NFED Conference, England

by

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When my husband James and I first heard about the Conference, we weren't at all sure it would be for us. Our two daughters have ED - they sweat normally, but have tooth abnormalities. Our 8-year-old, Hannah, had sparse hair as a baby, but it's now growing well. Our 4-year-old daughter Ruth seems to be less severely affected.

Since the initial shock of being diagnosed - when Hannah was 3 and I was just two weeks away from giving birth to Ruth - James and I felt we had come to terms with ED. It's really not a major issue for us as a family at the moment. We've also had first-rate treatment from the health service. So would the Conference stir up all sorts of anxieties and emotions better left untouched?

After much agonising, and exchange of e-mails with Diana Perry, we decided we'd attend for just one day - the Thursday - and to leave the children at home. Apart from anything else, it gave James and I the chance to have a blissful night away in a hotel on our own - very welcome after our family camping holiday in the rain in France.

We wanted to find out as much as we could about dental care, and to talk to families who were further down the road in dealing with ED - particularly girls or women with ED. How did they cope with the adolescent years when our daughters face the prospect of some serious dental treatment at the same time as coping with all the other challenges of being a teenager?

As soon as the first session began, we felt a huge sense of relief. Both Birgitta Bergendal and Frank Farrington's sessions on dental implants and dental care for children told us more in a few hours than we'd learned in the past 5 years. Frank's humour and practical outlook made a deep impression on us, and we realised that there's a lot that can be done for our children while they're still growing - if they need and want it. The strongest message I came away with from those two sessions, is that treatment of ED symptoms really must be a team effort involving all the health professionals but keeping the child's interests at the forefront. The other message which emerged loud and clear is that the approach to the treatment of ED in the UK and indeed throughout the rest of Europe, is fragmented. Health professionals with experience of ED really aren't sharing enough information about their work, and probably most importantly, about their failures.

We heard some horror stories from other families about the off-hand and even cruel ways they'd been dealt with when they'd been diagnosed with ED. All the more important, we felt, to be involved and share information in a group like the NFED and the Ectodermal Dysplasia Society.
The last session we attended before setting off home was the Parenting forum. It was our chance to question the 'experts' - those who have ED and have grown up with it - on what their mums and dads had done well for them - and where they might just have handled things differently. How did they cope with things like being teased?

Again, it was a great confidence booster. It demonstrated that many of the fears that we as parents have will probably never become reality. And if there are problems, then, with enough support, we can all emerge intact, and maybe even strengthened.

One of the 'experts' summed it up for us when she told us what someone had once asked her: "Is ED going to be a problem, or a nuisance in your life?" In her case, she decided, it was a nuisance. Although it's going to be different for everyone affected by ED - and I'm fearful of under- or over- estimating the impact on my children, or anyone else - that put it into perspective for us.

The whole day was humbling and enriching - we will bring our children next time, and we look forward to keeping in touch with other families we met.

Some names and locations have been changed in order to preserve confidentiality.
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