Welsh Assembly Petition submission P-04-682

(Anthony Cook/ Beth & Stuart Baldwin)

Campaign to prevent late diagnosis of Type 1 diabetes

Peter's Story

Peter Baldwin turned 13 on 10th December 2014; he loved life, school and his friends. He was a fit, healthy teenager who had the world at his feet. As Christmas approached Peter got a winter cold which seemed to be worsening so we called the GP for advice and got an appointment on 31st December as by this time Peter was very unwell. The GP diagnosed a chest infection and gave us antibiotics. No Type 1 test was offered or discussed. I explained Peter was sleeping and drinking lots. (We now know 2 of the 4 signs of type 1)

24 hours later, 4.30pm on New Year's days we called the out of hours GP and explained we were very concerned about Peter who seemed to be deteriorating, with laboured breathing and a delirium. After insisting this was VERY URGENT we were transferred to 999 which was engaged for a short time. I, Beth Peter's mum then asked for an ambulance, which I had to be very direct about, the operator kept asking if I deemed it necessary and was it that much of an emergency. Thank goodness I stuck to my guns (many at this point would've given in and thought they were wasting the callers time) the rapid response paramedic arrived shortly and the very first thing he did after giving Peter some oxygen was prick his finger. He diagnosed Peter on the spot with Type 1 Diabetes; it took less than 30 seconds. The paramedic called an ambulance immediately and within less than 15 minutes we were in the resus department in UHW and Peter was being given the right care.

Had the GP pricked Peter's finger we would have had a 24 hour head start & Peter's body would have had more chance to recover from the diabetic ketoacidosis.

Please make GP/HCP testing for Type 1 Diabetes (finger prick/ urine sample) mandatory when presented with an ill child who has an obvious illness that could be masking Type 1 signs.

What do we want to achieve-

To reduce the number of children presenting with diabetic ketoacidosis (currently 500 per annum in the UK)

We are 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.

Why do we believe this is achievable?

We believe this petition can have immediate results. The National Assembly for Wales has powers to make/change laws to the devolved Health sector. We want Wales to lead the way and make Type 1 testing mandatory.

It has cost saving benefits, public awareness benefits and ultimately can prevent 500 children per year in the UK being diagnosed before the condition becomes life-threatening.

In response to your latest letter; dated 1st November 2016

We understand the Children and Young People's network are working closely with Diabetes UK Cymru to raise the profile and awareness of the dangers of misdiagnosis and late diagnosis/ detection. There are campaigns being developed at present. The CYPWDN only has direct access to secondary care (via paediatric clinics - 14 in Wales) so would not be in a position to ensure implementation of clinical guidance and promote appropriate testing, particularly in primary care. Diabetes UK Cymru is able to provide more information on the mechanisms *obtaining primary care evidence* in more detail. Once this is obtained we hope you the committee can use this information to implement direct action and positive change to implement protocol for more testing to prevent unnecessary DKA type 1 diabetes diagnosis.

The CYPWDN can only provide so much information. Feedback **directly from Local Health Boards** in Wales would provide a more accurate picture of levels of DKA/Type 1 pathways, which would enable all parties to identify gaps in service provision and make recommendations for changes and standardised practice across all boards.

What we aim to see actioned is additional training (e-learning is an option) and measures put into practice to encourage more testing amongst ill children, alongside blood glucose monitors being given **to every** GP not just every practice (pharmaceutical companies give these away – the income comes from purchasing the strips) these actions we believe are achievable, cost effective and can be rolled out quickly. A public health campaign to support these actions would increase awareness, profile and impact effectiveness. We encourage this is information to be shared with the Cabinet Secretary for Health, Well-being and Sport.

In relation to the study taking place in Germany to conclude in 2017, we welcome this research and all others into the development of screening for antibodies/ genes testing at birth/ very young age, to establish whether Type 1 onset will occur. We appreciate this is on-going and will continue to follow the progress and updates. With regard to the feasibility study of screening, we would urge the Committee to take note of this, but to highlight the widely accepted approach of testing as being the most effective way of early identification of Type 1. Thank you for looking into this study, we look forward to receiving the findings and recommendations for us here in Wales with focus on increased testing until such time where screening is feasible.

Our petition is very much a moving document, since the discovery and development of insulin in 1921 many advances have been made. No-one, especially children, should die from undiagnosed/ misdiagnosed Type 1 Diabetes. We have the tools to detect and diagnose this autoimmune non preventable disease that can be managed if caught in time. A simple finger prick can save a life, please make testing mandatory for GP’s and primary care professionals. The NICE guidelines state the pathway and the signs; rules need to be in place to make sure ALL ill children are tested. There needs to be accountability if these guidelines and pathways are not followed.

The previous committee made the following closing suggestions suggested by Bethan Jenkins AM and unanimously adopted by the other members. Bethan was particularly frank about the Committee doing as much as it can within its powers to assist our family with our petition.

1. The Petitions Committee committed to 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, they would 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.
2. The Petitions Committee would write to Health & Social Services Minister at the time, Mark Drakeford AM, to request clarification of his Ministerial response to the petition. Bethan Jenkins particularly highlighted the area of Beth’s response that draws attention to the inconsistencies in the Government’s position. The Committee will also 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.

3. The Petitions Committee would also 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.

We look forward to hearing your responses and recommended actions working closely with the Health, Social Care and Sport committee, thanks for your time,

Kind regards,

Peter’s Family.