Trevor Dahl: Chair

I am struck by the indomitable spirit and courage of those affected by endometriosis and count myself lucky to be associated with such a worthwhile and important cause. I am also fortunate to work with a committed executive team and trustee board here at Endometriosis UK, not to mention our many volunteers up and down the country.

The prospect of new funding for the coming year is hugely encouraging and will enable us to develop new and innovative ways of working with relevant organisations through our wonderful volunteers, many of whom I have met at the information days and fundraising events during the last year.

I cannot not let the opportunity go by without making special mention of trustee and treasurer Carol Pearson. She received the Everybody Counts award by the ICAEW (The Institute of Chartered Accountants in England and Wales). It was a privilege to attend the award ceremony with her friends and family. Those that know her will also know how richly deserving she is of this recognition.

Helen North: Chief Executive

2011-2012 proved an exciting year for the charity offering challenges and opportunities in equal measure. With a changing healthcare landscape, women with endometriosis and their families need us more than ever, using our information, help and support to obtain a diagnosis, to decide a treatment path, to manage symptoms or to enjoy their lives as best they can. We are unerringly grateful to all our volunteers who give so much of their time to improve the lives of other women: thank you.

The development of our trustee board, our Medical Advisory Panel and our governance and staff policies has helped stabilise the charity and our links with the British Society for Gynaecological Endoscopy (BSGE) offer potential for further positive change.

The provision of information and support remain the main activities of our charity but aspirations still exist to raise greater awareness, to campaign and to support further research into this potentially devastating disease.

It has been a very challenging time financially and we are therefore ever thankful for the continuing financial support of members, donors, fundraisers and the grants we have received this year. Your future support will allow our aspirations to become realities. With positive signs for the future, we are looking forward to 2013.
Information

Key Achievements:

- Over 25,000 information packs and factsheets distributed
- Over 9,000 ‘Living with Endometriosis’ booklets sent out to consultants and hospitals
- Review and update of all information leaflets
- Four issues of Endolink magazine distributed to over 1,500 members
- New leaflets produced for Awareness Week 2012 aimed at teenagers and young girls
- New leaflets in production including severe endometriosis, finding a consultant and adenomyosis.

Tina’s Story...

Living in Gibraltar played a significant part in the delay to reaching a diagnosis for Tina. Having pushed hard for a scan the resulting medical report in Spanish led to further delays until she eventually secured a referral to a gynaecologist.

The diagnosis of severe endometriosis was a shock and Tina even offered her engagement ring back to her fiancé when she understood more about the disease. He refused and they faced the treatments together. For Tina and her partner the news has been good – and they are now proud parents of a baby boy.

“Endometriosis UK has been a massive help to me through my journey so far. The most useful thing for me was the info packs... I was worried how I would explain my diagnosis to my boss (male) and colleagues especially and the info packs made it so easy for me.”
Amanda’s Story...

Amanda’s struggle with endometriosis started almost as soon as her periods did, pre-teens and her life was blighted by a lack of diagnosis. Support from her mother, who herself was ill, and from her partner, helped her cope, and although occasional treatments and surgery gave some relief it was not until radical surgery last year that she felt her life had really turned around.

“I would urge all girls and women to persist with going back to the doctor about your symptoms and to follow your instinct. If you know it is not right you are probably correct. Endometriosis UK has given me the support of knowing I am not alone. We can all help each other with this disease.”

Communications & Campaigns

Key Achievements:

- Over 210,000 visitors to the website, average over 14,000 new visitors per month
- Exceeded 17,000 subscribers to monthly e-newsletter
- Reached over 4000 facebook followers
- Awareness Week 2012: ‘is this normal? What every teenager and young women needs to know’ – guide produced by paediatric gynaecologist
- Early Diagnosis Campaign – e-petition, facebook group and charity alliance established
Kerry’s Story...

Even with a family history of endometriosis, Kerry struggled to get the help she needed from her local GP. It was only through persistence and the support of her parents that she eventually received the treatments she needed. Even though she is still searching for the right treatment option, Kerry is looking forward to the future.

“Endometriosis is a difficult illness to battle with, but due to the amazing Endometriosis UK support groups and the amazing website it’s hard to feel alone... I may only be 21, but I’m determined to be stronger than the endometriosis.”

Support
Key Achievements:

**Helpline**
- Nearly **2000** callers to the helpline
- Sessions increased by **25%**, delivered by **15** volunteers
- Helpline open 264 days (over **70%** of the year)

**Support**
- **35** active local groups around the UK, run by over **40** trained volunteers
- Over **1700** women attended

**Information Days**
- **London** - October 2011: attended by over **120** people
- **Altrincham** - April 2012: attended by over **80** people

**Online Support**
- EUK messageboard: **c11** posts per day with **6500** members
- Launched **Health Unlocked**: an online community reaching **800** members so far
Staff & Volunteers

Key Achievements:

- Interim Chief Executive has been made permanent
- Key staff team members have been appointed
- By the end of March 2012: over 60 trained volunteers actively providing time and expertise worth at least £40,000
- Office volunteers and interns were recruited for fundraising, research and support services

Joyce’s Story...

Working as a Support Network Intern, Joyce joined Endometriosis UK as a volunteer to help deliver an evaluation of the support services, having graduated with a First Class Honours BSc in Health Promotion.

“My aspirations to promote awareness of endometriosis led me to carry out primary research for my degree into why there is still a lack of awareness of the disease after my own struggle to obtain a firm diagnosis of endometriosis as a woman of colour 30 years ago. It is with this aspiration to improve the awareness of endometriosis amongst women at large and particularly amongst ethnic groups that brought me to Endometriosis UK. I am hoping that this evaluation will highlight where the gaps in accessing services are.”
Governance

Key Achievements:

- **Four new trustees** from a variety of backgrounds recruited and trained
- New lead **medical trustee** appointed
- **Medical Advisory Panel** established
- Final technical report on the **ENE Project** submitted

TRUSTEE BOARD (as of October 2012)
- **CHAIR:** Trevor Dahl
- **TREASURER:** Carol Pearson
- Kay Logan
- Ertan Saridogan
- Sonya Timms

MEDICAL ADVISORY PANEL (March 2012)
- **CHAIR:** Ertan Saridogan - Consultant Gynaecologist, UCLH
- **Dr Kiranna Arambage:** Speciality Registrar Obs & Gynaec Whipps Cross Hospital
- **Hilary Denyer:** Retired Nurse, Nutritional Therapist
- **Prof. Janesh Gupta:** Consultant Gynaecologist, Birmingham Women’s Hospital
- **Dr Uma Marthi:** GP with special interest in women’s health, Rochdale
- **Wendy-Rae Mitchell:** Gynae Nurse Specialist, Royal Surrey County Hospital Guildford
- **Caroline Overton:** Consultant Gynaecologist, University Hospitals Bristol NHS Foundation Trust
- **Kevin Phillips:** Consultant Gynaecologist, Hull and East Yorkshire Hospitals NHS Trust
- **Dr Veena Rao:** GP with special interest in women’s health, Cockermouth

Research

Whilst aspirations still exist to pursue future direct research activities into the causes, treatments and effects of endometriosis, the prohibitive costs involved in undertaking any significant research means activity of this nature is out of reach for the charity at present. However we continue to give our time and make our resources available to researchers as far as possible within our current policy. This year we have:

- Worked with researchers at the De Montfort University on the Endopart programme – a study into the impact of endometriosis on couples.
- Contributed to the World Endometriosis Society Consensus Statement on Endometriosis, due for publication later in 2012
- Joined the RCOG Clinical Studies Group for Menstrual Disorders
- Recruited a volunteer PhD student to produce overview reports of recent research in specific aspects
It continues to be an extremely demanding financial climate and during the year, the charity made a loss of £41,413. Income fell from £165,798 to £150,806, with the main falls being seen in grants and donations and fundraising. However the main driver of the expenditure this year has been the investment in staffing the organisation; without staff we cannot endeavour to grow the charity to provide resources to achieve all our objectives. Investment has been made in grant fundraising in particular but this will take time to show results.

At end March 2012, the charity showed reserves of £94,053 which included restricted reserves of £17,559 to be spent on charitable activities within the next 12 months. Funds worth £42,868 were also recorded in the accounts, being the remaining grant held with regard to the ENE project. It is anticipated that these funds will be distributed during the next twelve months according to the determination of the European Commission.
For the next year we will...

- Conduct a member and user survey
- Evaluate and improve our support services
- Develop an improved fundraising strategy to cope with the challenges faced by a small healthcare charity
- Conclude the European Network on Endometriosis project
- Review our office and administrative structure, with a particular focus on IT improvements to achieve maximum efficiency
- Maintain and improve our information services and assess future development opportunities
- Consider our campaigning role and assess how to develop this further

Fundraising & Thanks

We are extremely grateful for the donations, fundraising and contributions from the many funders and individuals who have supported us during the year. In particular we would like to thank Sovereign Healthcare, Awards for All/Big Lottery, Garfield Weston Foundation and the Brewer Family.