

Health & Social Care Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

6th February 2017

Dear Chair,

Re: National Assembly for Wales: Petition submission P-04-682 (Campaign to prevent late diagnosis of Type 1 diabetes)

We would like to thank the Committee for continuing to review our petition to reduce DKA diagnosis of Type 1 diabetes. We would like to respond to the recent evidence provided to the Committee by the Children & Young People Wales Diabetes Network and the recent letter from yourselves to the Petitions Committee.

We appreciate the Committee researching and following the German study currently underway but are disappointed to learn that the Committee might await its outcome prior to taking action in Wales.

As previously noted, we accept that a screening programme for Type 1 diabetes may not be feasible across a large population at present. We re-emphasise the aim of our campaign is for detection of Type 1 to take place as early as possible in primary care settings. As advised by Diabetes UK Cymru's evidence to the Petitions Committee, approximately 1,500 children and young people have Type 1 diabetes in Wales. Up to 20% 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%.

We were very heartened by the previous Petition Committee's promises to take the following actions to help us:

1. Write to local health boards for Type 1 Diagnosis/ DKA policies & on receipt of responses commission a research paper to form basis to raise awareness and shared best practice on best policies/ pathways and systems.

2. Request a response from the Cabinet Secretary for Health, Well-being & Sport on the evidence from the initial response given.
3. Recommend that the Cabinet Secretary meet with us to discuss how Wales can lead the way with prompt procedures for primary care testing and prevent unnecessary hospital stays/stress/ costs/ death from late diagnosis.

These actions were suggested by Bethan Jenkins AM and unanimously adopted by the other members of the previous committee.

Whilst we wait for the results from the study in Germany, will the Committee take these actions now?

We are not asking primary care / GP's to test ALL children, we appreciate the complexities and demands on GP's. We would like a process in place that 'prompts' the right questions if a child is unwell to eliminate cases like Peter's. NICE guidelines exist however it all comes back to interpretation and the questions asked at the time of appointment. It's not on many GP's radars to check for Type 1, a prompt is needed; the 4T's questions need to be mandatory to eliminate risk (with a blood glucose monitor readily available if there is any doubt). Type 1 needs to be a consideration, a thought; targeted questioning (4T's) can help differentiate between those who are at risk.

If our GP had followed NICE guidelines, Peter may still be with us.

Peter was unwell, had laboured breathing and was 'flu like'. We attended our GP and told them that he was drinking lots of water, not eating, lethargic and was coughing. They diagnosed a chest infection, used a stethoscope, checked his glands and gave us antibiotics for him. The GP did not notice ketones on his breath or ask about any of the 4T's symptoms of Type 1 diabetes (toilet, thirsty, thinner and tired). Had they asked and pricked his finger, Peter would have had a 24 hour head start. The onset of Type 1 can be very quick. We now know Peter was already in DKA when we were at the surgery.

We await your response and proposed actions moving forward and thank you for your time.

Yours faithfully,

The Baldwin family

