

## The Dentist's Tale

Long-standing members of the Ectodermal Dysplasia Society's Medical Advisory Board (MAB) were recently invited to comment on the 21<sup>st</sup> Anniversary of the Society and Diana Perry's work in this field for over quarter of a century; this is a dentist's tale.

In 1977 three young consultants from different specialities, working at the Eastman Dental Hospital in London, established what is believed to be the UK's first multidisciplinary hypodontia clinic. Their proposals emerged after each had individually received several referrals of patients with ED and hypodontia. They initially met every three months to plan and coordinate treatment. Demand for the service soon grew, fuelled by presentations at national and later international meetings. As a result, the team was expanded, and the clinic frequency eventually increased to fortnightly. The historic significance of this development is reflected in the time capsule in the new Royal National ENT and Eastman Dental Hospitals building which includes material relating to the treatment of hypodontia.



It was at a conference in Copenhagen that the whole Eastman team first met Diana Perry. This was a relationship which proved pivotal in building links between clinical teams and patient support groups. Diana had a very effective and positive attitude to the ED cause, and she and the UK dental team agreed that, if possible, the next conference should be in London. Her diplomatic support helped in the birth of the ECT04 meeting held at the Eastman in 2004.

At that time, it was uncommon to hold conferences attended by both lay and professional individuals in significant numbers, and it was a tribute to Diana and other national delegates that they were able to foster this relationship. Articulation of the challenges faced both by individuals with ED and their carers helped to formulate professional responses at a time when this did not always have strong collective professional support.

The ECT04 conference was attended by a wide range of international delegates, representing both clinical and patient support groups. Many recall Diana's vigorous questioning of a very senior dental civil servant, after his presentation, in relation to NHS funding of implant treatment for patients with hypodontia.

The meeting included group sessions on Dental MDTs (Multi-disciplinary Teams) from which emerged a consensus statement on their structure and roles, which was subsequently published.

The Society's MAB includes representation from a wide range of medical and dental specialities. Its responses to the sometimes-challenging questions fielded by Society members is, we hope, as of much of help to them, as it is to us in increasing our knowledge of the condition.

The Eastman Clinic began to be copied nationally and the Society took on the role of maintaining and publishing a data base of clinics in the UK. This is coordinated by a dental member of the MAB.

As readers will know one of the highlights of the Society is its Christmas party, to which members of the MAB are invited. It is always an extremely enjoyable family occasion enabling people to mingle. For the clinicians attending, it is an opportunity to meet former patients. In the case of senior members this may span two or three generations of the same family!

My congratulations to Diana for 25 years of sterling work and to the Society on its 21<sup>st</sup> birthday.

John A Hobkirk