GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Abertawe Bro Morgannwg University Health Board

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DEPARTMENT OF CHILD HEALTH
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Our ref: CB/hjw
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Date: 16/11/16

Dr Dai Lloyd
AM & Chair of Health & Social Care & Support Committee
National Assembly for Wales
Health & Social Care & Support committee
Cardiff
CF99 1NA

Dear Dr Lloyd

Thank you for your letter dated 10th November 2016. The Children and Young People's Wales Diabetes Network (& Brecon Group) welcomes the aim of the petitioners to see an earlier diagnosis of type 1 diabetes and a reduction in the number of children and young people where a delay leads to potential life-threatening Diabetic Ketoacidosis (DKA).

The Children and Young People's Wales Diabetes Network (& Brecon Group) is comprised of multi-disciplinary team members working in all 14 paediatric diabetes units in Wales. Our membership includes paediatricians, specialist nurses, dietitians and child psychologists. We also have representation from the third sector and parent representatives on our steering group.

Engaging primary care colleagues to reduce the incidence of DKA at diagnosis is one of the priority areas for our network. We continue to pursue a number of different themes to attempt to reduce the frequency of DKA at the time of diagnosis for children and young people with Type 1 diabetes in Wales by making an earlier diagnosis where possible. This includes:-

Research

The Early Detection of Type 1 Diabetes in Youth (EDDY) study carried out in Cardiff University recently reported the results of their feasibility study. The study aimed to assess the feasibility of developing / delivering a community educational intervention for parents of children under 18 years of age and GP / practice nurses in Cardiff, the Vale of Glamorgan and Bridgend, to increase the awareness of early symptoms of type 1 diabetes. The intervention included 120,000 reusable shopping bags and bilingual leaflets for delivery via 329 schools and nurseries (covering 105,000 children) and for GP's and practice nurses the delivery of glucose / ketone meters and single use lancets with posters, stickers and education sessions delivered to 102 practices.

The conclusion of the study was that delivery of the intervention was feasible and although the study was not designed to show a clinical effect, (such as a reduction in rates of DKA at diagnosis), anecdotal reports suggest the impact from the process evaluation is encouraging. The study authors are now looking for funding to conduct a much larger study that would be powered to show a reduction in DKA at diagnosis.

Collaboration with third sector organizations

The network continues to work closely with Diabetes UK Cymru regarding their planned 2017 public health campaign. We have met regularly with Diabetes UK Cymru to provide advice and support for their activities and will continue to do so.

As part of this collaboration we are working on conveying key clinical messages to primary care colleagues through NHS communication channels. These messages will urge primary care colleagues to proactively ask about the ‘4 Ts’ used to diagnose Type 1 (Toilet, Thirsty, Thinner, Tired) and encourage the use of a fifth and sixth ‘T’ – to TEST TODAY. Immediate near patient blood glucose testing of suspected diabetes in children and young people is the NICE standard.

Collaboration with primary care colleagues

The network coordinator has met with Dr Alistair Roeves and Dr David Miller-Jones, who both have leadership roles with regard to diabetes in primary care in Wales. We will continue to work with them to develop interventions and education to support learning in primary care. Dr Roeves has suggested making every new diagnosis of a child with diabetes a learning event within GP Clusters, led by primary care colleagues and we will explore this further with him. Dr Roeves has also suggested including a commitment to following the correct procedure at diagnosis within GP Cluster plans as part of this learning programme. This would be in addition to the communications campaigns listed above.

We have recently heard of a scheme in the West Midlands introducing a prompt on the electronic request system that the GP’s use, such that should they ever request a formal laboratory blood glucose test for a child under the age of 18, then a message will appear on screen reminding them that this should be done as an immediate finger prick glucose. We will raise this with our colleagues and see if a similar electronic prompt is feasible in Wales.

Dr David Millar-Jones has also suggested that all GPs in Wales complete the e-learning module on diagnosis of diabetes produced by the Primary Care Diabetes Society. As a network, we support this proposal and would like to see all primary care clinical colleagues complete this learning.

Research and screening

There are a number of research pathways being explored around the world to consider the potentially attractive possibility of screening for Type 1 diabetes in children. One suggested pathway would be to identify children at increased risk, either because of their family history, through genetic screening of all children done at the time of birth or through screening of all children via blood testing for auto-antibodies around the age of 2 years. I believe the petitioners refer to the FR1DA study in their correspondence currently taking place in Bavaria. It is suggested that if 2 auto-antibodies are present in the blood stream, then children should be repeatedly screened at 1-6 monthly intervals with oral glucose tolerance tests looking for the emergence of abnormal blood glucose levels. Once abnormal blood glucose levels are present, some authors suggest that it may be possible to intervene with as yet unproven immune therapy to either prevent or defer the onset of Type 1 diabetes. In addition to repeated blood glucose testing, the FR1DA study is evaluating education for families to attempt to reduce the incidence of DKA at diagnosis. The FR1DA authors acknowledge that a limitation of their study is that it does not attempt to address the socio-economic cost of screening. Given the highly intensive nature of the screening process described, it is unclear whether it will be possible to prove that it will be of overall health benefit, or deliver a health economics model that makes it applicable to clinical practice. Indeed, in a journal article in 2015, the conclusion drawn from a health economics evaluation of population screening was that current screening costs far outweigh the economic benefits.

The Wales network continues to work closely with the 10 English networks to evaluate research and introduce best practice into our clinics.

Difficulties with the petitioner’s proposal to screen unwell children

As a clinical network, we are unable to support the specific proposal raised by the petitioners calling for, “a **mandatory** duty for all GPs and healthcare professionals in a primary care setting to carry out the finger prick blood test for all children who present to them with an illness that could be masking Type 1.” There are several reasons why such an approach would not meet the essential criteria of a good screening test:

1) There is a lack of evidence from research studies that testing whole populations of unwell children is of benefit to prevent DKA at diagnosis. Tragic cases, such as that of Peter Baldwin, appear to be exceptionally rare.
2) Transient stress hyperglycaemia is very common in unwell children. Studies report that between 3.8 and 4.7% of children presenting to emergency departments for any reason have elevated glucose levels and for febrile children this rate rises as high as 11.9% in one study. Transient stress hyperglycaemia does not appear to be associated with an increased risk of later developing diabetes.
3) Due to the lack of specificity of glucose testing in unwell children, there is a significant risk of harm from this approach; i.e. that in order to identify a very small number of cases such as Peter’s, very

large numbers of normal children with transient stress hyperglycaemia then undergo follow up including unnecessary painful investigations and anxiety for their families.

As a Network we strongly recommend all NHS staff adhere to NICE guidelines, which state that the characteristics of type 1 diabetes in children and young people include polyuria, polydipsia, weight loss and tiredness and that children and young people with suspected type 1 diabetes should be referred immediately (on the same day) to the Paediatric Diabetes team.

Many of the recommendations the petitioners make in their correspondence to the committee are of excellent value and many are being pursued by ourselves, primary care colleagues and Diabetes UK Cymru. These include additional training for primary care staff, the provision of glucose meters to GP's / practice nurses and a need for health boards to be aware of and report on pathways of care and DKA rates at diagnosis.

I am happy to be contacted to answer further queries if this would be beneficial to the committee

Best wishes,

Yours sincerely

Chris Bidder

Dr Christopher Bidder

On Behalf of Children & Young People Wales Diabetes Network (& Brecon Group)