

ECTODERMAL DYSPLASIA SOCIETY: 2017 ANNUAL REPORT TO MEMBERS

From the Chairman:

At the close of this financial year end (31st December 2017), we have 10 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 again 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 – modern technology can be a wonderful thing.

In addition to the meeting immediately following the May 2017 AGM, some of the Trustees were able to meet in November. Whilst it is just about possible to manage on a small number of meetings, we hope to be able to increase the rhythm 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 – there is now a total of 1234 on the database. 621 of these 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 89 (10 have indicated that they will not continue with their membership). We need to reconsider what membership means, as it is clear from the number of contacts that overall demand is far from declining.

Diana and her support team are the people who keep the show on the road and are the source 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. Danielle has been with us for well over a year now and is working independently on all of the DLA/PIP applications. Emma Phillips-Mealins who had come into the office during 2016, stayed with us only until late September. Jaye Dix has come in to replace her. Diana oversees all of the activities and is freed up to deal with the many difficult cases that come our way. Huge thanks are due to Diana, Sue, Danielle & Jaye for all their hard work to make sure that the charity runs properly. Our Trustees continue to provide the behind-the-scenes advice on wider issues, using their combined expertise of other sectors.

The Medical Advisory Board, which refreshes itself from time to time, continues to serve the society very effectively. They are a source of vital knowledge and advice in this field. Diana maintains the contact with them and, working in combination, they provide a powerful advocacy and help for the people who need it. We are so grateful to them.

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)