

## **ECTODERMAL DYSPLASIA SOCIETY: 2018 ANNUAL REPORT TO MEMBERS**

### **From the Chairman:**

At the close of this financial year end (31<sup>st</sup> December 2018), 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. We have very much concentrated on the financial position over this past year, leaving the day-to-day running of the Society to Diana and the team. 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.

In addition to the meeting immediately following the May 2018 AGM, the majority of the Trustees were able to meet in October for a meeting that focused on the financial issues alone. We had been getting increasingly concerned that the income would not match our needs for giving members good service and took the view that it was prudent to decide on some actions so that we would not drift into a crisis.

Among other things, we noted that it was important for a charity these days to devote some of the time of our paid staff to help with the all-important fund-raising. Part of this effort is to keep the society more in the public eye and alive to all the possibilities of social media. Members will have noticed, I believe, that we have been much more active in this arena.

Alan has covered the detail in his Treasurer's report but, following the October meeting we were very happy to receive a large donation, a substantial response to a grant application and other fundraising has been on the up. 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. We are still working on what membership means now and would hope to put forward new ideas in the near future.

Our international profile continues to grow. It is very important to keep connected with developments in other countries and spot the right opportunities. Diana is our main expert on all of this and we ensure that she has the opportunity to go to the right international conferences, share our experiences and learn from others.

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 is working independently on all the DLA/PIP applications with the help of Jaye. Diana oversees all 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.

We are so grateful to our 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. Equally, it is important to us to participate in the appropriate national projects which produce longer-term benefit for those with ED. The Medical Advisory Board provide both the appropriate contacts and the necessary governance for us to make decisions in this arena.

We are so grateful for the efforts of very many people in the past year. A big thank you to you all. I am particularly glad that we took a serious look at the financial aspects in October and made the structural changes that were necessary. It augurs well for a bright future.

Paul Collacott (Chairman)