

ECTODERMAL DYSPLASIA SOCIETY

2012 ANNUAL REPORT TO MEMBERS

From the Chairman:

At the close of this financial year end we have 9 Trustees. We have welcomed Liz Beckmann and Mark McNair on to the Board. Of the 9 Trustees, 2 have come to the end of their term and both of them are willing to stand again. The remaining trustees are willing to continue serving the Society.

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

- Our financial needs and our overall approach to fundraising;
- Contacts with members and the further development of the website;
- Requests for support
- Medical Advisory Board and its excellent development.

You will note that the first item I mentioned in the list of discussion topics for the Trustees was finance. In his Chairman's report last year, David said that "Employing staff does of course greatly increase our financial outgoings ... and if we were unable to employ an Administrator the Society would not be able to continue efficiently and would have to rely upon Diana to offer a hugely reduced service to members." I'm pleased to report that we have maintained healthy finances this year but that is not a signal for us to relax. I believe that we have benefited from the efforts of a number of individuals who have given their time and talents to fundraising and it is vital that this continue. We have discussed various initiatives and have some new ideas on fundraising but our overall approach will be to continue to offer support to members and their friends who wish to carry out fundraising on our behalf. Our grateful thanks to those who have done so for us this year.

Keeping in contact is very important to us and our Facebook presence has continued to grow. Through the newsletter EDLines, which was published 4 times during the year, you will be aware of much of the work that is being done and with a new and improved website, which will be easier for us to maintain, we hope that the coming year will be even better for us in terms of communication and information. Another great highlight was the Christmas Party which attracted 144 people and was thoroughly enjoyed by everyone.

The Society is still growing numerically and are currently maintaining around 549 contacts on our database.

The Society continues to gain huge benefit from the employment of Sue Beard as Administrator, with Julie Cox to help out in the office and take responsibility for the IP strand of work. Sue works for 15-20 hours per week and Julie 10 hours per week. 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. 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 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