

## **ECTODERMAL DYSPLASIA SOCIETY: 2013 ANNUAL REPORT TO MEMBERS**

### **From the Chairman:**

At the close of this financial year end we have 10 Trustees. We have welcomed Sharon Cooper on to the Board and are looking forward to benefiting from her professional experience and from her personal connection with ED. Of the 10 Trustees, 2 have come to the end of their term and 1 of them is willing to stand again. We say a particular thank you for their dedicated service to two trustees who have decided not to stand again: David Wyatt who was a Trustee for 12 years, 8 of them as Chairman, brought us excellent experience, particularly on internet issues and designing the original website and database; and Steve Preston who, as Treasurer, consistently made sure that Society remains both legal and viable. We are very grateful to both of them and wish them well for the future. The Trustees are pleased to report that Alan Waller, who is a professional accountant, has agreed to act as Treasurer. We hope that the members will see fit to support him at the AGM. The remaining Trustees are willing to continue serving the Society.

The Trustees have met twice since the 2012 AGM. We have particularly discussed:

- (1) The overall financial climate and ensuring that our position remains solid;
- (2) How we demonstrate our support for our members;
- (3) Some fundamental policy and ethical issues;
- (4) The development of medical research and how we best support that.

The financial climate looked as though it would make life really tough for charities this year, particularly small ones like ours. However, it would appear that our members have been determined to buck the trend and have made substantial efforts so that the society has been able to maintain its levels of service and support to everyone. It is an easy thing to say thank you but the simple thanks does not, I know, represent the effort that many people have put into this. We are very grateful and this has meant that we have been able to continue working to help a range of people with very individual needs.

We have also continued to make funding applications to various grant-awarding bodies and this year saw our first success, after many years of trying, to win a grant from the British Association of Dermatology, which enabled us to revamp the website.

Keeping in contact continues to be very important to us and our Facebook presence has continued to grow. The new website has meant that it has been much easier to maintain up-to-date information for everyone and this has been a great success for us. As usual the Christmas Party, which attracted 121 people in December, proved its usual great highlight. We owe a great deal to Sue who puts in so much effort to ensure that it is enjoyable for everyone (and affordable by the Society).

In terms of numbers, we are currently maintaining around 459 contacts on our database, of which 84 come from overseas; there are 105 full members and 12 associate members. This is consistent with previous years.

The Society continues to gain huge benefit from the employment of Sue Beard as Accounts /Website Manager, with Julie Cox as Administrator who maintains the Contacts Database and correspondence. This allows Diana, who works voluntarily and tirelessly, to be released from administrative duties and deal with the large number of detailed queries and new challenges that arise. These include assisting families to deal with applications for Disability Living Allowance, appeals and tribunals. This year, we have tried to make it easier to demonstrate how much work goes into this support work by showing the costs in the support fund. Traditionally we have used the Support Fund solely to assist members with physical purchases of equipment but we realised that showing Diana's work in the accounts in this way gave a rather better picture of the amount that we do for our members.

I would particularly like to thank Diana for the way in which she uses her knowledge and skills for the benefit of members and Sue and Julie for the way in which they support the work. Thanks are due also to the Trustees for the time, effort and thought that they give voluntarily to the Society.

Another group of people who deserve a big vote of thanks are the members of the Medical Advisory Board, whose supportive and thoughtful approach is much appreciated. I continue to maintain that it is remarkable for a small Charity to have the backing of a group of highly professional people in this way. And long term, of course, it is vital that we improve the understanding of ED through medical research.

So we look forward with optimism, grateful for the efforts of many people in the past year. A big thank you to you all.

Paul Collacott  
Chairman