA). It offers major research funding of up to €225,000 per annum.

In addition, DIRA has joined forces with Juvenile Diabetes Research Foundation (JDRF) to ensure Irish funds are donated to specific Type 1 cure possibilities.

At the moment, those DIRA/JDRF funds are donated to the Nano Versus Micro Encapsulation for Islet Transplantation based at Kings College London. This is developing new techniques using nano-technology to provide very thin porous coatings. These coatings will protect new implanted beta cells to replace the ones that have been destroyed by the immune system in Type 1 diabetes.

## Epidemic of Type 2 diabetes

During the 1960s, Type 1 and Type 2 diabetes were differentiated by whether or not the person needed insulin treatment. The epidemic of Type 2 diabetes that escalated through the 1990s to the current tsunami was only just starting. Now Type 2 diabetes accounts for 85-90% of all diabetes diagnoses.

Initially, doctors relied on persuading people to adopt the dietary and activity changes to daily behaviours known as daily self-management behaviours.

## First diabetes nurses

The first diabetes nurses were employed in the early 1980s to help hospital staff safely administer insulin. Insulin was procaine insulin and there was only a small availability of bovine insulin in either 40 unit or 80 unit strength.

## Disposable syringes

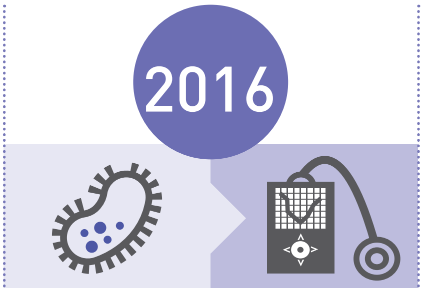
The introduction of 100-unit insulin required meticulous attention to drawing up insulin. With its introduction came the disposable 100-unit insulin syringes which revolutionised insulin administration. At the same time the introduction of the first ward-based blood-glucose machines required nurses with specialised knowledge.
As their role developed, their focus shifted from

## INSULIN
### IMPROVEMENTS

1967

In 1967 the only option for the treatment of Type 1 diabetes was to inject animal insulin, which came from cows or pigs

2016



In 2016, human insulin is produced by microorganisms and can now be given as injection or continuously by pump, using disposable needles

## Diabetes Ireland professional journal

With the support of Medmedia, Diabetes Ireland has a professional journal, *Professional Diabetes & Cardiology Review*. It is delivered four times a year to professionals working in the fields, focusing on Irish and international best practice, latest news and research findings.

teaching fellow colleagues to teaching people with diabetes.

## Professional study days

Diabetes Ireland has contributed to the professional teaching of all healthcare professionals through its annual professional multidisciplinary study days. Up to 2016 there were two study days a year, but with the growing number of people with diabetes this is expected to increase in the future.

## 'Teaching' people with diabetes

Some 50 years ago, 'teaching' was the term first used to give information to people diagnosed with diabetes. It was assumed that knowledge alone would entice people to follow doctors' orders, and then be labelled as 'compliant' or 'non-compliant'.

This approach was based on the medical model of health which was designed to treat acute medical problems. This approach meant the doctor was the authority responsible for the diagnosis, treatment and health outcomes.

Over time, this model was deemed unsuitable for chronic (long-term) conditions. It was recognised that a more holistic approach was needed. It is still evolving and recognises that people are in control of and responsible for their daily diabetes self-management.

The responsibility of the healthcare professional is to align the self-management plan with the person's goals, priorities and lifestyle, as well as their diabetes.

## Ultimate control

Diabetes Ireland has always striven to push the reality of living with diabetes to professionals by offering opportunities for people with diabetes to voice their story at professional training. In this way, we strive to push the professional focus on to choices, control and consequences.

Daily choices have a greater impact on outcomes than professional inputs. It is the person with diabetes that has control over their behaviour. They are also in control of what professional advice they put in place or ignore.

Advances in the field of education and more knowledge on learning techniques have also impacted on diabetes education. That combined with increasing numbers diagnosed resulted in development of group education programmes in the early 2000s.

CODE
Community Orientated Diabetes Education

## CODE education for Type 2

The prevalence of Type 2 diabetes in Ireland is now so great that Diabetes Ireland has had to focus on providing Type 2 diabetes education throughout the country. This was the start of a new era for Diabetes Ireland as it pushed into the field of service delivery due to the long waiting times and recognition by the HSE of the need for service level agreements with alternate service providers.

CODE (Community Oriented Diabetes Education) provides group educational sessions for up to 16 people over three consecutive weeks. There is follow-up at 10 weeks by phone call and at six months.

Each session is two hours long and is facilitated by a professional with a set curriculum.

To date, Diabetes Ireland has run almost 400 programmes for almost 5,000 people with Type 2 diabetes, pre-diabetes or their carers. In addition, in recent years the organisation has focused more on specific training for carers of people living with diabetes, through, for example, targeted delivery of programmes in residential institutes.

# Support for people with Type 1 diabetes

**With Type 2 diabetes, the focus is on education, but the prevalence of Type 1 diabetes is much lower. People with Type 1 diabetes have complex insulin adjustment needs and group education is limiting. Therefore, for this group, Diabetes Ireland has focused on providing psychological support.**

Each year, camps, days out and tournaments offer younger people and their families the chance to meet up and socialise together. The younger individuals gain much from seeing their peers dealing with diabetes-related tasks and parents always welcome the opportunity to meet other parents.

In the early 2000s, Diabetes Ireland supported the need for more professional psychological support by training qualified professional counsellors in diabetes. This extended the base of counsellors with better understanding of the issues facing people with diabetes. However, as the service was a private service at normal fees, it never really developed. Last year, Diabetes Ireland shifted focus and now has a counsellor offering the service in the Santry Diabetes Ireland Care Centre, which is being extended to the Cork Care Centre.

Over the past 50 years, the Irish Diabetic Association evolved to become the Diabetes Federation of Ireland and now Diabetes Ireland to meet the needs of the growing organisation and the diabetes community. Much has been done, but it still is only the tip of the iceberg in terms of providing support to people living with diabetes.

Diabetes Ireland

*Teens with diabetes*
*National activity day*
**Friday 10 July 2015**

- Want to meet other people your own age with diabetes?
- Like to try your hand at new activities?
- Enjoy competitive team activities?

Then sign-up now for Diabetes Ireland's Activity Day for 10-16-year-olds. To find our more contact Siobhan on Lo-call 1850 909 909 or email info@diabetes.ie

Birr Outdoor Education Centre **Offaly**

Eclipse Activity Centre **Kerry**

***Nationwide Centres***

Buses travelling from various locations to these venues

Dunmore Adventure Centre **Waterford**

Northwest Adventure Centre **Sligo**

Phone Siobhan
**1850 909 909**

For more information visit
**www.diabetes.ie**

Diabetes Ireland |CHY6906 | 19 Northwood House, Northwood Business Campus, Santry, Dublin 9 | 1850 909 909 www.diabetes.ie

Offaly Teen Day 2015

> We are progressing in finding new ways of managing diabetes, but are we any closer to a cure for Type 1 diabetes or stemming the tsunami of Type 2 diabetes that threatens the very core of our society?

# **Fundraising** is a **TEAM** effort

As is the case with many charities, Diabetes Ireland would simply not exist without fundraising and the support of the diabetes community nationwide, writes Gary Brady, Fundraising Manager, Diabetes Ireland

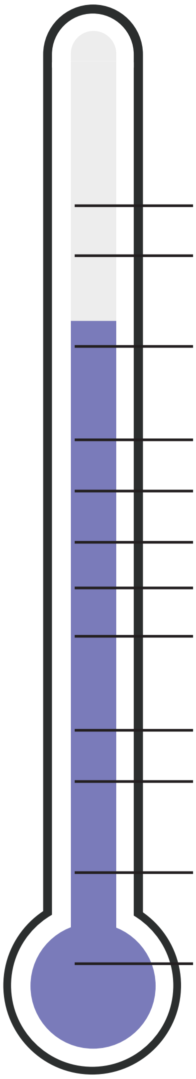
Gary Brady

**Fundraising in modern times takes many forms and is constantly evolving to mirror societal changes. The increase in the role digital and social media play in fundraising is perhaps the easiest example to demonstrate this.**

We at Diabetes Ireland are no different from any national charity in the breadth of our fundraising platforms and the avenues we look to raise money through. Our current fundraising platforms are listed in the graphic below.

There can sometimes be a misconception in relation to Diabetes Ireland's funding relationship with the HSE. To reinforce the reality once again, we are a wholly independent charity.

Our annual published accounts show HSE funding accounting for approximately just 50% of our income. It should be noted this funding is specifically in relation to our Service Level Agreement for specific projects and services. These include our podiatry partnership in the



- **Membership scheme**
- **Grants and funding** (for example, Ireland Funds, National Lottery Health Grants)
- **Corporate support** (mainly from pharmaceutical brands working in the diabetes field)
- **Overseas treks** (Mount Kilimanjaro Trek in 2016)
- **Our own organised events** (for example, walks and cycles)
- **TEAM Diabetes Ireland** (participants fundraising through sporting events)
- **Biannual raffle** (spring and winter)
- **Donations** (for example, one-off donations, direct debit, wills and legacies, in lieu of wedding favours)
- **Branch fundraising**
- **Locally organised community fundraising events** (for example, coffee mornings and table quizzes)
- **Corporate Charity of the Year** (we have recently been Charity of the Year for Bord Gáis and the GAA)
- **HSE funding** (to provide nursing, dietetic and podiatry services)

North East and Southern Regions where we employ podiatrists and the HSE gives us the funds to pay their salaries. It also includes elements of our health promotion services, for example CODE (Community Oriented Diabetes Education).

In line with our growth as an organisation over the past decade, Diabetes Ireland's fundraising platforms have extended to meet the demands of society. There are more than 8,000 registered charities in Ireland making the competition for fundraising money more demanding than ever. It is becoming an ever more difficult area to be successful in.

The amount of money spent by other major national charities to raise funds greatly exceeds our total annual turnover. In recent years, we have seen the explosion of mental health and homelessness issues in Ireland and the subsequent charity fundraising which has followed.

Support of the diabetes community in Ireland is essential to the growth and extension of our services. We also place an ever greater focus on corporate funding and applying for other grants.

A key part of our fundraising is that all fundraising supporters may choose which area of our services they would like their funds to go to. These areas are:

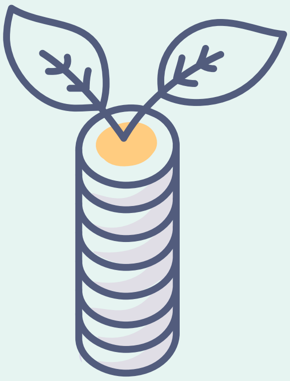
- Type 1 diabetes research
- Type 2 diabetes research
- Education and support services
- Teen Activity Day and Sweetpea Kidz Club
- 2016 Type 2 Online Education Programme
- 2016 Type 1 Awareness Initiatives
- Cork Care Centre.

In the past number of years we have secured a number of new and large funding grants:

- In 2014, we applied for and were awarded Charity of the Year for Bord Gáis and received €40,000 to help set up the Diabetes Ireland Dublin Care Centre
- In 2015, we applied for and were awarded GAA's Charity of The Year, which delivered €20,000
- In 2016, we received large-scale funding from Medtronic through its US headquarters for projects in the Midlands.

These funding streams will continue to be a key area of greater focus for us. Our success in this revenue stream is certainly aided by the ever increasing media and societal focus on diabetes as a major health issue.

# Other sources of funds



## Pharmaceutical support

Pharmaceutical corporate support is a very important part of our income. We have a strong stable of pharmaceutical brands who support various areas of our everyday activities and are essential to our sustainability.

## National Lottery funding

Annually we receive varying amounts of regional funds from the National Lottery, which we use to help hold our local meetings and other projects. In 2015/16 National Lottery funding allowed us to run a successful Diabetes Course for carers working in Intellectual Disability Care Homes and Facilities. In 2016, we focused on a similar nationwide project for Nursing Homes.

TEAM Diabetes Ireland was an umbrella project we created in 2013 for all our fundraisers who raise vital funds for our services. They do this through many sporting activities that take place annually, both nationally and internationally. Our TEAM jersey has been worn for example at:

- Marathons
- Cycles
- Triathlons
- Mud runs
- Skydives
- And as far afield as
  - The New York Marathon
  - The top of Kilimanjaro
  - Phuket Marathon in Thailand

There is an ever increasing number of nationwide fundraising and general sporting participation events, such as the Women's Mini Marathon, most weekends. It is increasingly becoming more economically beneficial for us to encourage people to take part in these events to raise funds for Diabetes Ireland than to organise and run our own events.

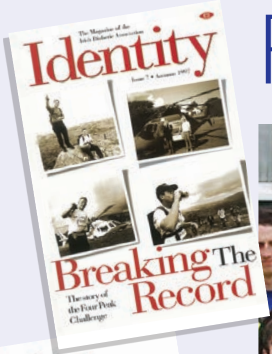
Historically overseas treks, our biannual raffle, the membership scheme, the Women's Mini Marathon and donations would have been the core of our fundraising.

In the late 1990s, we were the first national diabetes charity in the world who brought a group of people with Type 1 diabetes to the top of Mount Kilimanjaro, the highest mountain in Africa. A major medical study was undertaken as part of this trek and overall this trip was an important landmark in our history. At that time there was a strong push to show that Type 1 diabetes should not be a boundary to sport, activity and life success.

In recent years there has been a decline in the funds raised through our annual raffles and the Women's Mini Marathon. This reflects societal changes and highlights the 'swings and roundabouts' nature of charity fundraising.

It is important to note the role one particular supporter played in our recent history. We were very fortunate to have been left a property in Dublin through a supporter's Will. This major legacy was used as the principal funds for us to purchase and fit-out our Dublin Diabetes Ireland Care Centre and allow us for the first time to provide direct medical services. The Centre now sees more than 8,500 people a year due to this great personal legacy which we will never forget.

# Fundraising 1967 2016



The Magazine of the Irish Diabetic Association

Identity

Breaking The Record

The story of the Four Peak Challenge

Climbing Kilimanjaro

LUNAR WALKS

## Dublin, Cork walks

LUNAR WALKS

## Big thank you to Women's Mini-marathon fund raisers

he Diabetes Federation of Ireland
would like to thank all those who
part in the Women's Mini Mara-
n Monday 6 June and helped raise
20 to date.
oluntary organisation the Federa-
y dependent on public support
ervices and help for people
nd research into finding a
herefore of tremendous
its work.
money chose which
ces they would like
They chose:
453.80
69.00
038.75

Martina McDermott, from Co Monaghan, and her friends who raised €2,044 for the Diabetes Federation of Ireland by running in the June Women's Mini-marathon. These were just some of the women who donated the funds they raised to the Federation

- Annual Teen Activity Day – €243.00
- SweetPea Kidz Club – €865.55.

"I would be very grateful if anyone who has not returned sponsorship card and money would do so at their earliest conven-ience," says Linda Doyle in the Federation.

If you have any queries please do not hesitate to contact Linda on 1850 909 909, (01) 836 3022 or email linda.doyle@diabetes.ie

BRANCH NEWS: SOUTH

## KERRY WALKERS RAISE OVER €4,600

34

# Ask not what **Diabetes Ireland** can do for you...

**Gráinne Flynn**, who won Diabetes Ireland Volunteer of the Year in 2012, writes that volunteering has been key to managing her own Type 1 diabetes

What has Diabetes Ireland done for me?

Gráinne Flynn being presented with her Volunteer of the Year Award, by Steve Williamson of Roche

**I've been volunteering with Diabetes Ireland for 10 years. Yes, I have given a lot, but what I've received in return has been 10-fold. Proving that, as the saying goes, you have to give in order to receive. And I have received bucket loads!**

Diabetes Ireland enabled me to create a local diabetes support community when I desperately needed it; it helped me become empowered as a person with diabetes and fostered me as a diabetes advocate. Diabetes Ireland has given me numerous volunteering opportunities, which allowed me to grow and develop as a person and ultimately to find my calling.

But it didn't start out that way. My first experience of Diabetes Ireland was soon after I was diagnosed in 1993. My diabetes nurse recommended that I join and I went to my first diabetes public meeting in Tullamore, Co Offaly as a 20 something-year-old who was still trying to navigate her way through this new life with diabetes.

I wasn't impressed. I felt I was surrounded by older people – they probably weren't that old, but to a 20-something-they seemed *ancient*. So, when my membership of the organisation lapsed after 12 months I didn't renew it and spent most of my 20s largely ignorant of diabetes management.

After I got married, my new husband and I moved from Dublin to the US, where I had my first experience of diabetes education and how diabetes care could be. Moving back to Ireland was a big decision for us. We knew that Ireland was lagging behind when we left and hoped it had advanced in the time we were gone. We decided that if the health service didn't show significant signs of improvement within five years we would leave again. We settled in Co Clare and wanted to access diabetes care more locally than Dublin.

By 2007, I had two very small children and I was a stay-at-home parent. I wasn't happy with my diabetes care options, having tried a couple of them over two years. My lowest point was after the most humiliating clinic appointment I have ever had. I broke into tears as soon as I got into my car.

I had had enough – there *had* to be better care

out there and if I had to travel to the other side of the country to get it with two toddlers in tow then I would. This was my health, my life, and my children needed to grow up with a healthy mother.

This is where Diabetes Ireland came back into the picture. This time, the organisation came through for me, and more.

### Diabetes Ireland fostered me as a peer support facilitator

Just when I needed it, the Clare branch of Diabetes Ireland was being set up. As soon as I got home from that clinic appointment, I pulled out the newspaper and rang the number. The woman who answered was a person about the same age as me who also had Type 1 diabetes, and was also new to Co Clare.

We talked for ages about our frustrations with our diabetes services and about how if we knew more people with diabetes we could ask them what other local services were available. By the end of the phone call we had decided to start diabetes support groups.

Diabetes Ireland provided us with the advice we needed to get started and has been supporting our groups for almost 10 years in whatever way it can.

### Diabetes Ireland fostered me as a diabetes advocate

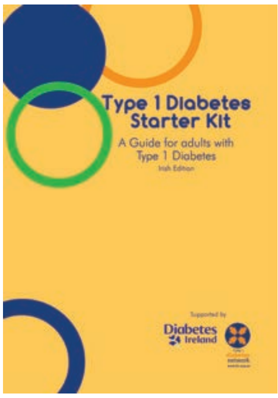
In 2010, Diabetes Ireland launched an advocacy campaign to push for the implementation of a national podiatry programme – the first of a series of such campaigns. It provided advocacy training to volunteers in how to help with this campaign. The training and support I received during this campaign I have been using ever since and continue to learn.

### Diabetes Ireland enhanced me as a graphic designer

When I came across the Australian Type 1 Diabetes Network's version of the *Type 1 Diabetes Starter Kit: A Guide for Newly Diagnosed Adults,* I knew it was something that could be adapted easily, or so I thought, for people with Type 1 diabetes in Ireland.

I approached Dr Anna Clarke, Diabetes Ireland Health Promotion and Research Manager, about it, but the resources that were needed, Diabetes Ireland just didn't have. So, when Anna told me to "Go for it!" I thought "Why not!" I'm very proud of the resulting Irish edition of *Type 1 Diabetes Starter Kit: A Guide for Adults with Type 1 Diabetes,* and am very grateful for Diabetes Ireland's support. The knowledge I gained during the process of adapting this information kit has helped me organise *Thriveabetes.*

During the time I was working on the Starter Kit, Diabetes Ireland decided to shorten its name from the Diabetes Federation of Ireland to Diabetes Ireland and it needed a new logo. As a graphic designer, the organisation approached me to take on this task. I still have to remind myself wherever I see it that I helped do that.



The guide that Gráinne fundraised for and for which she co-ordinated the production and distribution

### Diabetes Ireland fostered me as 'Thriveabetes' founder and event organiser

*'Thriveabetes: The Thrive with Type 1 Diabetes'* conference is probably what I spend most of my volunteer time on these days. This event is independent of Diabetes Ireland, but everything I have done with the organisation up to this point has enabled me to pull it together – with the help of a very supportive diabetes community.

When I approached Kieran O'Leary, CEO of Diabetes Ireland, with this idea stating unequivocally that we didn't want the organisation's money, but we did need its support and help with it, he made sure we knew what we were getting ourselves into. No question or idea from us has ever been too ridiculous or too small for Diabetes Ireland. And no email (and there have been hundreds) has ever gone unanswered. Having Diabetes Ireland in your corner means that the people you want to hear you, start to listen.

## Volunteers make us stronger

And there you have it! What started out as a cry for help, over time became 'What can I do to help you?' Diabetes Ireland has been an amazing source of support and growth to me, allowed mad ideas to become real things and I can't wait to see where we find ourselves next!

# Parents will always need the **support of other parents**

Charlotte Pearson describes how her life changed when her daughter Karen was diagnosed with Type 1

Charlotte Pearson

**1998**
Daughter Karen diagnosed at age 5

**My daughter Karen was diagnosed with Type 1 diabetes at the age of five on December 18, 1998 – three days after her fifth birthday. Anyone who has experienced this would know that when you have a child diagnosed, every detail of that day stays with you.**

My first support contact was with another mother just like me who was about to go home with her newly diagnosed daughter. As she was leaving and we were being admitted she handed me a note with her phone number and all she said to me was *"Ring if you need someone to talk to, I know exactly what you are going to go through"*. We became friends and would ring each other constantly for support. When we first arrived home from the hospital, I was hungry for information so I would read whatever I could find. We would share information with one another.

While in hospital I was given contact details for the Southern Counties Diabetic Association and sent off a cheque to become a member. However, six months later my cheque was returned with a note to say that it was disbanding, I was very disappointed with that because I felt I needed more contact with families living with this condition.

In September 1999 my friend (whom I met in the hospital) was doing the Cork Evening Echo Mini-Marathon and while she was walking it she noticed a lady wearing a t-shirt with 'Cork Parents Support Group for Children Living with Diabetes' and a phone number on her back. She asked the woman for more information and then in turn passed that number on to me. That was when I first spoke to a fantastic person, Anne Conroy who listened to me for hours at a time and gave me so much support

> *"Ring if you need someone to talk to, I know exactly what you are going to go through".*

## ‘As parents know, the first year of diagnosis is the milestone year much like having a new baby’

when I needed it the most. As parents know, the first year of diagnosis is the milestone year – much like having a new baby.

The regime for Karen was twice daily injections which was very regimented to control the condition, having to inject and eat at set times, day in day out. It was hard on all the family, not just the child with Type 1. Having Anne to turn to in that first year helped me to decide to become involved with the Diabetes Federation of Ireland (as it was known back then).

I attended the very first AGM that the Diabetes Federation of Ireland held in Cork, when it amalgamated with the Southern Counties. I joined both the parents and branch committees, and I am still active on both.

The people I have met from being involved with Diabetes Ireland have meant the world to me – Margaret Phelan, Jacinta Cottor, Anne Conroy, Therese Crotty, Sheila Stokes and Aileen Horgan. The support I received from them when I needed it made me want to help and give something back. Parents will always need the support of other parents. We know what it is like to have the worries of having a child living with Type 1, the hypos and hypers and the worry of complications. Family and friends, although kind and caring, will never understand this like another parent of a child with Type 1 diabetes.

As time went on and I became more involved in the organisation, I enjoyed meeting new parents and their children through the activities we were now organising with the help of the newly opened office in Cork. Our letters to parents were being sent out for us from there and the number of contacts grew. One person who was my most important source of support was Trish O’Donovan who helped with organising our Teddy Bears Picnic, Oyster Haven Activity Day, our Christmas party and numerous educational meetings. She will always be in my heart and I still miss her support since she passed away over two years ago.

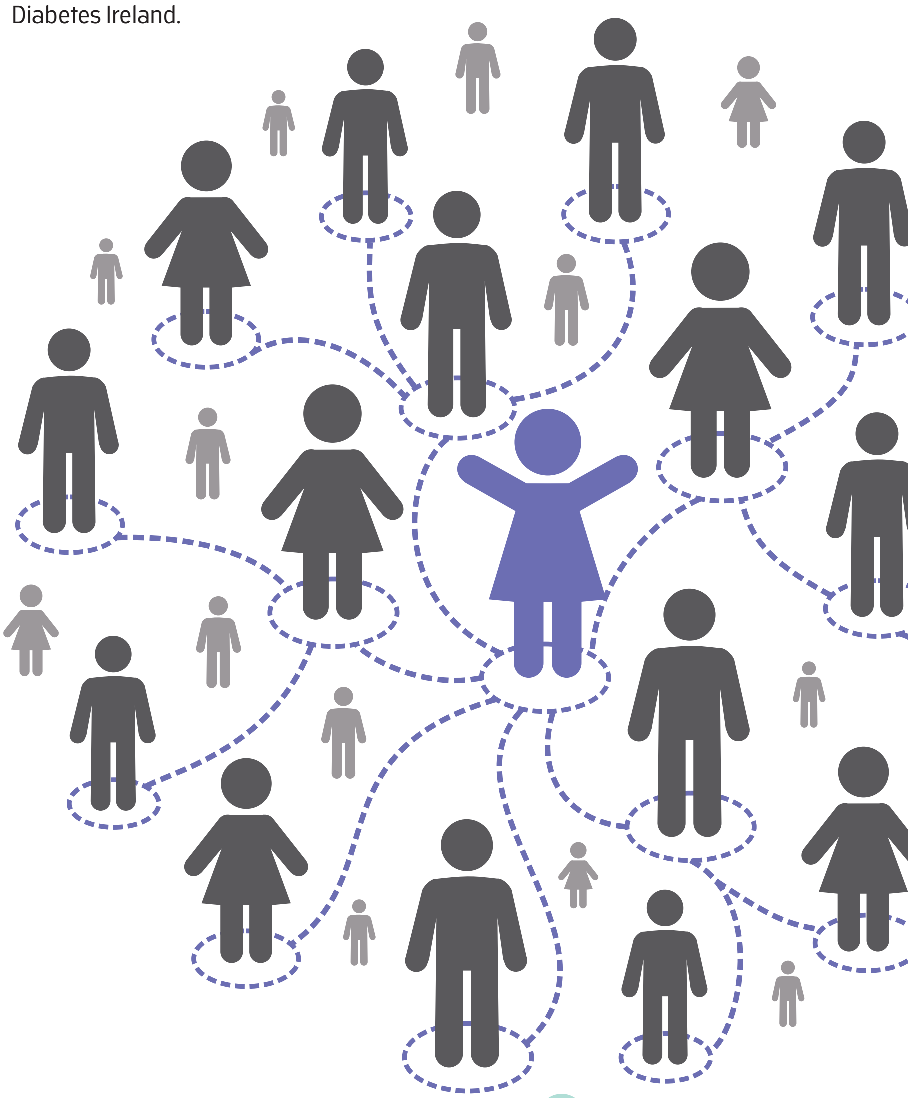
Over the years Anna Clarke from Diabetes Ireland helped me in so many ways. On one occasion when I needed someone to talk to the primary school Karen was attending, Anna gladly helped out and paid a visit to the school to give much needed education on Type 1 diabetes. Anna has always been a great source of information to me even today I know I will always get sound advice from her.

Diabetes Ireland CEO Kieran O’Leary supported us in improving hospital services by providing documentation on best practice and guidelines.

I was fortunate to start working in the Cork office, filling in initially for a maternity leave vacancy. The position involved supporting the Regional Development Officer in the Southern Region, Pauline Lynch.

I can honestly say that Diabetes Ireland means the world to me as I am doing a job I love and still meeting people with diabetes, especially parents and their children living with Type 1. I have enjoyed all the events and campaigns with which I have been involved. These included a few crazy things, the most memorable being a parachute jump for my 40th birthday.

Without having diabetes and Diabetes Ireland in my life, I would not have met all the amazing parents living and coping with having diabetes every day. I know I am a stronger person with the support I still get from other parents and from Diabetes Ireland.



# Awakening of the West to **diabetes awareness**

Strenuous campaigning spearheaded by branches in the west of Ireland has led to vastly improved services for people with diabetes in recent years

**The Sligo Branch (now the Western branch) of the Diabetes Federation of Ireland was founded in 1988. Founding members included Donal Conway, Suzanne Donnelly, Marie Fowley, and Denis and Caitriona Coleman. After many years of campaigning it is looking forward to the opening of the new Diabetes Care Centre in Sligo University Hospital.**


Diabetes Ireland
COMHALTAS
JOINT VENTURE
ANNUAL SPONSORED WALK ON KNOCKNAREA
Sunday 16th June at 2.15pm
(meet in car park at bottom of mountain)
Join us on top at 3pm to sing or play
THE SALLY GARDENS
bring your own instrument
A FUN DAY
HOT DOGS AND DRINKS FOR ALL
Contact:
Suzanne (086) 8867348 (Diabetes Ireland)
Regina (071) 9146001 (Diabetes Ireland)
Martin (086) 0551027 (Comhaltas)

Initially the branch began by running children's events and public meetings. In the 1990s, the branch set up a small office in a room made available free by a local pharmacy. The office was open one day a week. That was the core from which the current office has grown.

Suzanne Donnelly has been a stand-out volunteer and along with other members of the Western Branch, Donal Gilroy and Patricia Crocock, has been the recipient of the Volunteer of the Year award.

The Sligo branch ran its first one-day diabetes conference in 1999 aimed at healthcare professionals, people with diabetes and parents of children with diabetes. It was a huge success with more than 200 people attending.

"It went very well and was an eye-opener as to what could be done anywhere in the country," said Donal Gilroy.

Donal has been a member of the branch since the early 1990s and was 'Volunteer of the Year' in 2006. He donated his €1,000 prize to Cregg House in Sligo where his wife works. This provides care for people with intellectual disabilities – many of whom have diabetes.

As the Sligo branch grew, it moved on to office space in the local Citizen's Information Office. In 2001, May McConnell was appointed Resources Officer serving Sligo/Leitrim and Donegal. This was the branch's first professional appointment.

A few years later May's position was retitled Western Regional Officer as the office was expanded to include nine counties along the west coast. New offices in Wine Street were set up as the branch expanded. When May retired in 2008 Regina Patton took over as Regional Development Officer, West.

From a single part-time diabetes nurse in Sligo Hospital in 1988, services have expanded.

"We now have three specialist consultants and six diabetes nurses that we lobbied for. A new diabetes centre for adults and children is due to open soon at Sligo Hospital," said Donal Gilroy. This will enable many more children in the North West to take advantage of insulin pump therapy. In addition it will provide more space for diabetes patient care, as existing conditions are quite cramped.

The Western Branch has always been very strong. In the early days members helped to set up branches in places like Castlebar, Carrick-on-Shannon, Cavan, Mullingar and Longford.

Expert speakers were invited to meetings from Sligo, Donegal, Galway and Dublin and the format of these gatherings proved very successful.

"When I first did local radio and newspaper interviews, you would find that people knew practically nothing about diabetes. These days people are much better informed and more aware. GPs have changed too, in that they test older people for Type 2 diabetes more regularly.

One of the early diabetes campaigns in the West was for an eye-screening service. This led to a successful mobile eye-screening service, which was a precursor of the national Diabetic RetinaScreen programme, now available nationally.

## Donegal branch

The Donegal Diabetes branch, part of the Western branch, was formed in the 1970s and in the early days the main volunteers were Liam McGlinchey, Grace Mulligan, Frank Morris and Bernadette O'Donnell.

Danny McDaid, two-time Olympian, got involved in the organisation in 1991, shortly after his two daughters were diagnosed with Type 1 diabetes. Danny has been nominated for Diabetes Ireland Volunteer of the Year several times.

Danny's 13-year-old daughter was diagnosed in August 1991 and his eight-year-old a few months later. When Danny joined, the chairperson was Harry Cheevers, who was very supportive. The McDaid family were also helped along the diabetes path by Kelly Hyndman who had three children with diabetes.

"We were totally ignorant of diabetes, how to look after someone with the condition or what

having diabetes meant," said Danny.

The most important role for branches is to support people newly diagnosed with diabetes, said Danny.

"I have stayed involved for so long because of the tremendous support that we got when we badly needed it. It's traumatic when it happens, but when you see other people in the same boat as yourself you get good comfort.

"Of course when you see the likes of Bernadette O'Donnell who has had diabetes for more than 60 years, you know that with good control you can lead a normal life," said Danny.

Danny was very well known as an Olympic athlete and he used this as a tool to highlight awareness about diabetes and to campaign for better services. He competed for Ireland at two Olympic Games, Munich 1972 and Montreal 1976. He also took part in nine World Championships and was captain of the Irish Senior Cross Country team from 1975 to 1981.

The running track at the Letterkenny Regional Sports and Leisure Complex is named in his honour. The Danny McDaid 15k, which begins and concludes at this track, is also named after him.

Danny introduced the church gate collections for the Diabetes Federation of Ireland to Donegal in 1993.

"The first year we raised about €3,000. It went to a high, before the recession, of €25,000 a year. The money was used to support family events, hospital equipment, and towards the national office in Dublin," said Danny.

From Danny's early days, the Donegal branch has had close contact with the diabetes nurses in the hospitals. Members of the branch find that the nurses are very good about putting newly diagnosed people in contact with the branch.

"When my kids were teenagers, the clinics were mixed so you could have a teenager sitting in with an old man who had had amputations and telling her the worst stories you could ever imagine," said Danny.

When Diabetes Nurse Specialist Kathleen Crerand came on board she managed to carve out a bit of space to give people privacy.

When Danny joined the Diabetes Federation of Ireland, hospital services were provided by Dr Liam Bannon, who had an interest in diabetes. After many years of strenuous campaigning by the branch and Diabetes Ireland, a Consultant Endocrinologist, Dr Amjed Khamis, was appointed to Letterkenny in 2012.

In 2014, a full-time paediatric diabetes nurse specialist was appointed to Letterkenny Hospital. In addition, there is now a Paediatric Endocrinologist in Sligo Hospital, which saves many a long trip to Dublin. However, with 160-170 children with diabetes under the age of 16 in Donegal, the branch there felt that the numbers warranted a Paediatric Endocrinologist in the county.

The numbers of children being diagnosed with Type 1 diabetes in Donegal has increased significantly.

"When my children were diagnosed with diabetes there was an average of eight to10 children a year diagnosed in Donegal. Now it is more than 16 children diagnosed a year," said Danny.

"We have a good working branch here at the moment. Gerard Gallagher who has Type 2 diabetes joined the branch as treasurer and is now the chairman. He and myself are on the National Council of Diabetes Ireland. The treasurer is Paul Gillespie," said Danny.

Back in 1998 Danny, Kelly Hyndman and a young man called Edwin McCloughan, who has sadly since died, organised the first family weekend away. They took about 20 children and 25 adults to the Carrigart Hotel. Prof Gerald Tomkin joined the families and spoke to them about diabetes care.

"That was the start of the family weekends and they have continued ever since. In 2016, some 180 people attended the family weekend at the Inishowen Gateway – and they were all just from Donegal," said Donal.

Danny has seen major changes in diabetes care since his daughters were diagnosed, including much more user-friendly insulin pens, insulin pumps and carbohydrate counting and the DAFNE course.

**– Sheila O'Kelly**

Danny McDaid, from the Donegal Branch, is pictured above (third from left) with some of his fellow Diabetes Ireland stalwarts (l-r): Liam O'Doherty, Dublin; Pat Power, Waterford; and Leonard O'Connor, Dublin

# Uniting for a stronger voice

Diabetes services in the Southern region have moved from strength to strength in the years since the Southern Counties Diabetes Association united with Diabetes Ireland

Margaret Phelan

**Margaret Phelan has been involved in diabetes support and campaigning since her daughter was diagnosed with Type 1 diabetes at the age of four in 1987.**

"There have been big changes since then. Appointing a development officer and the dietitians made a huge difference. There is more awareness and better services now. The new Care Centre and the free eye screening is a huge improvement. The podiatry services have also improved hugely and become more available. The new system is way, way better," said Margaret.

"There are more people coming into the office now because they are coming for the eye and foot services. It is totally different to the office we had in the start. It is a big improvement," said Margaret.

Back in the late 1980s, the Southern Counties Diabetes Association (SCDA) representing Cork and Kerry were active in the South. The SCDA liaised with the British Diabetes Association.

At one of the SCDA meetings, a group of parents got together to form a diabetes parents' support group. A member of the SCDA attended the parents' support group meetings.

"We organised days out for the children and meetings with the consultants. We began to send the children away on holidays to Northern Ireland. One of these was a trip to Castlewellan Co Down, organised through the British Diabetes Association," said Margaret.

At the time the SCDA did not hold public meetings so the parents' support group stepped in to organise these. The group liaised with the hospitals, especially Dr John McKiernan who was the paediatric consultant and helped the group communicate with newly diagnosed children,

In the late 1990s, when Phil O'Donovan, the chairperson of the SCDA was retiring, the Diabetes Federation of Ireland approached the SCDA and the parents' support group about affiliating with the Federation. CEO Kieran O'Leary organised a meeting in Cork in late 1999 and out of that the new Cork Branch of Diabetes Ireland evolved some months later. The Cork office opened in May 2002 on Grand Parade after a lot of work and many meetings with the then Southern Health Board.

"Pauline Lynch was appointed the first Southern Regional Development Officer, which put it on a professional footing," said Margaret.

**– Sheila O'Kelly**

**Diabetes Ireland** would like to thank everyone who has contributed to the organisation over our 50-year history.

## This page is dedicated to:

The founders

Staff – past and present

Our members, parents and families nationally

Board members including presidents and chairpersons

Branch officers and other local activists

Regional development officers

All those involved in health education and promotion

Health professionals who have given generously of their time

Fundraisers and all those who have contributed

Diabetes researchers and funding bodies

Our corporate supporters

**We could not have done it without you all!**

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