

Hello

In this edition of the Diabetes Voices newsletter:

- Read about the winners of the Raise Your Voice awards.
- Get updates on Diabetes UK's current campaigns.
- Find out about the new and improved Diabetes Watch online tool.
- Read 60 seconds with...
§Robert Lee from Wales.

Keep up to date

For up-to-date information about current opportunities to get involved, check the Take Action notice board online at www.diabetes.org.uk/diabetesvoices

Get in touch

The Diabetes Voices team is here to help you.

Email diabetesvoices@diabetes.org.uk or call **020 7424 1008**.

We are always keen to find out what's happening where you live, so please keep in touch.

The Diabetes Voices Team

Diabetes UK Inspire Awards – Raise Your Voice award

Diabetes Voices who campaign tirelessly for improvements to diabetes services and care are recognised each year, regionally and nationally, with the Raise Your Voice award, part of Diabetes UK's Inspire Awards.

The awards are a chance to honour those whose contribution to diabetes care has been truly outstanding.

Diabetes Voice Fiona Faure from Essex was this year's winner of the National Raise Your Voice award. Fiona has worked tirelessly on our Make the Grade campaign, which aims to ensure that children with Type 1 diabetes get the care they need from their school. Her award was presented to her by Adrian Sanders MP, Chair of the All Party Parliamentary Group for Diabetes.



Fiona Faure receiving her award from Adrian Sanders MP in June 2014

Fiona played an important role in the campaign, and Diabetes UK recently celebrated the introduction of a new law, which makes it a legal obligation for schools to provide support for children with long-term conditions, including Type 1 diabetes. Fiona is also a Service Champion for West Essex and has pushed for improvements for people with diabetes.

Diabetes UK president Richard Lane said: "Fiona is a committed campaigner and is passionate about ensuring all people living with diabetes, whether child or adult, receive quality care wherever they live."

This year's regional winners were Shelia Burston (London), Fiona Faure (Eastern), Corinne Wykes (South East), Robert Edge (North West), Claire Allom (Northern and Yorkshire), Di Oxley (Midlands), Henry Bartlett (South West), Megan Lott (Scotland) and Ray Highton (Wales).

NEWS

Can the Type 2 diabetes drug Metformin help to increase lifespan?

A new study has suggested that people treated with metformin, a blood glucose lowering drug widely prescribed for Type 2 diabetes, can live longer than people without the condition.



The study compared the survival rates of Type 2 diabetes patients prescribed with metformin with both patients prescribed with sulphonylurea, another Type 2 drug, and people without the condition.

The study was published in the journal *Diabetes, Obesity and Metabolism*.

Simon O'Neill, Director of Health Intelligence and Professional Liaison at Diabetes UK, said: "This study supports the recommendation that metformin be the first line drug of choice for lowering blood glucose levels in people with Type 2 diabetes, because it shows the drug to have a better survival rate when compared to sulphonylurea. But metformin isn't suitable for everyone with the condition, so there should be alternative treatments available, such as sulphonylurea, to be used when appropriate.

"Although it may seem to imply that metformin could lead to increased life expectancy, this study doesn't take into consideration other factors which could mean that people with Type 2 diabetes taking the drug might live longer than people without the condition, such as undetected health conditions. Until we see further research and clinical trials in this area, the prescribing of metformin should be limited to people with Type 2 diabetes, for whom we know it can successfully help to manage their condition."

Update from the APPGD

Diabetes UK is currently working with fellow diabetes charity JDRF and the All Party Parliamentary Group for Diabetes (APPGD) to increase access to education and support for everyone with the condition.

The APPGD raises the profile of diabetes in Parliament, as well as looking into methods of prevention, monitoring new initiatives and working to ensure a better deal for people with diabetes.

The APPGD held a meeting in June to launch an investigation into the current state of education and support available to people for self-management of their diabetes. Discussion focussed on the importance of education in diabetes care, the effectiveness of courses currently on offer and the barriers that many people face in accessing a course. The meeting was attended by MPs, clinicians, researchers and others. Diabetes Voices were represented by Lauren Proctor, Maureen McGinn, Anne Joy and Angie Whitmarsh, who shared their experience of diabetes education and the impact it's had for them in terms of self-management.

The APPGD are meeting again later this year to continue investigating the state of diabetes education. A Diabetes Voice with Type 2 will be there to share their experience.

ExPAND: A one-stop toolkit for championing diabetes

Diabetes kills more people than breast and prostate cancers put together, and costs society more than all cancers combined. Despite this, it often seems that the political will to ensure people living with diabetes are getting the best care possible, and the action being taken to stop the rise in diabetes, is lacking.



The European Policy Action Network on Diabetes

That's why the European Policy Action Network on

Diabetes (ExPAND) toolkit was created, by an alliance of MPs from across Europe. The toolkit is a practical guide to help diabetes champions call on their governments to combat diabetes and raise its profile. The toolkit contains the economic argument for investing in diabetes, evidence of what works and practical examples of steps to get new policies in place. There are also sections dedicated to the care and treatment of children and older people.

The toolkit paints a picture of why action on diabetes is needed across Europe and contains useful information that you can share with your MP. Check it out at:

www.idf.org/sites/default/files/ExPandPolicyToolkitonDiabetes_0.pdf

Putting Feet First campaign update

In our last issue we reported that the postcode lottery of diabetes-related amputations in England was getting worse, with the gap

between the best and the worst performing areas getting bigger.

Since then, Diabetes Voices in the 50 worst-performing Clinical

Commissioning Groups (CCGs) in England have been taking action, writing to their MPs and CCGs to call for plans to improve the situation, as part of our Putting Feet First campaign.



We want to say a big thank you to everyone who's taken part. We've had a amazing response to the campaign, with many CCGs committing to improving services

To find out more about what's happened in your area, contact the Diabetes Voices team at diabetesvoices@diabetes.org.uk or call **020 7424 1008**

Over the coming months we'll be focusing on improving foot care services for people in hospital. Watch this space for more information on how you can take part.

Families attend Westminster event to celebrate new law



Families and children affected by Type 1 diabetes attended a special event in Westminster on 2 July, to help raise awareness of a new law to support children with Type 1 diabetes.

The families were joined by more than 100 guests, at a reception held by Diabetes UK at One Birdcage Walk, near St James's Park in London.

The new law means that all schools in England are now legally required to provide the support that children with medical conditions need, such as those with Type 1 diabetes. The law came into effect in September, and means that schools will have to have individual healthcare plans and a medical conditions policy in place. They will also have to commit to working closely with parents and relevant healthcare professionals, such as diabetes specialist nurses.

Families got the chance to meet with their MPs

At the event, families got the chance to talk with their MPs, asking them to write to schools in their areas to let them know about the new rules.

Guests also heard from Zoe Sherwood and her 10-year-old son Lewis, who was diagnosed with Type 1 when he was four. Zoe spoke movingly about her decision to take his school to tribunal after he was told he couldn't go on a school trip because of his Type 1.

All children have the right to a happy and safe education

Zoe said: "For three months we were told Lewis's inclusion was not an issue. Then, four weeks before the

trip, there was a class meeting in which all the children were told about the trip in more detail. We were asked to stay after the meeting and then asked if we could collect Lewis at teatime and return after breakfast, as the teachers didn't want the responsibility of Lewis attending overnight. Those few words crushed our then eight-year-old. After the meeting, Lewis began to cry himself to sleep and hid when it was time for school.

"We decided we had no other option but to address this wrong through the courts. The whole process was extremely stressful, as we had no legal representation and had to prepare the case ourselves. This is why the new law is so important. There can be no misunderstanding. All children have the right to a happy, safe education and childhood, with the same opportunities as their peers, regardless of medical conditions."



Zoe Sherwood, Lewis Sherwood and Andy Sherwood at the Make the Grade launch event.

Speaking at the event, Lewis said: "It really upset me when my old school wouldn't let me be with my friends and join them on the school trip. The new law makes me happy, as I don't want any other boys and girls going through what I went through."

Speeches were also made by the assistant headteacher at Lewis's new school, Diabetes UK Chief Executive Barbara Young and Education Minister Lord Nash, who is responsible for the new law.

Speaking about the work which has been done to get the new law implemented, Lord Nash said: "Meeting children with Type 1 diabetes played an essential role in changing the law. It was clear that something needed to be done. I'm aware that many schools already treat pupils with diabetes well, but my department will keep a close eye to ensure the new legislation turns into good practice in all schools."

Baroness Young said: "This exciting new law wouldn't have happened without the support of thousands of

families of children with Type 1 diabetes, who made it clear to the government why support in school for children with the condition is so essential.

"They have helped change the lives of not only children with Type 1 diabetes but also millions of children with conditions such as asthma, cancer and epilepsy, who will also benefit from the new law.

"Meeting children with Type 1 diabetes played an essential role in changing the law."

Lord Nash, Education Minister

"Our event was held to thank all of those families, and to put them in touch with their MPs. But we know that there is still a lot of work to do to ensure that all children are fully supported, which is why we have produced free resources for schools and parents, which set out exactly what good care in school for children with Type 1 diabetes looks like."

What next?

We may be celebrating the change to the law and the launch of our new resources for parents and schools, but the campaign isn't over and our work doesn't stop here. We still have lots to do to make sure that every school knows about these new guidelines and the resources we have available to help them. This is where we need your help.

TAKE ACTION

MPs are in a great position to let schools and local authorities know about the change in the law in England, and the resources we have available to support them. You can ask your MP to contact local schools to raise awareness of supporting children with Type 1 diabetes in school.

You'll find template letters for your MP to send, along with lots of other ways to take action, in the Make the grade take action toolkit. Download it at

www.diabetes.org.uk/make-the-grade

Diabetes Watch

Diabetes UK has launched a new tool called Diabetes Watch, to help people see how their local diabetes service is performing. Different areas are shaded in different colours, so you can see at a glance how your area compares to the rest of the country.

The data on Diabetes Watch shows that the postcode lottery of diabetes healthcare is now so great that people with diabetes in the best performing areas are four times more likely to get vital annual checks than if they live in the worst. For example, just 18.5 per cent of people with the condition in the Mid Essex area get the eight annual checks recommended by the National Institute for Health and Care Excellence. It's one of 27 areas in England where less than half of people with diabetes receive these checks.

In contrast, the Stafford and Surrounds CCG gives the checks to 78.3 per cent of the 6,893 people diagnosed with the condition in its area. It's one of 25 areas where over 70 per cent of people with diabetes get the checks.

Poorly performing areas should set out plans to improve

If over 70 per cent of people with diabetes in areas with significant health challenges are getting the checks, then there is no good reason why this should not be happening everywhere.

At Diabetes UK we're calling on poorly performing areas to set out how they plan to improve, and for the Government to explain how it intends to ensure that people with diabetes across the UK have access to good quality healthcare. We also want people like you to use Diabetes Watch, so you can hold your local NHS services to account.

TAKE ACTION

Find out how your diabetes services compare by going to diabeteswatch.diabetes.org.uk/

England

- Write to your local Clinical Commissioning Group, asking them what they're going to do to improve the situation. You can find contact details at www.nhs.uk
- Write to your Member of Parliament to ask for their help in raising the issue. You can find their details by visiting www.theyworkforyou.com

Wales

- Write to your health board, asking them what they're going to do to improve the situation. You can find contact details at www.wales.nhs.uk/ourservices/directory
- Write to your Assembly Member to ask for their help in raising the issue. You can find their details at www.assemblywales.org

Scotland

- Write to your NHS Board, asking them what they're going to do to improve the situation. You can find contact details at www.nhsinform.co.uk
- Write to your Member of the Scottish Parliament to ask for their help in raising the issue. You can find their details at www.scottish.parliament.uk

Northern Ireland

Unfortunately data is not available for Northern Ireland yet. Our team continues to work with the NHS to make it available in the future.

Resources to help you:

- For tips and ideas on how to get involved, download our campaigning and how-to-guides at www.diabetes.org.uk/get_involved/campaigning/diabetes-voices/more-information/guides/
- For template letters or help and advice, contact the **Diabetes Voices team** on **020 7424 1008** or email diabetesvoices@diabetes.org.uk

Don't forget to let us know what's happening where you live and how you've got involved. Contact us at diabetesvoices@diabetes.org.uk or call **020 7424 1008** to tell us how you've taken action.

DVLA Update

In March we invited Diabetes Voices to complete a survey from the Driving Vehicle Licensing Agency (DVLA), asking for their views on the letters the DVLA are planning to



send out to people who treat their diabetes with insulin.

The DVLA would like to thank all Diabetes Voices who took the time to complete the online survey. Your comments have helped them improve their understanding of the concerns of people living with diabetes.

The letters you reviewed in the survey are currently being amended to reflect some of your suggestions. For example, they will now include advice on driving while you have outstanding medical enquires

More people getting NHS Health Check

Over the past few months, Diabetes Voices have been helping us in our campaign to increase the number of people getting the NHS Health Check, which tests



40 to 74-year-olds for their risk of Type 2 diabetes, heart disease, strokes and kidney failure.

According to new figures, the number of people getting the check has improved, with 9 per cent of the eligible population receiving a check during 2013/14 – an increase of 7.9 per cent since 2011/12.

We're really pleased to see the increase, as the programme has the potential to help find the 7 million people who are at high risk of Type 2 diabetes and the estimated 630,000 who have Type 2 diabetes but don't know it yet.

However, while the new figures are very encouraging, we're still concerned that too many members of the public are missing the opportunity to get the check, with less than half of the people who are offered the check taking it up.

Spread the word

- Urge everyone you know aged 40 to 74, who has not yet had an NHS Health Check, to contact their GP to ask for one.
- If you're a member of a Patient Participation Group at a GP surgery, ask what they're doing to increase the number of local people getting the check.
- Some parts of the UK are not doing as well as others. If you live in an area which still has more to do to increase the number of people being offered the check, we'll be in touch to let you know about ways you can support the campaign.

We're always keen to hear from our Diabetes Voices. Let us know what you've done to spread the word by contacting us at diabetesvoices@diabetes.org.uk or calling **020 7424 1008**

Public Health England seminar

In May 2014, Keith Spurr (a Diabetes Voice from the East Midlands) attended a Public Health England seminar on Involving the public in setting local public health priorities.

Public Health England is a government body which exists to protect and improve the nation's health and wellbeing and reduce health inequalities. Stakeholders attending the seminar discussed different ways that Public Health England could help people become more involved in shaping health services. The use of focus groups, local media and web-based public consultation were all highlighted as ways of increasing public involvement.

Public Health England has also developed a new marketing strategy approach to help them involve the wider public in setting public health priorities. This will include doing more at a local level as well as using new technologies such as social media.

WALES UPDATE

Diabetes Voices meet assembly members in Cardiff

On 11 June, Diabetes Voices had the opportunity to meet their assembly members (AMs) at the National Assembly for Wales in Cardiff Bay. The popular event was



well attended and included speeches from the Minister for Health & Social Services, Mark Drakeford AM, and Chair of the Cross Party Group on Diabetes, Jenny Rathbone AM. Diabetes Voices were able to attach their concerns about diabetes services to a map of Wales, providing a visual guide to those present.

Some of the concerns raised were:

- hostile appointment letters
- withdrawal of structured education in North Wales
- lack of patient choice

- lack of patient engagement
- limited emotional support
- variability of GP services
- low levels of diabetes specialist nurses
- limited access to pumps and continuous glucose monitoring equipment
- no information at diagnosis.

All of the AMs present offered their support and assistance in talks with Diabetes Voices. Since the event we have been busy chasing up commitments made to help, as well as securing support from other AMs across Wales who were unable to attend. The recent appointment of a clinical lead on diabetes in Wales will encourage the seven health boards to move forward together and co-ordinate their progress centrally for the first time since 2009. The Diabetes Delivery Plan is underway in Wales, and with the health boards' implementation plans in the final stages, Diabetes Voices have a greater role than ever in ensuring that patients provide feedback on how successfully the plans are working.

For more information about Diabetes Voices in Wales, please contact Sara Moran at sara.moran@diabetes.org.uk

SCOTLAND UPDATE

Making connections

Scotland has the fifth highest incidence of Type 1 in the world. Currently there are 3,733 children and young people in Scotland under 20 with Type 1 diabetes.



Diabetes Scotland, along with the Scottish Government and NHS Scotland, has recently issued new guidelines for teachers, schools, parents and healthcare professionals to make sure children with Type 1 receive the support they need.

Diabetes Voices throughout Scotland have been providing their feedback on the guidelines, and the overwhelming response has been positive. All feedback has been welcomed, and will inform future projects associated with the guidelines.

The Diabetes Action Plan refresh

The “refresh” for the Diabetes Action Plan is underway and Diabetes Scotland is working hard to ensure that there is a proper patient-centered approach. The Scottish government needs to build on the success of the last plan and address the failings in the provision of service that we identified. However, if things do not pan out as planned then there will be a real need for Diabetes Voices to shout loud and clear about what the next plan needs to contain, to ensure that all people with diabetes and those that care for them receive the appropriate care and provision of services. So if you're a Diabetes Voice in Scotland, be on alert.

For more information about Diabetes Voices in Scotland, please contact Rupert Pigot: rupert.pigot@diabetes.org.uk

N. IRELAND UPDATE

Service Champion receives Inspire Award

Kathryn Cooney, a Northern Ireland Service Champion, received the Supporting Others award at Diabetes UK's National Inspire



Awards ceremony on 30 June. Kathryn, whose daughter Sarah was diagnosed with diabetes in 2009, was judged to have made an outstanding contribution in supporting others with diabetes.

In August Kathryn went on to win a Point of Light award, from Prime Minister David Cameron. The Prime Minister said:

“Having a child diagnosed with diabetes can be heartbreaking. Parents naturally have lots of questions and can feel uncertain and alone. Kathryn has been instrumental in working with parents, online and in person, to show them that it is possible to live well with diabetes. She is an amazing pillar of the community and a real inspiration. I am pleased to give this award in recognition of her remarkable achievements.”

Integrated Care Partnerships update

A meeting was recently held to review the progress made by 17 new Integrated Care Partnerships (ICPs). Dr Sloan Harper, Regional Director of Integrated Care, noted that Diabetes UK representatives had provided excellent examples at ICP meetings of how care could be improved across a range of diabetes services. Roberta McCullough, a Diabetes Voice on the South Belfast ICP, raised the 15 Health Care Essentials as an appropriate programme of work for all ICPs. She was supported by a range of health care professionals, clinical leads and commissioners in attendance.

4Ts campaign adopted by the five health trusts and education boards

In our June newsletter we reported that the Southern Trust and the Education Board used Diabetes Week to send out Diabetes UK's 4Ts posters and leaflets to all their hospital clinics and GP practices. Now the other four health trusts have agreed to follow this example, and began to roll out in September. One education board requested 60,000 symptoms leaflets, enough for all the primary pupils in their area. The benefits have already been seen in the Southern Trust's area, where in June a GP diagnosed Type 1 symptoms in a child. The child received care at home with minimal disruption to family and school life. This is clear evidence that better care is possible, with less disruption and less cost to the health services. .

Diabetes Voices at Diabetes UK Roadshows, sponsored by BUPA

A big thank you from our new Volunteer Development Officer Joji Min to the many Diabetes Voices who volunteered at the July and August Diabetes UK Roadshows. The Diabetes Voices, "posed for countless photographs with MPs, MLAs, Mayors and Councillors," helping to promote the events. Of the 1,181 members of the public risk assessed at the roadshows, 478 (40%) were referred to their GP at risk of Type 2.

For more information about Diabetes Voices in Northern Ireland, please contact Brendan at brendan.heaney@diabetes.org.uk

To read other inspiring Diabetes Voices stories please go to www.diabetes.org.uk/Get_involved/Campaigning/Diabetes-Voices/What-others-have-done/

More Diabetes Voices = a louder voice

Help spread the word about the power of Diabetes Voices and encourage your contacts to sign up. Order free promotional postcards from us now and give them to anyone you know who has been affected by diabetes.



Email diabetesvoices@diabetes.org.uk or call **0207 4242 1008**.

Online Guides



Check out our online guides to find out how to start campaigning in your area:

www.diabetes.org.uk/Get_involved/Campaigning/Diabetes-Voices/More-information/

60 SECOND INTERVIEW



“By getting involved you can influence how people with diabetes are treated”

ROBERT LEE Diabetes Voice

Why did you decide to join Diabetes Voices?

I joined Diabetes Voices because I wanted to let people know what help is available for people with diabetes. It's important that the right information gets from healthcare professionals and policy makers to people living with diabetes in Wales. Diabetes UK does a great job and I want to support their work in any way that I can.

How have you been involved in campaigning?

I have been involved by engaging with my local health board, to ask them what they are doing to ensure that their services are in line with the latest diabetes strategy in Wales (Together for Health: Diabetes Delivery Plan). This is so that they can give people with diabetes the best possible care. I have also spoken to my local assembly member, highlighting my concerns over budget cuts to the health service here in Wales and the impact this has on people living with diabetes. I've also tried to raise awareness through the media. I've been interviewed by the BBC and been quoted in local and national newspapers, to draw attention to

diabetes-related issues.

What has been the result of your work?

I believe I've brought to the attention of policy makers my concerns about how diabetes is managed, and I have supported the work of Diabetes UK. By visiting my local GPs I've raised awareness of the lack of information that people with diabetes get from their healthcare professionals. I feel that I'm championing the cause of people living with diabetes so that they are getting the best possible help and support.

What advice would you give to other people who want to get involved?

Diabetes UK is a great organisation, with a voice which we can use to raise important diabetes issues to healthcare professionals and the government. By getting involved you can influence how people with diabetes are treated. It will also enable you to become more informed about your condition. It has been a great experience and I've enjoyed every moment of it.

Look out for the next issue of
DIABETES VOICES newsletter
in December 2014