

Petition submission P-04-682 – Petitioner to Committee
Anthony Cook/ Beth and Stuart Baldwin

Chair of the Petitions Committee Mike Hedges
National Assembly for Wales
Cardiff Bay
CF99 1NA

6th June 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 conducting research into pathways and processes of the diagnosis of Type 1 Diabetes from the Health boards across Wales.

We would like to respond to the recent evidence provided to the Committee by the Health Minister Vaughan Gething and the responses from the health boards.

Response to the Health Minister –

We are very upset and distressed by the Minister's response that he is unable to meet with us at this time. The response rebuffs NICE guidelines and the refreshed diabetes delivery plan (which makes no extra recommendations for primary care focus of detection Type 1) falls short of what we would hope to see to prevent another case like ours. If NICE guidelines (not mandatory, just guidelines) had been followed, Peter would've had a 24 hour head start on fighting his onset of Type 1 Diabetes. Peter's life mattered, his tragic death could've been prevented, and we feel this deserves a meeting with and a commitment from the Minister. We have some very simple suggestions and aims alongside further hopes for future development in research into Type 1. Wales can really lead the way with the great framework that already exists, we're asking for tweaks, not reinventing the wheel!

Response to the 7 Health Boards –

We thank the health boards for their responses and appreciate the information given. The policies, pathways and processes presented should form the basis for the development of a standardised approach in Wales. The Committee is well-placed to further review and investigate the responses with the assistance and expertise of stakeholders. Perhaps the Committee could provide recommendations

to Welsh Government following this evidence-gathering? We note that a similar exercise was carried out by the Committee to improve detection of ovarian cancer.

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.** Whilst the information from health boards in Wales is useful (and is now gathered in one place for the first time), there remains a requirement to investigate primary care procedures, pathways and processes. Would this be something that the Committee could include in any potential future investigation?

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%.

With regards to this point, as pleased as we were to receive the responses from the health boards, we would reiterate our focus on **Primary Care and GPs/ Health care professionals** who are most often the first to see a child who is unwell, it is at this time that Type 1 is missed due to being masked by other common illness (chest infection/ virus/ flu) it's critical that GPs/HCPs ask the questions to consider/ discount Type 1 diabetes. (The common signs are known as the 4T's Toilet / Thirsty/ Tired/ Thinner)

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

We await your response and thank you for your time.

Yours faithfully,

The Baldwin family

