

ECTODERMAL DYSPLASIA SOCIETY 2011 ANNUAL REPORT TO MEMBERS From the Chairman:

At the close of the 2011 year end we currently have 8 Trustees. Four of whom are coming to the end of their term. Four other Trustees are willing to continue to stand and do not need re-electing as they are in the middle of their terms. David wishes to stand down as Chairman and Paul has agreed to stand for this role.

The Trustees have met twice since the last AGM, the main items under discussion being: (1) setting up Facebook Fan Page; (2) fundraising and the need for corporate sponsorship and a patron; (3) continued development of the website; (4) continuation of the Christmas Party; (5) moving office; (6) the NFED Registry and Edimer Network.

The past year saw the continued employment of Sue Atkins as Administrator and Julie Cox to help out in the office. Sue works for 15-20 hours per week and Julie 10 hours per week both relieving Diana Perry of administrative work allowing her to concentrate on other work.

Employing staff does of course greatly increase our financial outgoings and now we have the added outgoings of office rent, but as the Annual Accounts for 2010 show we are at present showing signs of the credit crisis and are in need of more funding. It should be noted that we need an annual income of £20,000 just to maintain our current level of activity. 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.

During the year, Diana Perry supported by Sue and Julie has continued to work hard on a voluntary basis for the Society. Through the newsletter EDLines, you will be aware of much of the work that they are doing. However, what will be less apparent is that Diana also spends much of her time working on individual cases and problems, particularly assisting with DLA applications, appeals and tribunals. As Chairman, I would like to thank Diana in particular for her efforts without which the Society would scarcely exist. I would also want to thank the other Trustees who also give their time voluntarily to further the work of the Society.

Mention should also be made of the continuing work of our Medical Advisory Board (MAB) whose members give much of their time, expertise and support to Diana freely for which we thank them.

The Society continues to grow numerically and are currently maintaining around 500 contacts on our database many of which (between 100-150) come from overseas; there are 102 full members and 8 associate members.

Four issues of EDLines have been published during the year highlighting much of the continuing development of the Society.

The development of the website continues with information being updated regularly, more information has been put on the protected members section and the gallery has more pictures. The Society has a new logo and all the leaflets, information, documentation will be changed over the coming months.

Finally, we continue to gain credibility and influence in the professional medical world through the attendance by Diana Perry at various conferences, the publication of articles about the Society and ED by Diana and the Medical Advisory Board, and of course by the continuing involvement of MAB.

Finally, the Trustees wish to thank those many members who have worked so hard on fundraising in the past year.

David Wyatt
Chairman