

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 finger prick blood test was offered or discussed. I explained that Peter was sleeping and drinking lots. We now know that these are two of the four symptoms of Type 1 diabetes.

24 hours later, at 4.30pm on New Year's Day, 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 resuscitation 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 life-threatening state of diabetic ketoacidosis.

Please make GP/Healthcare professional testing for Type 1 Diabetes (finger prick) mandatory when presented with a child who has an illness that could be masking the symptoms of Type 1.

Yours in hope,

Beth, Stuart & Lia Baldwin

The outcome for our family can't change but we can change the outcome for another family with your support.

We are calling for mandatory testing in primary care by GPs and other healthcare professionals for Type 1 diabetes when a child presents with unexplained flu-like symptoms or a general feeling of being unwell. The finger prick blood test provides an instant result and is incredibly low-cost.

Viruses and infections can mask the symptoms of Type 1 diabetes, exacerbating the condition with potentially fatal consequences. The symptoms are embodied in Diabetes UK's campaign, the 4Ts (toilet/thirsty/tired/thinner). Identification of the symptoms is time critical and so we propose that healthcare professionals test in the following scenarios:

- IF ANY of the 4T'S are present (on their own, in combination or all together).
- IF the child is lethargic and has shallow breathing.
- If the child has a fever/chest infection/cold/ flu/virus or ANY common ailment.

Background

1 in 400 children has Type 1 diabetes (approximately 1,500 in Wales). Of those who are diagnosed with Type 1 diabetes, 16% will be in the fatal stage of having diabetic ketoacidosis. This rises to 24% in the under 5s age category.

We understand that many GPs will carry out the finger prick blood test, but this not standardised in GP procedures and can lead to misdiagnosis/non-diagnosis or a diagnosis when it is too late, as in Peter's case.

Current guidance/protocol: NICE Guidance (2015)

Recently updated NICE Guidance in this area suggests that healthcare professionals should measure capillary blood glucose at presentation in children and young people **without** known diabetes who have increased thirst, polyuria (increased frequency of passing urine), recent unexplained weight loss or excessive tiredness **and** any of the following:

- nausea or vomiting
- abdominal pain
- hyperventilation
- dehydration
- reduced level of consciousness.

If the plasma glucose level is above 11 mmol/litre in a child or young person without known diabetes, and they have symptoms that suggest diabetic ketoacidosis (DKA), suspect DKA and immediately send them to a hospital with acute paediatric facilities.

What do we want to achieve-

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

In light of recently updated NICE guidance, 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.

Short term Goals-

- Make Type 1 testing mandatory
- GP and health care professional training on the dangers of misdiagnosis
- Aim for 100% participation in the National Diabetes Audit response to monitor Type 1 testing
- Public health campaign on awareness & dangers

Long term Goals:

The ideal standard would be to screen all babies from birth to see if they carry the antibodies which can increase their risk of type 1 diabetes onset.

Response to the Minister for Health & Social Services, Mark Drakeford AM's letter

The letter raises some key activities being carried out by the Welsh Government, which I would like to respond to in turn below:

1. Together for Health: A Diabetes Delivery Plan (2013)

Point 7.3 *Detecting Diabetes Quickly* states that the Welsh Government will

‘Work with primary care and allied healthcare professionals to raise their awareness of the risks and symptoms of diabetes and explore innovative approaches for early detection’.

Whilst we welcome this key point, I do not see a commitment/procedure to test for Type 1 outlined or mentioned in the plan.

2. The Health Board Diabetes Delivery Plans

The individual, localised health board diabetes delivery plans do not include information on how this is being achieved either (as stated by the Minister). We would hope to see an all-Wales approach to this issue to avoid variability and to ensure that each child receives the same service wherever they live in Wales.

3. All Wales Diabetes Implementation Group

The Minister states also that the All Wales Diabetes Implementation Group is carrying this work forward. I have checked with Diabetes UK and they have advised that the Group will measure the awareness levels of

GP, practice nurses and school nurses who are aware of the symptoms of Type 1. This is positive news and I would like to know more about how this will be done to support the proposal of testing in primary care.

4. Children & Young People's Wales Diabetes Network

We appreciate the work undertaken by this network and look forward to the response that the Minister receives from them in how they plan to ensure early diagnosis of Type 1 diabetes in children and young people.

5. National Screening Committee (UK NSC)

We accept the information received about the current feasibility of national screening and hope this is an option for the future. At present, we are aware that the screening test used in research purposes does not provide accurate enough results to be deemed feasible, though it is hoped in the not too distant future that screening will be a more viable option. We are following this research closely.

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.

What has already been done?

We are working closely with Diabetes UK Cymru to develop an awareness campaign to reach out to primary care and education audiences.

Professor Lesley Lowes, Professor John Gregory and their teams developed the EDDY study (Early Diabetes Detection Young). This involved the production of a blue, reusable bag displaying the symptoms of Type 1 diabetes. The campaign reached over 105,000 school children in the Cardiff, Vale of Glamorgan and Bridgend areas.

We thank you for your time and consideration in memory of Peter, who we speak for today.