

ECTODERMAL DYSPLASIA SOCIETY: 2014 ANNUAL REPORT TO MEMBERS

From the Chairman:

At the close of this financial year end we have 10 Trustees. As we indicated last year, we have welcomed Alan Waller on to the Board as our new Treasurer and he has started work for us with a will, as you will see from the accounts that he has submitted. Of the 10 Trustees, 5 have come to the end of their term and 5 of them is willing to stand again. We now have a stable group of Trustees who are swift in their responses to the various queries that come to them between the meeting that we have. The remaining Trustees are willing to continue serving the Society. We have also welcomed Elaine Aylward who leads the Irish branch of ED to be a co-opted member, particularly since we have now agreed to incorporate their accounts into the overall Society's management figures.

The Trustees have met just once since the 2013 AGM. However, that particular meeting was very full, given the presence of Edimer and we have done a great deal of our work this year by taking advantage of technology. We have particularly discussed:

- (1) The overall financial climate and ensuring that our position remains solid, including how we ensure that we are making best use of the funds available to us;
- (2) The continued individual support that is offered to members;
- (3) The issues that are raised when other agencies/companies would like to use our members to help them, whether that is for research or for broadcasting (the particular instances that we have seen this year);
- (4) Medical research.

We have continued to remain stable in a financial climate that is still difficult. Oddly, it feels to have been more difficult since the alleged recovery has started. There are really positive signs already in this new year that we will continue to do as well as we need to maintain its levels of service and support to everyone. 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, with a lower level of success this year – but this does not daunt our enthusiasm or commitment to trying to get money from these bodies.

Keeping in contact continues to be very important to us and our Facebook presence has continued to grow. The new website has meant that it has been much easier to maintain up-to-date information for everyone and this has been a great success for us. As usual the Christmas Party, which attracted 132 people in December, was very much appreciated by those who were able to come. I remain amazed year on year by Sue's amazing eye for value and entertainment and how she can manage to run this annual event so successfully (and affordably) each year.

In terms of numbers, we are currently maintaining around 468 contacts on our database, of which 102 come from overseas (including ROI); there are 94 full members and 12 associate members. This is more or less the same as previous years.

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. This allows Diana to deal with the many questions and cases that arise. I cannot stress how much value we get from Diana who works voluntarily and yet with so much commitment. Her knowledge and ever-growing experience of the UK legal system in the area of disability is absolutely invaluable to us. We are pleased that our decision to show Diana's work as part of support fund activity has made sense and allows us to gain a more accurate measure of how we are supporting members.

Huge thanks are therefore due to Diana, Sue and Julie 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 must also give huge thanks to our Medical Advisory Board, who, if anything, seem to have been more active than ever this year. In addition to their medical work, they make active and extremely helpful contributions to Trustee debates, particularly regarding ethical issues. I continue to marvel at their dedication to our relatively small society.

Last year I said that we could forward with optimism. I believe that to be no less true this year. We are so grateful for the efforts of very many people in the past year. A big thank you to you all.

Paul Collacott
Chairman