

ECTODERMAL DYSPLASIA SOCIETY: 2016 ANNUAL REPORT TO MEMBERS

From the Chairman:

At the close of this financial year end (31st December 2016), we have 9 Trustees. We continue to have a relatively stable group of Trustees who are trying to tackle the issues that currently beset many charities. It is good to note that financially we are still in a stable position although there are challenges. Possibly as a reflection of busy lives and the dispersed membership, it has been difficult to meet as a group this year. However, the Trustees have made themselves available to Diana and the team to give advice as required.

In addition to the meeting immediately following the May 2016 AGM, some of the Trustees were able to meet in November. Whilst manageable, we hope to be able to meet more during this year.

The main focus continues to be on providing advice and support to members and contacts through the office. This is our main expenditure and is the most important service that we can offer. And this is the reason that we need to ensure a good supply of finance. Alan has covered the detail in his Treasurer's report but, notwithstanding the reasonable financial position, the Trustees will have to continue to ensure a supply of funds for this most important work. We are very grateful indeed for all the support and fund-raising money that we receive to help us continue.

The numbers of contacts keep increasing – 1184 on the database in total of whom 593 count as main contacts. One point for the trustees to consider, is that the number of paid-up members currently recorded is down by just under a third from 124 to 86 (10 have indicated that they will not continue with their membership). We may need to reconsider what membership means, as it is clear from the number of contacts that demand is not going down.

Diana and her support team are the people who keep the show on the road and are the sources of huge amounts of knowledge and wisdom. Sue Beard continues to provide a very thorough and efficient service as our accounts and website manager – Alan notes that his job is made so much easier by Sue. As Danielle has been with us for well over a year now and is working independently on all of the DLA/PIP applications. This year, the office team said goodbye to Julie Cox after some years of work with us and said hello to Emma Phillips-Mealins. This all allows Diana to deal with the many questions and cases that arise. And I know I've said this before but I cannot overestimate how much value Diana gives to the Society because of her ready grasp of large numbers of issues, some of them very subtle, and also her commitment to and knowledge of the families we serve. Huge thanks are due to Diana, Sue, Danielle & Emma for all their hard work to make sure that the charity runs properly. Our Trustees continue to demonstrate an impressive commitment to and understanding of the work that is necessary to make a small society such as ours to run.

We continue to benefit from our skilled and experienced trustees, who in combination have a great range of experience in many subject areas. We are sorry to say goodbye to Mel Davis from the Board and thank her very much for a considerable number of years of service to us.

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 (as I have done in, I think, every year that I have been Chairman of the Society) that it is remarkable for a small Charity to have the backing of a group of highly professional people. And long term, of course, it is vital that we improve the understanding of ED through medical research.

We are so grateful for the efforts of very many people in the past year. A big thank you to you all. Looking forward, there continue to be challenges but we look forward to tackling them. .

Paul Collacott (Chairman)