

input

INSULIN PUMP THERAPY
An independent voluntary organisation



Dear Mr Feinmann

RE National Diabetes Audit - Paediatric information 2005-6

I am writing as a mother of a teen with diabetes, a member of INPUT and UK Children with diabetes Advocacy Group, and note a mere 19% of children nationally achieved an acceptable HbA1c of 7.5% or under, which incidentally includes children still in the honeymoon period, and 81% failed. Whilst I realise this is an improvement on the previous figure of 86% failing, I am still disappointed at:

1. yet another year of the majority of children failing to achieve reasonable glycaemic control, or even HbA1c targets
2. Lack of audit information supplied from many hospitals/centres in this IT age
3. Lack of collection of some current very relevant related information that could be used to audit, interrogate and improve staffing and services for children with diabetes and their long-term prospects of future complication-free or reduced, healthier life and determination of compliance with NICE guidelines. Namely lack of questioning as to whether children use pumps or injection regimens, spilt into figures for age and glycaemic control by delivery device and regimen.
4. Additionally, I would like to see, of those children failing to achieve HbA1c targets, or experiencing hypo problems, how many are offered insulin pump therapy during the year, and how many are not, and reasons for not offering pumps for children with HbA1c's over 7.5% (at present, if NICE guidelines change, over 8.5% in future).

I think it is very important that public health organisations, including NICE, The Information Office and government health departments, should listen to us parents who are involved in the care of these children 24/7/365, as we unfortunately have so much lived experience of the condition and of the questions that need asked and answered, and we

need you to do this on our behalf as part of the UK's NHS and governmental partnership.

My son was diagnosed at 8 years of age, had 2 years of pretty poor control until he went on a pump at aged 10 years, and has had reasonable control since, i.e. HbA1cs ranging from 5.1% - 7.3%, yet on 5th November this year we received the bad news that he has the start of retinopathy, having a haemorrhage in his left eye. I obviously have no comeback on the less than adequate care and education we received during those first 2 years, and in fact since as well, yet there are massive implications for his future, 9 years after diagnosis. I do not want others to share this experience, and am pleased NICE guidelines and national Audits are there to help provide basic good standards for practise.

However, unless these standards are enforced, and there *are* many places that do not comply with the 2004 NICE guidelines for diagnosis and management of type 1 diabetes and the Technology Assessment for CSII, (I am also a nurse, I know this from both sides), and without collecting data that can help improve outcomes, how are we ever going to get to having a majority of our children achieving reasonable control? And all the research has shown that reasonable control can indeed be achieved for children and young people.

Suggestions?

- That lay parents of children with diabetes be included in the National Audit preparation, and their views listened to.
- That NICE guidelines be enforceable, and adequate numbers of lay parents/inspectors/members of patient support groups such as INPUT and UKCDWAG be used either voluntarily or employed, to give national feedback on every single diabetes centre where children are treated in the UK. We are happy to do this, we want improvement.
- That data about pump and sensor use be included in the national data collected.
- That's every diabetes centre/hospital that treats children return information, for all we know the real situation may actually be very much worse!

I would very much like to hear your views on this, thank you for taking the time to read this letter and hopefully give it due consideration, and reply.

Yours sincerely

[Redacted signature]

[Redacted contact information]