

13th December 2016

Dear Petitions Committee Members,

Petition P-04-682 Routine Screening for Type 1 Diabetes in Children and Young People

Thank you for your letter relating to the above petition currently under your consideration. Your request for more information is welcomed and we are very happy to provide assistance to the Committee. The Baldwin family, who are the petitioners in this case, have worked closely with us since Peter's death in January 2014.

Approximately 1,500 children and young people have Type 1 diabetes in Wales. 16% will have been diagnosed late in the life-threatening stage of DKA, or diabetic ketoacidosis. In the under 5s age group, this increases to 24%. A range of common childhood illnesses, such as flu, water infections or chest infections can be misleading and can lead to misdiagnosis. Type 1 diabetes is a rapid onset condition, resulting in a child becoming critically ill. If left without immediate testing, referral and treatment, this can be fatal.

Please find our views on the petition itself and additional information below:

Screening

- Routine screening for Type 1 diabetes has not been successfully adopted by any nation worldwide, although there is current research in Germany that has not yet been finalised. It is thought to be very difficult to do and the the numbers affected would be small.
- The National Screening Committee doesn't screen for a condition that can't be treated or prevented and so screening would not come under the Committee's remit.

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- If population-wide screening were to be adopted, a test for genes or antibodies to detect high risk would first be needed, followed by a blood glucose test to narrow this down. The evidence is not clear that a national screening programme is the right thing to do, at present.
- The petitioners highlight a situation in North Carolina as an area that does carry out screening. This is not the case when looked at in more detail. The commitment in North Carolina is to raise awareness amongst parents via family healthcare visitors of the symptoms of Type 1 diabetes. This is similar to the Personal Child Health Record or 'Red Book' system that we have in the UK in providing health information to new parents in baby packs.
- Regardless of the above, the primary element of the petition, and clearly the intention of Peter's family, is the need to reduce the instances of undiagnosed Type 1 diabetes.
- The recommended way to action this within current systems is via testing for Type 1 diabetes in primary care if a child presents with the 4Ts (tired, thirsty, toilet, thinner) or unexplained symptoms.

Awareness of undiagnosed Type 1

- Diabetes UK Cymru is currently working with Baldwin family and other families affected by late diagnosis to develop and deliver an awareness raising campaign targeting primary care staff, education staff and parents.
- We note that the recently published Welsh Government *Together for Health: A Diabetes Delivery Plan* commits the Children & Young People's Wales Diabetes Network (the Network) to a number of actions in this area.
- We are aware that in October 2016, the Health & Social Care Committee intended to contact the Network for more information and to potentially use the response in writing to the Cabinet Secretary. We would be interested to learn of any outcomes so as to enable all parties to work collaboratively.

Next steps:

- We would welcome the Committee's experience and expertise in (i) raising awareness amongst primary care staff in Wales and (ii) influencing primary care procedures so as to increase the testing of blood glucose in Wales.
- On 8th March 2016, the Petition Committee of the Fourth Assembly made the following commitments. The Baldwin family and Diabetes UK Cymru were encouraged by the planned action of its members and would like to request that these are taken forward:

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- (i) The Committee will write to all Local Health Boards in Wales requesting more information on their DKA/Type 1 diagnosis policies and pathways. When all responses have been received, the Committee will write a Research Paper on DKA/Type 1 diagnosis in Wales to assist them in their work and to raise awareness of the issue amongst other AMs who may sit on the relevant Committees.
- (ii) The Committee will write to Health & Social Services Minister to request clarification of his Ministerial response to the petition following the initial response received. The Committee will request to see the evidence on which the Ministerial response is based, as this is also unclear, especially to those who are not familiar with diabetes.
- (iii) The Committee will recommend that the Minister meet with the Baldwin family to discuss the possibilities available to us in Wales to implement any future procedural measures that could be put in place for testing for Type 1.

The family has requested that I pass on the message that they are particularly impressed and pleased with the Committee's discussions and commitments thus far.

We are happy to provide further evidence to the Committee and would like to extend this offer to the Health & Social Care Committee. Please do not hesitate to contact me if you have any questions.

Wishing you all a Merry Christmas,



Sara Moran

Policy & Public Affairs Lead, Wales