

ECTODERMAL DYSPLASIA SOCIETY: 2019 ANNUAL REPORT TO MEMBERS

From the Chairman:

Although this report is for last year (ending on 31st December 2019), it would be wholly inappropriate of me not to mention the current Coronavirus crisis and the consequences that have been felt so far. We are very aware that although many people in the UK who have an ED diagnosis have not received an NHS letter putting them in the “shielding” category, they should be considered high risk. The updates to our website give simple and clear information to help people and it has been more important than ever to have our own staff available to answer queries and give immediate help. After some discussion among the Trustees we were able to make some changes to our normal processes that meant the staff could largely work from home, whilst still maintaining the excellent levels of support to our members and contacts. It is a difficult time for everyone, and I’m sure that I speak for all the Trustees when I say how grateful we are to Diana and the team for maintaining, if not increasing, the levels of service at this difficult time. Please ensure that you do everything possible to stay safe.

It feels as though “routine business” ought to take a back seat after that but it’s also important that we maintain our standards of reporting. Therefore, I am pleased to report that at the close of 2019 we had 11 Trustees with Martin Williams having joined the board during the year. The Trustees have continued to monitor the measures that we put in place for financial management during 2018 and are pleased to report that the Society has remained stable financially. The day-to-day running of the society is left to Diana and the team with the Trustees available for consultation as they require. 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.

Alan has covered the detail in his Treasurer’s report, but I am pleased to note that we have been financially very stable during 2019, with the majority of our income coming from three sources – donations, fundraising and grants. The first two of these are directly attributable to the generosity and hard work of supporters. Whilst it is always invidious to single people out, I must note that fundraising has been given an excellent personal boost by the commitment and devotion of Stuart Atkiss, who is the Trustee looking after fundraising for us.

The number of contacts we have had during 2019 is as follows: We now have 1427 people on our database with **697** of these being main contacts. This continues to demonstrate how important it is to be able to curate the right information and give assistance to people who have very few places to look for the information they need on the subject of ED.

Although we are in a hiatus at the moment, it is still true that our international work is very important. There are developments and progress in other countries, and we have to be able to spot and take advantage of the right opportunities which will help our community. Diana is our main expert on all of this and where possible, we ensure that she has the opportunity to go to the right international conferences, share our experiences and learn from others.

One of the most exciting developments in 2019 was the publication of the ED books which also resulted in prestigious awards for the Society. This is important as it enables our profile to increase in the wider world.

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 looks after our social media presence and works on all the DLA/PIP applications with the help of Jaye. Jaye is our main point of contact for liaison with families. Diana oversees all the activities and the work of the other members of the team leaves her free 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. I am grateful to them for their support and continued commitment. My thanks are

particularly due to Alan Waller, who provides the Trustees with solid financial advice and gives us excellent indicators of issues to which we need to turn our attention.

We are so grateful to our Medical Advisory Board which continues to serve the society very effectively. They are a source of vital knowledge and advice in our field, where information gains are hard won. 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 affected by ED. The Medical Advisory Board provide both the appropriate contacts and the necessary governance for us to make decisions in this area.

And finally, 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)