

## Proud of the ED Society

My first son was born in 1991 and diagnosed with ED 2.5 years later, my second son was born in 1995 and was diagnosed with ED within days. Once we had a diagnosis I realised I had a lot to learn to help the boys and found a support group.

The group was set up in 1984 when two mothers of children affected by ED met by chance, and with the help of Angus Clarke arranged a meeting for the few families known to them. At that time there was no internet or emails, so running a support group and finding new families was extremely difficult. However, I contacted the group in 1996 to offer some help.

The next I knew, I was sent the address book of families who were part of the group, given the Building Society book which held £200, and my journey began. I worked from home and produced our first newsletter in 1997, together with a leaflet which I sent to every NHS Trust in the UK.

During 1998 the NFED in America, who have been a wonderful support to me over the years, mooted the idea of holding their annual family conference in the UK. Two years later in August 2000, the NFED held their first annual family conference outside the US here in the UK. After this, with the help of Angus Clarke, I created a Medical Advisory Board to add credibility to the group. At the same time, I created a Board of Trustees and moved forward to becoming a Charity in 2001.

In 2002 the very first International ED Conference was held in Sweden and was organised for medical professionals, specifically dental. I was invited to make a presentation which was very scary as I had never done anything like this before, but it was well received. By this time a few bits of paper and an address book soon turned into a filing cabinet and I needed help. In 2003 Sue joined me, and although she had no knowledge of ED, she brought her expertise in organisation and accounting.

2004 saw the launch of the second International ED Conference at the Eastman Dental Hospital in London, organised by Prof. John Hobkirk, who had become a member of our Medical Advisory Board in 2000. These conferences are now held every three years. The International ED Support Groups came together for their first meeting in 2007 and these meetings are now held every 18 months, which I co-chair.

Soon, two people became three and we could no longer fit into the little room in my home; it was time to find our own offices. In 2011 we moved into our new office, we continued to go from strength to strength, the filing cabinets multiplied, and we were receiving national and international recognition. During 2016 a fourth person joined us, we increased our office space by renting the office next door to ours and refurbished them into one larger office.

From the little address book in 1996 we now have over 1600 contacts worldwide, an eminent Medical Advisory Board, a Board of Trustees bringing highly skilled expertise, an array of information, are involved in research programs (some of which have been instigated by the ED Society), assist other countries in setting up their own support organisations, assist individuals and families in their applications, appeals and tribunals for Disability Living Allowance and Personal Independent Payment, assist schools to provide the correct level of care for children affected by ED, the list goes on.

In 2018 we launched our new website which will be mobile friendly, and an ED dedicated booklet.

I am so proud of how far we have come but couldn't have done it without the help and support of the Trustees, Medical Advisory Board, Staff, and most importantly Sue who has been a huge asset.

## Supporting a normal lifestyle

Ectodermal Dysplasia Society (Registered Charity No. 1089135). Disclaimer: Any views or opinions are made by the author in good faith. No liability whatsoever is accepted by the author or the Ectodermal Dysplasia Society. Recipients should make their own additional enquiries of medical and other relevant authorities before acting on these views. The use of a product name does not constitute a recommendation or endorsement by the author or the Society.



Thank you to all our members for your support and encouragement over the years, especially in helping us survive the hard times and making the Society the success we are today. For the future, we can only continue to grow and bring Ectodermal Dysplasia to the forefront. Please continue to support us by bringing awareness of Ectodermal Dysplasia and funding through your donations and fundraising events.

Diana Perry

## **Supporting a normal lifestyle**

Ectodermal Dysplasia Society (Registered Charity No. 1089135). Disclaimer: Any views or opinions are made by the author in good faith. No liability whatsoever is accepted by the author or the Ectodermal Dysplasia Society. Recipients should make their own additional enquiries of medical and other relevant authorities before acting on these views. The use of a product name does not constitute a recommendation or endorsement by the author or the Society.