

## **ECTODERMAL DYSPLASIA SOCIETY: 2015 ANNUAL REPORT TO MEMBERS**

### **From the Chairman:**

At the close of this financial year end (31<sup>st</sup> December 2015) we have 10 Trustees. We continue to have a stable group of Trustees who have started to tackle some of the fundamental questions about how we set the direction to ensure the effective continuity of the Society in the future and how we, once again, update our communications and information mechanisms.

The Trustees have met twice since the May 2015 AGM.

We have particularly discussed:

- (1) Finances and how we maintain a balanced budget in an era which is still difficult for charity fundraising;
- (2) The continued individual support that is offered to members;
- (3) Our image, our website and what we need to do to remain current and easy to consult;
- (4) The question of long-term organization and succession planning.

We have continued to remain relatively stable in a financial climate that is still difficult, although this is the first year for a while where we have felt that the finances are really under pressure. This is partly because we have deliberately tried to improve the service to members – and this takes money. We know that many people have made great efforts on our behalf and we are very grateful for all of this support – please do keep running, walking, setting up coffee mornings on our behalf – the money genuinely does go to a good cause. We continue to make funding applications to various grant-awarding bodies but it has been relatively unrewarding this year. We will continue to make efforts in this direction.

Keeping in contact continues to be very important to us and our Facebook presence has grown again this year. As usual the Christmas Party, which attracted 138 people in December, was very much appreciated by those who were able to come. I've commented on this before – probably in every year – but we very much value Sue's ability in being able to run this event so affordably and successfully year on year.

In terms of numbers, we are currently maintaining around 553 contacts on our database, of which 137 come from overseas; there are 124 full members and 18 associate members. Over the last year as well, we have incorporated the Republic of Ireland ED Group into the Society, welcoming Elaine Aylward as the Irish representative.

The Society continues to gain huge benefit from the employment of Sue Beard as Accounts /Website Manager, with Julie Cox as Administrator maintaining the Contacts Database and correspondence and our new member of staff Danielle Gue to look after DLA/PIP, correspondence and assist Sue with the website. This allows Diana to deal with the many questions and cases that arise. Again at the risk of repeating myself year on year, 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. Our discussions around the future of the society have been a "how do you clone Diana?" question and be able to reap the benefit of the enormous amount of knowledge that she carries in her head. The plans we have for the future revolve around creating regions around the country but using Cheltenham as a central hub for all the information. This has lots of implications, including safe data storage and access and consistency across the Society. We have not yet finalised plans but we will be reporting to the membership as soon as there is something concrete.

We have also benefited a great deal this year from the experience and knowledge of all our trustees, but I would like to single out Sharon Cooper, whose practical knowledge of websites, communications media and how to make best use of them has been invaluable, Scott Gallacher, one of our newer trustees, who brings with him a wealth of experience from the Finance Sector and who has been key to our being able to sort out our position with regard to the new pensions legislation and Alan Waller, who deals with all the accounting matters with calmness and great assurance.

Huge thanks are due to Diana, Sue, Julie and Danielle 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.

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 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.

We are so grateful for the efforts of very many people in the past year. A big thank you to you all. Looking forward, we have financial challenges and we have organisational challenges. We are up for the challenge.

Paul Collacott (Chairman)