

ENDOMETRIOSIS UK

REPORT OF THE DIRECTORS AND TRUSTEES

The Directors and Trustees present their report and the audited financial statements for the year ended 31st March 2007.

LEGAL AND ADMINISTRATIVE INFORMATION

The Society is a registered charity and a company limited by guarantee, governed by the company's memorandum and articles. All the directors of the company serve as the Society's trustees. Full legal and administrative details are set out on page 1.

PRINCIPAL OBJECTIVES AND ACTIVITIES

The principal objectives and activities of the Society are:

- to provide services to women for the relief of endometriosis,
- to advance the education of the general public and health professionals regarding endometriosis
- to promote research into the disease

The charity regularly reviews its strategy and during the year Trustees and staff undertook a planning away-day. Our commitment is to raise the profile of endometriosis and improve the care available to women with endometriosis. Our long term vision from which our strategic objectives are driven, measured and evaluated is encapsulated in a five point plan. We aim to ensure that:

1. Every woman is aware of endometriosis, its symptoms, effects and treatment options
2. Health professionals understand what endometriosis is, its symptoms, effects and treatment options
3. Time to diagnosis is significantly reduced
4. Everyone has ready access to fast, appropriate treatment, care and support
5. Increased funds for endometriosis research

REVIEW OF DEVELOPMENTS AND ACTIVITIES DURING THE YEAR

Every women is aware of endometriosis, its symptoms, effects and treatment options

Endometriosis affects some 2 million young girls and women in the UK. Despite being so common, awareness and understanding of endometriosis is unacceptably low. There is an urgent need to increase the profile of the condition and of our work in order to tackle many of the issues surrounding endometriosis.

In 2006, the charity announced the results of a survey completed by 3,500 UK women that highlighted the huge impact endometriosis can have on all aspects of a woman's life including work, education, relationships as well as health. For those that completed the survey, it took on average eight years to receive a correct diagnosis, whilst they were living in pain for an average of three years before going to see their doctor.

Previous MORI research highlighted the need to raise awareness with the majority of women questioned (80%) not knowing what endometriosis was, bringing associated risks that women are not relating their symptoms to the condition, or understanding that their symptoms are abnormal, hence the three year wait before seeking medical assistance.

What we have done

For some time the charity has needed a clearer and stronger brand, but due to time and money restrictions we were unable to take this important step. However, after previously winning 14 days of free PR from Weber Shandwick, one of the UK's largest PR companies, we were finally able to establish a new look for our charity.

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Weber Shandwick were shocked at the issues surrounding endometriosis and wanted to ensure their support provided something that would be long term and significant. They believed that creating a new brand for the charity was vital. They oversaw the entire rebranding process, and the charity officially re-launched as Endometriosis UK in November 2006. Importantly, the entire process cost the charity nothing except the printing of our new stationery.

With the internet frequently being the first port of call, we knew we had to improve the content, look and navigation of our website and set ourselves the task of undertaking a redesign during 2006-7. This was achieved and we now have an improved and more extensive site. Feedback has been positive and we are already seeing a rise in enquiries on all aspects of our work, including information packs, volunteering and fundraising. During 2007-8 we will continue to review our website and explore ways we can reach all of our target audiences.

Last year we set a target to explore ways we could reach teenagers girls and during 2006-7 developed a partnership with a secondary school to design a micro-site of our own website, which will focus on menstrual health. We will be working with the school during 2007-8 to ensure the new site will be relevant and appeal to teenage girls.

During the year we launched a new hard hitting campaign called *Bloody Hell*, which aims to increase understanding of the impact of endometriosis. In particular, the campaign through images and text is targeting younger women and in 2007-8 we will be exploring ways to increase the reach of this important campaign.

The charity has limited funds in which to actively build the profile of endometriosis, but despite this, our ongoing awareness programme has continued to achieve much. During 2006-7 we have seen increased interest from the media in writing articles about endometriosis and journalists are now approaching us proactively.

During Endometriosis Awareness Week (March 2007) we gained much national media coverage including GMTV and Metro Newspapers, as well as significant local interest. Thanks to this coverage, we distributed 300% more information packs during March compared to other months of the year, whilst the number of calls to our main helpline was on average 50% higher. Awareness Week 2008 aims to focus on the impact endometriosis can have on education.

Increasing knowledge about endometriosis is vital as 48% of requesters for our information packs felt isolated before contacting us. Our information programme makes huge differences to women's lives: only 3% still felt isolated after contacting us, and on average, 60% of women reported an increase in their confidence discussing their condition with health professionals, friends and family. During the year we distributed approximately 100,000 publications on endometriosis.

Raising public understanding of endometriosis is essential and during 2006-7 a number of our trustees played a lead part in a consumer's forum at the Royal College of Obstetricians and Gynaecologists which sought patient feedback on how best to manage endometriosis.

We were delighted that the Department of Health agreed to fund the role of an Information Manager for the next three years, enabling us to develop our information programme. We have already produced materials to support the needs of our users including new leaflets for employers, those working in primary care, a pain diary and leaflet on disability for women with endometriosis. The need for other new publications has also been identified and we will be producing them in 2007-8.

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Health professionals understand what endometriosis is, its symptoms, effects and treatment options

The charity is fortunate that it has a number of medical trustees offering a range of expertise in the field of endometriosis and primary and secondary care in general. They also offer vital links to relevant medical Societies and provide vital input into the development of our medical information.

Results of the Quality of Life survey, mentioned earlier in this report, demonstrated the major challenges to diagnosis: women are experiencing a 6 year delay in referral from GP to gynaecologist and 68% stated that they were initially misdiagnosed. As a result, we wrote a new leaflet for those working in Primary Care and during 2006-7 sent the leaflet to 30,000 GPs, thanks to funding from GlaxoSmithKline. We were pleased that a number of surgeries have since requested our information materials to place in their surgeries.

Feedback from our members in 2005-6 showed that on average 66% of hospitals they attended had no information about endometriosis or the work of the charity. As a result, we invited every UK Health and Trust Board to take part in a survey in the aim of obtaining UK data on current healthcare provision for endometriosis. To date over 60% of the Boards have responded and over 90% have agreed to display information about endometriosis. We will be seeking funding during 2007-8 to support this important project.

During the year we also ran two educational roadshows in Cardiff and Birmingham, each of which was attended by a variety of health professionals including GPs, practice nurses and gynaecologists. We plan to continue with this effective project, running five more roadshows during 2007-8.

Significantly reduced times to diagnose endometriosis

Recent surveys of women with endometriosis have highlighted a diagnostic delay of eight years, considerable variation in treatment(s) and care across the UK, a lack of follow-up for efficacy, an adverse impact on quality of life and a major socio-economic burden. As a result Endometriosis UK, with support from key medical experts in the field of endometriosis submitted an application to the National Institute for Clinical Excellence earlier this year, asking them to consider a new guideline topic on *The Diagnosis and Management of Endometriosis*. We hope that during 2007-8 we receive a positive response to this request.

During Endometriosis Awareness Week 2007, a new early day motion was launched seeking MPs support for our request that NICE considers new guidelines. We also held a briefing for MPs at the House of Commons to highlight the impact of endometriosis. To date, 77 MPs have signed the Early Day Motion.

In 2005-6 thanks to extensive lobbying, we announced that for the first time endometriosis had been included in the EU Public Health Work Plan. During 2006-07 we heard that a major application for funding had been approved and in 2007-08, our eight European partners began work on a three year project to develop vital support for the estimated 15 million women in the EU who are living with endometriosis.

This project has 3 goals: developing a European Endometriosis Support Alliance to coordinate and provide comprehensive support in the EU; to run a comprehensive pan-European epidemiological study looking at health, quality of life and socio-economic impacts; setting up an internet based Endometriosis Community Gateway to provide a focal point for individuals and organisations wanting information on endometriosis.

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Everyone has ready access to fast, appropriate treatment, care and support

We launched a new campaign to help raise awareness of endometriosis in the workplace in response to a survey that highlighted challenges women can face in the workplace. Eighty two percent of those who replied had lost time from work, 43% were too scared to tell their employer and the average time off per year was a shocking 67 days. We estimate that this could cost UK business £2.8 billion a year in sick leave alone.

We have produced a new leaflet which is in particular targeting occupational health teams. The leaflet explains endometriosis, its impact and how employers can support staff affected by endometriosis. We believe that with greater awareness many absences from work can be avoided by reducing the taboos, embarrassment and fear associated with the condition to enable a positive working environment for all.

The leaflet has been positively received both from members who have passed it on to their employers and from occupational health departments. During 2007-8 we will look to build on this important work with more employers.

The charity offers direct support through its local groups, free helpline, free information packs and a range of information materials. The helpline received over 8,000 calls during the year; of these 2,600 were individual callers, 740 of whom were connected to a volunteer. Our Helpline was open on average for three hours a day and feedback has shown that for 72% it is the first time that the caller has spoken to another in the same situation. We had on average 30 local groups and 841 people either attended group meetings or roadshows. During 2007-8 we will be looking at ways to increase the number of groups.

During 2006-7 we recruited 60% more volunteers compared to 2005-6 and we anticipate a further 50% increase during 2007-8. This rise is due to improved recruitment materials, the impact of our new website and also regional roadshows that were run during the year.

We are very grateful to our committed group of volunteers without whom we would not be able to run these vital services. We provide regular training for all new and current volunteers to ensure they have the skills necessary to undertake their role. We met our 2005-6 target of reviewing the content of our training courses during 2006-7 which has resulted in more focussed training. Feedback from our volunteers has been positive.

The use of our website as a source of support and information continues to grow. There are now over 4,000 members of our popular message board, an increase of over 15% in the year. Our new website was launched in March 2007 and we anticipate that there will be as much as a 40% increase in requests for information packs by year end as a direct result.

In a 2006 survey, 90% of our members stated that they would have greatly benefited from speaking to a trained volunteer when they attended gynaecology clinics at local hospitals. We have since developed plans to run a new Hospital Visiting Service and submitted a major application for funding. The project has been endorsed by gynaecologists who feel it will be of great help to the patient but also aid their own work.

We regularly review the services we offer to ensure that they are appropriate for all our key audiences. During 2007-8 we will begin to explore new ways we could offer support such as through email, texts and widening our volunteer base to include training men to take helpline calls from partners of women with endometriosis.

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Increased funds for endometriosis research

Endometriosis UK does not currently fund medical research due to the huge costs involved. In the meantime we continue to focus our efforts on securing funding for research such as from UK research bodies, and influencing the Health Technology Assessment Programme of the NHS to see more international collaborative work and to encourage the best young scientists to enter the field of endometriosis research. We also continue to disseminate the results of research such as via its newsletter and website.

In addition, the comprehensive pan- European epidemiological study that is part of the EU funding mentioned earlier will look at health, quality of life and socio-economic impacts due to endometriosis and will provide vital new data on how best to manage the condition and Endometriosis UK will be co-ordinating this important project.

FINANCIAL REVIEW

The charity's finances are overseen by both the trustee board as a whole and a finance sub-committee.

This has been another positive year for the charity with income increasing from £291,843 to £457,401. One major reason for this increase is that the charity received a legacy during the year to the value of £140,000.

Without this legacy our income would have been £317,000, which was ahead of the £300,000 target we set last year. Our income in 2005-6 included £39,000 raised from one challenge event. We did not run such an event in 2006-7 and so in real terms we have seen growth of over 25%. Year end balances are also more positive than last year with £130,239 being carried forward to our reserves.

The long term strategic objectives of the charity are to some degree held up by the challenges of the size of our small team and the large legacy has presented a number of opportunities. One area being considered is investing in fundraising, which will enable us to build up our income at a much faster rate, which in turn will allow us to directly support many more people affected by endometriosis. During 2007-8 the charity's trustees will be carefully reviewing how best to make use of this exciting opportunity.

We are very grateful for the support of many funders who have supported us during the year including The Department of Health, The Henry Smith Charity, The John Ellerman Foundation, The D'Oyly Carte Charitable Trust, The Garfield Weston Foundation, GlaxoSmithKline plc, Sovereign Health Care, Wickes Trust and Ipsen Ltd.

RESERVES

During the year our trustees changed our reserves policy and the target is to have reserves that cover between 3 and 6 months of total annual expenditure. The year end unrestricted reserve, which amounts to £238,441 at year end (£106,147 in 2005-6), represents approximately 9 months expenditure. Without the legacy income our reserves would have been £98,441, representing just under 4 months expenditure.

The restricted reserve of £1,199 relates to IT equipment which is being written down by 25% per annum over four years.

RISK ASSESSMENT

The charity undertook two reviews of all risks during 2006-7, covering the key aspects of the charity's work including finance, governance and management, operational and external factors. The major risks to which the charity is exposed, as identified by the trustees, will continue to be regularly reviewed and systems have been established to mitigate those risks.

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STATEMENT OF DIRECTORS RESPONSIBILITIES

The Directors are required to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Society and of the results for that period. In preparing those financial statements, the Directors are required to:

- select suitable accounting policies and apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on a going concern basis unless it is inappropriate to assume that the Society will continue to operate; and
- state whether applicable accounting standards have been followed subject to any material departures disclosed and explained in the financial statements.

The Directors are responsible for keeping proper accounting records, which disclose with reasonable accuracy at any time the financial position of the Society and to enable them to ensure that the financial statements comply with relevant legislation. They are also responsible for safeguarding the assets of the Society and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities. The Directors confirm that they have taken appropriate steps to make themselves aware of any relevant audit information and to establish that the auditors are aware of such information. As far as the Directors are aware, there is no relevant audit information which has not been disclosed to the auditors.

APPROVAL

This report was approved by the Board of Directors and Trustees on and signed on their behalf by:

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Edward Copisarow (Chair)

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Mona Patel (Trustee)