Hello

In this edition of the Diabetes Voices newsletter:

• Find out about the APPG report into structured education.
• Raise the profile of diabetes in the next Parliament.
• Get updates on Diabetes UK’s current campaigns.
• Read 60 seconds with… Fred Holland from Kidderminster.

Keep up to date

For up-to-date information about current opportunities to get involved, check the Take Action noticeboard 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 to speak to one of the team.

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

The Diabetes Voices Team

APPAG launches report on diabetes education

On Wednesday, 4 March, 12 Diabetes Voices went to Westminster for the launch of the APPG report on diabetes education.

Throughout 2014 the APPG for diabetes conducted a year-long investigation into education and support for diabetes self-management. The APPG heard from academics, healthcare professionals, commissioners, providers and individuals living with diabetes. The APPG sought to understand what types of learning and support are available to people living with diabetes and where the current gaps are in provision.

The results of the year-long inquiry have been published in Taking control: Supporting people to self-manage their diabetes, the report which was launched at the event:


The report examines why only a tiny proportion of people with diabetes attend formal education courses about their condition. It shows what steps can be taken to make sure more people take up offers of education and support when it is available, and outlines other types of learning that are also necessary, such as online tools and peer support groups.

Chair of the APPG Adrian Sanders MP and Shadow Health Minister Jamie Reed MP were both kind enough to speak at the event, which was also attended by Sir David Amess, Alan Campbell MP, Nigel Evans MP, Lord Harrison, George Howarth MP, Baroness Howe of Idlicote, Lord
Hoyle, Barbara Keeley MP, Charlotte Leslie MP, Baroness Ludford, Liz McInnes MP, Grahame Morris MP, Stephen Mosley MP, Lord Palme, Lord Patel, Dr John Pugh MP, Sir Bob Russell MP, Virendra Sharma MP, Mark Tami MP, Keith Vaz MP and Phil Wilson MP. The APPG invited MPs who are members of the Health Select Committee (HSC) to attend the event. The HSC examines the work of the Department of Health and its associated bodies, which is why it was so important to make them aware of this new report. Diabetes Voices who live in a constituency where their MP was a member of the HSC were invited to attend the event and meet with their MP.

Diabetes Voice Anne Ploss from Bristol met her MP Charlotte Leslie at the event: “I met with my MP, Charlotte Leslie, who is a member of the Health Select Committee. She examined the findings of the report about diabetes education, learning and support and agreed to raise a question with Bristol Clinical Commissioning Group relating to the shortage of education courses for people with diabetes in the Bristol area.”

Diabetes UK will be launching their education campaign this summer. We will be in touch soon with more information and details about how you can take action to support the campaign.

State of the Nation 2014 report

On 14 January Diabetes UK launched their State of the Nation 2014 report at Westminster. The report assesses the quality of diabetes care being provided across England and gives a snapshot of how well people living with diabetes are being supported. It also demonstrates how diabetes is currently the fastest growing health threat of our times. Diabetes Voices attended the event in Westminster, where they met with MPs and other decision makers to highlight the inequalities in care across the country and to call on decision makers to take urgent action over the next five years.

Two Diabetes Voices spoke at the event about their experience of diabetes care. Lauren Proctor has Type 1 diabetes and was diagnosed at 19. She gave a fantastic speech about the variation in care she has received and the opportunity she had to attend formal diabetes education, which she feels has helped her better manage her diabetes. Lynda Stewart has Type 1 diabetes and gave a very moving speech about living with diabetes and how important good care is in order to minimise the impact of serious complications. Lynda has experienced retinopathy, neuropathy, heart disease and kidney failure, but she has been able to manage these due to the excellent care she receives.

Following the event, Diabetes Voices sent press releases to their local press and we have seen some great coverage.

Raise the profile of diabetes in the new Parliament

With the start of a new Parliament, now is the time to make sure your new MP is committed to making a difference for people with diabetes. In the run up to the election on May 7, Diabetes Voices were busy contacting Prospective Parliamentary Candidates to let them know the importance of good diabetes care. Diabetes Voices across the country emailed, tweeted
and met with candidates across the country to get the message across. Many candidates responded, outlining what they would do for people with diabetes if they were elected.

We want to build on all the hard work done by Diabetes Voices before the election, and make sure diabetes is kept high on the political agenda during the new parliament.

The support of MPs can play an important role in helping us to end the postcode lottery of diabetes care. They will help make sure Clinical Commissioning Groups in their constituencies are providing the necessary services locally for people with diabetes.

**Putting Feet First campaign update**

People with diabetes have a much greater risk of developing problems with their feet, due to the damage raised blood sugars can cause to sensation and circulation. So everyone with diabetes (aged 12+) should have their feet and legs examined every year by a suitably trained healthcare professional.

From the time you are diagnosed you should have your feet checked once a year, every year. Any problems with your feet should be discussed and, if needed, you should then be referred to the appropriate specialist. Usually this check will take place at your GP surgery as part of your annual review.

With the right care, problems need not develop, and the vast majority of problems can be prevented by good foot care.

To help make people aware of this, Diabetes UK has produced a new checklist, *What to expect in your annual foot check*, which sets out what an annual foot check should involve.

**We want everyone living with diabetes to get a copy of the checklist, and we need your help to spread the word. You can:**

- take copies of our new leaflet to your local GP practice, hospital clinic or nursing home
- give people you know who have diabetes a copy of the checklist, so they know what to look for and what to do if there is a problem.

To request free copies of the leaflet, email diabetesvoices@diabetes.org.uk or call 020 7424 1008

We want to keep track of how many people we’re reaching, so please let us know what you’ve done to spread the word.

**Children and Young Person’s campaign update**

**4 Ts campaign**

The 4 Ts campaign started in 2012 to raise awareness of the four signs of Type 1 diabetes – toilet, tired, thirsty and thinner. A greater awareness of these signs will mean that more children are diagnosed with Type 1 diabetes before they become seriously ill with diabetic ketoacidosis (DKA). This is a life-threatening condition that needs hospital treatment and it’s extremely traumatic for children and families to go through.

Part of the campaign is about improving recognition of the symptoms of Type 1 diabetes in healthcare professionals. We really want to ensure GPs and other non-specialist healthcare professionals know exactly what they should do when a child comes in with a possible diagnosis.

This year we are focusing on getting the message out to
newly trained healthcare professionals who are about to go into practice and won’t necessarily have heard the 4 Ts message yet.

**How you can get involved**

We would like Diabetes Voices to help spread the word about the campaign further, getting our 4 Ts posters put up in their local area in key locations where parents may see them – GP surgeries, children’s centres and local schools. Why not take one along at your next visit?


For more information about the campaign you can visit the 4 Ts webpage (link below). Let us know where you manage to get posters displayed, or send us a picture of your poster once it’s up.

For more information about the children’s campaign please go to www.diabetes.org.uk/get-involved/campaigning/our-campaigns/4-ts-campaign

**Type 1 diabetes: Make the grade campaign**

We believe that care for children with Type 1 diabetes in schools must make the grade, and we know that you do too. That is why, through our Make the grade campaign, we are working together with children, parents and carers, schools, healthcare professionals, the Government and volunteers to raise awareness about what good diabetes care in school should look like.

The good news is that together we are heading in the right direction, and we want to say “Thank you” to all Diabetes Voices who are supporting our campaign.

We have exciting plans this year, and we would love you to get involved. Whether it’s sharing campaign links on social media, handing out resources to schools and parents, sharing our presentations with schools or putting up a poster, there are many ways in which you can help make good diabetes care in school a reality for all children and young people with Type 1 diabetes.

If you would like to find out more about our campaign, and how you can get involved, go to www.diabetes.org.uk/make-the-grade

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**Local campaigns update**

**Heywood and Middleton**

Having your eyes screened for retinopathy is one of the 15 Healthcare Essentials for people with diabetes. After the diabetic retinopathy screening service was withdrawn from Heywood in Greater Manchester, a number of local Diabetes Voices have started a local campaign to get it reinstated.

As part of the campaign, Diabetes Voices Janet Lees, Pearl Naylor and Debbie Goldrick have presented a petition of over 1,000 signatures to NHS England. They have also been in contact with their local MP and Chair of their local CCG to get their support.

With the help of Healthwatch Rochdale, they were able to meet with the NHS Commissioning Team responsible for withdrawing the service. During the meeting, representatives from the NHS team apologised to those in attendance for the loss of the service and have agreed to undertake a public consultation.

**Hull and East Yorkshire**

Members of the Hull and East Yorkshire local diabetes group have successfully campaigned to increase staff numbers from one to four diabetes specialist nurses at the Brocklehurst clinic at Hull Royal Infirmary. The increase has brought the clinic into line with recommended guidelines set out by the National Institute for Health and Care Excellence.

Having more specialist diabetes nurses at the clinic will make a huge difference to diabetes care for people with diabetes in Hull and East Yorkshire. In recognition of their campaign success, the group received a Diabetes UK Inspire Award at the Northern and Yorkshire regional volunteer conference in February.

**Medical exemption certificates**

A recent crackdown on people with diabetes claiming free prescriptions without a certificate has led to them being fined. However, we believe it is unfair that people
who had no idea they needed a certificate, and have never been sent a reminder about it, are being fined. We recently campaigned to get (now former) Health Minister Dr Dan Poulter MP to introduce a fairer system. It was a real success – Dr Poulter wrote to us agreeing that if people are fined then it will be cancelled if they get a medical exemption certificate within 60 days of receiving it.

We are making sure people who live with diabetes know that they must have a certificate. You will be able to find further information on our website about what to do if you haven’t got a certificate or have been issued with a fine: www.diabetes.org.uk/claiming-free-prescriptions

DON'T GET FINED FOR CLAIMING YOUR FREE DIABETES PRESCRIPTION

1. Get an application form for a medical exemption certificate from your GP
2. Your GP will sign and send off for you
3. Until your certificate is delivered to you at home, pay for your prescriptions. Get a receipt and refund form from your pharmacy so you can claim the money back.
4. Spread the word!

The more we know the stronger our campaign.
Call 0345 123 2390 or email policy@diabetes.org.uk.
www.diabetes.org.uk/claiming-free-prescriptions

WALES UPDATE

Diabetes Voices plan influencing activity at volunteer conference

In March we had record attendance at the Welsh Volunteering Conference’s Diabetes Voices workshop, with several new volunteers attending. The workshop focused on local influencing versus national influencing, and explained the current processes in place for patient engagement in NHS Wales. Those in attendance worked in Local Health Board groups to plan how they could influence services locally to complement the national system, which would ultimately maximise our reach and impact.

Diabetes Voices in Aneurin Bevan Local Health Board have been leading the way in local influencing by signing up to a new local authority initiative, the Wisdom Bank. The Wisdom Bank is a platform for local issues in Torfaen and some of our Diabetes Voices are contributing to the sections on diabetes by providing local group information, as well as general tips and advice on services in the area.

Diabetes Voice Bob Wright from Powys was awarded the Campaigning and Raising Awareness Award for his work in re-establishing patient involvement in Powys Health Board. Bob was also awarded our Harry Seacombe Award for the Diabetes UK Cymru volunteer of the Year.

We have seen a rise in complaints around the Jazz blood glucose monitor, particularly in Hywel Dda and Aneurin Bevan Health Boards. Those affected have been approaching their GPs and are being offered alternative monitors. We are working with those who have been motivated to take action after this success to find suitable equipment.

Diabetes Voices membership is now up to 174 members in Wales and this is rising weekly. In 2015 we will be providing more support and information to Diabetes Voices on local and national developments and will be providing you with even more opportunities to get involved.

For more information, please contact Sara Moran at sara.moran@diabetes.org.uk
Diabetes Voices in Northern Ireland had a busy quarter at the start of this year, with two service champions, Roberta McCullough and Helen Todd, taking on new leadership roles. Kathryn Cooney attended the All-Party Group on Diabetes when Health Committee member Jo Ann Dobson was voted in as Secretary and Fergal McKinney became Treasurer.

**Children’s campaign**
Kathryn also attended a joint meeting of the Assembly Health and Education Committees to discuss the needs of children with disabilities and the role of disability statements. New Service Champion Helen Todd attended the NAS/UWT teachers conference and met with education committee members. Education Minister John O’Dowd visited the Diabetes UK Northern Ireland stand and confirmed he would launch our new local guidance on ‘What Diabetes Care to Expect in Schools’.

**Integrated Care Partnerships**
Four Diabetes Voices attended a review of service user experience with the Director of Commissioning on 30 March, and he has agreed to recommend increasing the number of service users on all of the 17 Integrated Care Partnerships, making particular reference to the positive input of Diabetes UK service users in the last 12 months.

**Foot campaign**
Service Champion Arthur Templeton was a star turn at the Society of Podiatry event in the Long Gallery at Stormont, describing exactly what good care looks like in front of Health Minister Simon Hamilton. Arthur then took advantage of a one-to-one with Sir Liam Donaldson (former Chief Medical Officer in England) when he was in Belfast at the end of April, to discuss his recent report on reorganising the Health Service in Northern Ireland.
Roberta McCullough then won the Campaign and For more information about Diabetes Voices in Northern Ireland, please contact Brendan at brendan.heaney@diabetes.org.uk

**Disability Living Allowance (DLA) campaign**
In September 2014, Diabetes UK was approached by the group ‘Families Living with Diabetes’ (FLWD) who expressed concerns about the way the Department for Work and Pensions (DWP) was assessing...
applications for children and young people to receive Disability Living Allowance (DLA).

Diabetes UK had already provided comments to the DWP about the guidance they provide for their assessors and it was decided that more pressure needed to be put on them to respond. It was agreed that we would work with the Families Living with Diabetes group to support them with a campaign.

The aim of the campaign was to change the DWP guidance to accurately reflect the impact of Type 1 diabetes on children and families, as it is wrong at the moment. We agreed the best way to do this was to ask parents to lobby their MPs.

Many parents took action to support the campaign and in April 2015 Diabetes UK and representatives from the FLWD group were invited to meet with the DWP medical adviser and the DLA policy manager. Previous to the meeting they had already agreed to amend the guidance they give to assessors, but in the meeting they went even further:

- They agreed to look at further comments on the guidance from Diabetes UK.
- They will publish new guidance for assessors following the publication of NICE Type 1 guidance. This will include information on 7–8 times daily glucose level testing, night checks, aiming for a blood glucose level that meets NICE guidelines (soon to be published) and correcting the current misleading statements and assumptions.
- They will review evidence on inconsistency of awards to children with diabetes and will consider examining the consistency.
- They are looking into increasing the award duration guidance to the age at which the child completes their secondary school education (they have already agreed to extend it to include children up to the age of 15).

This will not happen for a few months (until after NICE Type 1 guidance published).

It was clear that Diabetes UK would not have got this meeting in the first place without the pressure from the families and their letters to MPs to lobby minister Mark Harper.

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**More Diabetes Voices equals a louder voice**

Help spread the word about the power of Diabetes Voices and encourage your contacts to sign up.

You can order free promotional postcards from Diabetes UK now and give them to anyone you know who has been affected by diabetes.

For more information, email diabetesvoices@diabetes.org.uk or call 0207 4242 1008.

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**Diabetes Voices online guides**

Check out Diabetes UK’s online guides and how to’s, to find out how you can start campaigning in your local area:

FRED HOLLAND
Diabetes Voice

Why did you decide to join Diabetes Voices?
I joined Diabetes Voices to find out more about how I could campaign for improvements to diabetes services where I live. I’ve been campaigning for better care for people with diabetes in Worcestershire for many years, and Diabetes Voices has given me even more opportunities to make a difference.

How have you been involved in campaigning?
I joined the committee of the local community health council and kept pushing for more attention to be given to diabetes. I have also been in regular contact with the local hospital trust to make sure they make diabetes a priority and commit to making services better. In January 2015 I attended the launch of the Diabetes UK State of the Nation report and met with Mark Garnier MP to discuss what the government are doing to ensure people get the care they deserve.

What has been the result of your work?
Diabetes care in my area has improved remarkably in recent years. Kidderminster now has a dedicated diabetes centre which offers education sessions, information and resources to people with Type 1 and 2 diabetes. Improvements have also been made to the children’s unit at the hospital and better provision has been made for diabetes specialist nurses. In 2013 it was named the Fred Holland Diabetes Centre. People now call me from all over the UK to ask advice on how they can improve diabetes services where they live. I have also received a letter from Prime Minster David Cameron in recognition of all the work I have done for people with diabetes in Worcestershire.

“Diabetes care in my area has improved remarkably in recent years”

Look out for the next issue of the DIABETES VOICES newsletter in August 2015