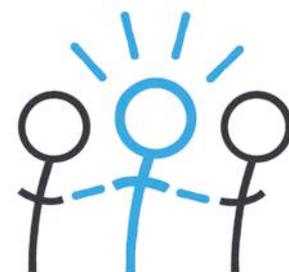


The Endometriosis Association of Ireland

*Annual  
Reports*  
2010



The Endometriosis  
Association of Ireland

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# Chairpersons Foreword

2010 was a year of growth for the EAI. As planned, we increased the number of support group meetings across the year to four, with two in Dublin, one in Athlone and one in Cork. World Endometriosis Awareness Week 2010 was a busy one for us; as well as the Information Day which has become an annual event, Kathleen King organised an information stand and information morning on our behalf in Letterkenny General Hospital. For the first time we made a support line available each evening of Awareness Week and created a format for members to host awareness- and fund-raising End to Endo coffee mornings. Our income in 2010 went up by 22% on the previous year, enabling us to fund the increase in activities.

Along with an increase in the activities of the organisation, the community that we reach expanded in 2010. More women came in contact with us as a direct result of the increased number of support group meetings, and through our presence on facebook and twitter. Membership was up by almost 50% and the number of people contacting us by phone and email increased substantially, as did the number of visits to our website. As more and more women come in contact with us, our emailing notifications list continues to grow.

Each year, the EAI is able to continue to provide its services and resources because of the dedication and commitment of women with endometriosis who volunteer their time, experience, expertise and energy. At the AGM in March 2010 we were delighted to welcome four new faces onto the committee, who brought a wealth of experience and an impressive range of knowledge and expertise to the operation of the Association over the past year. It has been a privilege and a pleasure to work with all of the committee, both long-standing and relatively new, and it is with sadness and regret, but profound appreciation that we say goodbye to those who are obliged to step down this year, for a variety of reasons.

Appreciation and heartfelt thanks are due also to volunteers who are not on the committee, but who contributed in 2010 in a variety of ways to the welfare of women in Ireland with endometriosis. Thanks in particular to those who volunteered to allow their experiences of endometriosis be published in the national media, helping to ease the isolation experienced by many women with the disease, to those who continue to contribute to the online members forum, providing invaluable information, moral support and practical advice to other women, to those who helped organise support groups, and to those who raised funds and raised awareness through End To Endo coffee mornings and sponsored events, such as the Flora women's mini-marathon.

Although the level of awareness and understanding of endometriosis, among both the general public and the medical profession, is still a long

way from satisfactory, the rise in numbers of women looking to us for information and support suggests that awareness of the disease is growing, however slowly. As an organisation dedicated to supporting women with this disease, we can only celebrate such growth. But we are conscious that as awareness grows, the demand for services and information provided by the EAI will also continue to grow. Looking forward, our focus must be on planning strategically so as to discover, develop and make effective use of the range of resources that we need in order to respond to the needs of the community that we serve, the community of women in Ireland who have endometriosis.



# Introduction

At present, we describe ourselves as a self-help group to provide support and info for sufferers of endometriosis and to promote research into this disease. We also strive to raise awareness of endometriosis amongst women and the medical profession, awareness of not just the disease but also the symptoms, effects and treatment options. We look forward to a time when all women have ready access to a timely diagnosis and receive appropriate treatment, care and support. We would like to see endometriosis becoming a high priority in bio-medical research, with the appropriate funding.

The Endometriosis Association of Ireland is a registered charity, founded in 1987. In 1989 it took the further step of becoming a "company limited by guarantee and not having a share capital", in other words a non-profit organisation which is a limited company and so has to be compliant with Company Law as well as charity regulations. One of the requirements is the auditing of the Annual Accounts, a condition for retaining our charitable status.

The main **aims** of the Association outlined in 1989 were as follows:

- (i) To promote and foster within Ireland the carrying out of medical research into the causes, cure or relief of Endometriosis and allied diseases.
- (ii) To undertake duties in relation to the care and welfare of sufferers from Endometriosis and allied diseases.

## **Our community:**

In 2010 we had 74 members ranging in age from teenagers to over 80 years. These members made it possible for the Association to reach out to a much wider community.

Around 10% of women are thought to have endometriosis. This disease has many devastating symptoms and is especially known for its excruciating pain and fatigue. Endometriosis sufferers have a lower quality of life as a result. Women with endo may not be able to complete their education, their careers can be affected, a wish for children may not be fulfilled and relationships with partners, family and friends can be terribly damaged. The difficulties women face in getting their symptoms acknowledged, and therefore diagnosed and treated, creates huge additional psychological stress. To this must also be added the psychological burden of not being able to talk about the effects of the disease openly, whether in a work situation or from not wishing to burden friends or family with the hardships of dealing with a chronic illness.

The isolation felt by women who have endometriosis is a big problem. It is important that endo sufferers know that they are not alone. This is the reason why the Association, through support group meetings, liaising with journalists for items in magazines and newspapers, posting out leaflets to hospitals, funding the website and any other means at our

disposal, tries to reach out to the many women out there in the wider community.

The EAI is the only charity in Ireland which works specifically with this community of endometriosis sufferers.

**Our contact details:**

The registered address of the Endometriosis Association of Ireland is at the Carmichael Centre for Voluntary Groups, Carmichael House, 4 North Brunswick Street, Dublin 7.

The telephone numbers are 01-8735702 and 086-3203855

The Association has a website [www.endo.ie](http://www.endo.ie) and is emailable on [info@endo.ie](mailto:info@endo.ie).

The 2010 management **committee** are as follows:

Clodagh Lynam, Chairperson

Bébhinn NicLiam, Secretary

Shauna Whelan, Treasurer

Adrienne Egan

Tracy Dixon

Helen Ryan

Colette Murphy

Niamh O'Connor was not on the committee but re-elected to the role of webmaster.

# Activities and Challenges

## **ACTIVITIES 2010**

The committee met 7 times during 2010, although the officers met informally also. Colette Murphy came onto the committee following the AGM in March 2010. We organised four support group meetings throughout the year. We also published four substantial newsletters, 8 pages long, for our members. Secretary Bébhinn NicLiam attended two training/information events during 2010 on behalf of the Association, one presented by Noel Murphy from the Communications Unit of the Houses of the Oireachtas about getting your message through to the Oireachtas and the second one was given by Billy Hawkes, the Data Protection Commissioner, about Data Protection and the Voluntary Sector.

The committee also organised the administration for the volunteers running the Flora Mini Marathon in Dublin, sending out sponsorship cards and T-shirts.

The Association purchased a mobile phone in February 2010 to enable people to contact us directly, instead of going through the Carmichael Centre. It was also used with great effect during Awareness Week.

### **International Contacts**

The Association is in contact with the international endometriosis network. Links are provided from [endometriosis.org](http://endometriosis.org) to our website, and they also list our events for Awareness Week along with other endo groups from around the world. We are kept in touch with developments internationally. The contact with the Polish endometriosis association has continued, potentially very useful considering the amount of Polish nationals living in Ireland. Elaena Havell from Endometriosis New Zealand visited us in our Carmichael Centre office and we had a very informative meeting about the work they do there, much of it alongside the medical profession.

### **The Presidential visit**

The committee created Information Panels for the visit of the President, Mary McAleese to the Carmichael Centre in January 2010. These panels have been displayed at Support Group meetings since then. Bébhinn NicLiam met the President on behalf of the Association, and was pleased to find out that she already was aware of the condition and the devastation it can cause.



President Mary McAleese's visit to The Carmichael Centre to meet the voluntary groups there

### **Contact with Endometriosis Sufferers**

Much of work of the Association involves responding to women who contact us through letters, email, telephone messages or personally at events we organise. They find out about us through our website, through internet searches, or because their doctor or hospital nurse has given them one of our information leaflets. Every week we get queries for information. We are not always able to deal with them all. In 2008 we received 31 email enquiries. By 2009 it had risen to 78 and last year, 2010, we received 95. The majority are from women who are understandably very upset and distressed, either by the shock of being diagnosed with endometriosis or feel that their treatment is failing causing their quality of life to diminish substantially. We cannot offer medical advice but we try our best to offer the help and support these women deserve.

We also receive a substantial number of enquiries through the post and also through telephone messages passed on to us by Carmichael House. We have build up an email mailing list of almost 300 endo ladies, and the number of people who get directly notified of any Association events is constantly growing. This email community is great in responding to requests for taking part in research or interviews with the media, and also by publicising the work of the Association further afield.

Much contact is also done though our events, such as support group meetings or Information Days. In 2010 approximately 100 people attended our events. Each person has their own story to tell about their experiences with the disease. We are also aware of the difficulty people often have in attending, and those who are simply in too much pain to travel.

### **Contact with the Medical Profession**

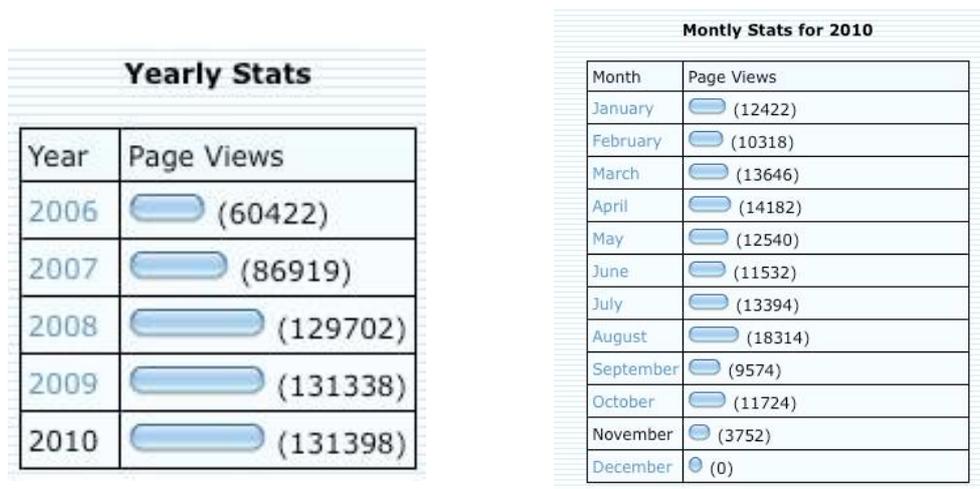
Contact with the medical profession is limited to the Royal College of Surgeons in Ireland. (RCSI). Following on from an initiative started in 2009, the Association was invited to speak to two groups of medical students in November 2010. The talk was about endometriosis from a patient's point of view with questions from the students afterwards. It is tempting to think that making medical students aware of endo and the

huge impact it has, may help some woman get a timely diagnosis in years to come!

We also supply hospitals with our information leaflets, as we have found there is a great need for them to be available on the gynaecology wards for women receiving a diagnosis following surgery.

### Website Activity:

Page Views: The amount of page views our website gets shows a year on year increase. From 60,422 in 2006 this has risen to 131,398 in 2010. This could be a combination of greater access to the internet but also a rise in awareness about endometriosis amongst women.



Web stats showing increased page views, and a monthly breakdown showing that even endo ladies like to take a break from it all in December!

### Utilising Social Networks

The way people interact with the internet is also changing, with the growth in social networking. A website is not the only way now to communicate with our community online. The Association set up a Page on Facebook. This requires individuals to "like" the page before they receive our updates, so the uptake has been quite slow. However it has given us easy access to many endo organisations that also utilise Facebook. It also gives access to the many loose groupings and individuals whose main concern is endometriosis, and also for people to contact us directly. All our events are now publicised through our Facebook presence The Association's page can be found at **facebook.com/EndoIreland**.

The Association can also now be found on Twitter:

**http://twitter.com/endo\_ireland** Twitter works in a different way to Facebook but has proved a remarkable source of information, whether newest research or newspaper interviews with endo sufferers around the globe. We retweet the most relevant information and also tweet when we have events etc. coming up.

### Facilitating Accredited Researchers

Towards the end of November 2010 we received a request from Philippa Davies, a 3rd year Biomedical Science student at De Montfort University in Britain. Her research was about people's experiences of living with

diagnosed endometriosis and in particularly the management of care and pain. The results are for her dissertation honours project and hopefully to educate and inform health professionals. We were pleased to be able to promote the study, which involved answering an anonymous questionnaire, to all the people on our email contact list.

### **Awareness Week 2010**

For endometriosis organisations, the big event of the year is Awareness Week. In 2010 we held a special Information Day in Kerdiffstown House near Naas. It was attended by around 45 people. We got the event advertised in the Irish Times and the Examiner newspapers and on the IrishHealth.com website, at no cost to the Association.



Nutritional Therapist Adrienne O'Dwyer



Dr Shelagh Wright explained what Autogenic training is, and gave a demonstration



Dr Shelagh Wright, lecturer in Psycho-oncology at DCU School of Nursing, who specialises in helping cancer patients deal with pain was one of the speakers. She gave an insightful presentation into Autogenic Training in the self-management of pain.

Adrienne O'Dwyer, a Nutritional Therapist, spoke about managing endo through diet and which foods to avoid and which to include in your daily diet.

The feedback we received was very positive and people found both presentations, and the question & answer sessions after each one, very helpful. The gluten-free scones provided by Kerdiffstown House were also much appreciated!

## **Awareness Week in Donegal**

A Donegal member of the Association, Kathleen King, organised an information stand for display in the main reception area of Letterkenny General Hospital to provide valuable information and support material for staff, visitors and patients. This was followed up by an information morning within the hospital open to everyone. It consisted of a number of presentations, followed by a discussion session.

Lorna Baldrick (Clinical Nurse Manager, Urodynamics) led off the presentations with her personal journey as a woman living with endometriosis. Deirdre Murphy (Traditional Chinese Medicine, Acupuncture) then presented an informative account of the valuable role that Acupuncture and Chinese herbal treatments may have in the management of endometriosis. This was followed by an overview of Chronic Disease Self Management for women with Endometriosis, by Kathleen King herself (Medical Scientist).

The last speaker of the morning was Rita Cassidy (Holistic Practitioner, Clinical Nurse Manager, Haemovigilance) who described the benefits of reflexology in management of symptoms associated with endometriosis, such as pain, fatigue and stress. Thanks go to Mary Gallagher (Clinical Nurse Manager, Gynaecology) for introducing the speakers and facilitating the discussions.

Following the success of this information morning, an evening of talks was organised for September 23rd 2010, in Letterkenny, Co Donegal. Invitations were sent to primary care centres, doctors, practice nurses, clinics etc in the wider North West of Ireland

## **Helpline**

During Awareness Week we publicised the telephone helpline. This was operational in the evenings and although the time was restricted it received a good number of calls. This was the first time in many years that the Association was able to provide such a service. The helpline continued to have a positive impact as women who had seen the number advertised in the newspapers during Awareness Week were still calling afterwards.

## **End 2 Endo coffee mornings**

We piloted a fund-raising/awareness raising End 2 Endo coffee mornings. This initiative was for members or supporters to host a coffee morning in their own home or venue of their choice, charging their guests per cup of tea or coffee and telling them about endo and sharing out information leaflets. There was not a big take up but the feedback we received was that even close friends were not fully aware of the impact of endo on people's lives and that we each in our own small way can create a "ripple effect" in raising awareness.

## **C H A L L E N G E S 2010**

### **Membership**

2010 was a difficult year for most charities in Ireland. The international financial crisis had a profound effect on Ireland's economy and the effects started to be felt by the general population. Charities throughout the country faced falling income and memberships.

The Association actually managed to increase its membership from 49 in 2009 to 74 in 2010. Of the 74 members, 48 joined for the first time last year. (This means that from the 2009 members, just over half, 26, renewed their membership and 23 did not.) A decision was made by the committee to introduce a special half-price rate for teenagers and other young women who could otherwise not afford membership.

One of the challenges identified by the committee was how to retain membership and to make it easier for people to renew their membership. This is important if the Association is to grow in a sustainable manner.

### **Funding**

The Association is dependent on membership fees as we do not get government funding. This income goes towards our rent, printing and postage costs, the annual auditor fee and website hosting. It also makes it possible to hold support group meetings. Membership fees are absolutely vital to the Association. When a person joins us, their membership does not benefit only themselves, but the women out there, suffering in isolation, who we are still trying to reach.

We asked for, and received a donation of €500 from Ipsen, a pharmaceutical company, for the purpose of holding support group meetings. The Royal College of Surgeons in Ireland promised us €100 in appreciation of our involvement there.

We also receive donations from members and supporters. Women have run the Dublin Mini Marathon, held end-to-end coffee mornings, added in extra to their membership fee, made contributions at events during the year

A major challenge which became clear over the year was the need by the committee to identify additional revenue sources, especially for one-off projects.

### **Volunteering**

As a charity, we rely on volunteers. The management committee is made up of volunteers who dedicate much time to the business of running the Association. As women with endometriosis, the time given is never "spare" – it is taken from time otherwise spent with family or friends, rest time, recovery time from work or even surgery. We really appreciate it when members and supporters volunteer their time and energy, no matter what extent, because we know the costs involved personally. As can be seen from the paragraph above on funding, volunteers really make a difference.

Fundraising, although important, is not the only way volunteers can help. In 2010 we developed links in Cork with a view towards setting up a Local Group. Like wise in Galway and Donegal. Women, despite the limitations put on them by endometriosis, or maybe who are in a period of remission and motivated to help other women in a worse situation, come forward and ask us what can they do to help. We have not been able to channel their good will and enthusiasm in the best way.

The committee recognised that volunteers are an essential part of the Association's work and have the potential to become a vital part of its structure. One challenge the committee identified was the need to have a frame work to match the interests and skills of the volunteer with specific roles and tasks, where ever that person lives or works. This is a substantial piece of work which needs to tally with the goals (and priorities) of the Association.

### **Support Group Meetings**

In 2010 we organised four Support Group Meetings, two in Dublin, one in Athlone and one in Mallow. Each meeting is publicised via our website, email, flyers and by informing local newspapers and radio stations. These meetings help to break the isolation and stigma attached to endometriosis. It is sometimes the first time women have been able to talk about their condition and the difficulties in dealing not just with this chronic illness, but also the attitudes encountered at work, at the hospital, or even from friends. They do so in a supportive and confidential environment, amongst other women who have had similar experiences.

These meetings are valuable in themselves but the isolation returns afterwards. The committee identified a need for the support to continue, but we don't have the resources to provide it. Ideally the meetings could be used as a catalyst for local women to get together on a more regular basis. The challenge identified by the committee was how this could be done, how can we support the women who would like to set up a Local Group.

### **Website**

The website is an essential part of the function of the Association ever since it was first set up in 2006. It is the first point of contact for many women, often soon after getting a diagnosis. It is a permanent presence for women wherever they are based in Ireland, at whatever time they search the internet for help in coping with endometriosis. Information about events coming up feature on the home page as do our contact details. It also provides a forum for members to discuss things in a confidential environment.

The website is starting to show its age and is difficult to administer. Information has been lost over time and the present committee are unable to upload newsletters, photographs or articles - an important part of keeping the website up to date and relevant to both casual browsers and registered users. In July 2010 a glitch occurred in the coding meant

that anyone applying to become a forum user had their application go through automatically instead of being vetted first by the webmaster as genuine. This is not acceptable. However getting the glitch repaired when the entire website was due for renewal did not seem economical, and so the applications have to be sifted manually after registration. This is time-consuming.

The challenge identified by the committee was to familiarise ourselves with the existing website as much as possible to make the most use of it and at the same time, to build up knowledge from that for creating an improved version. It is a huge piece of work, in figuring out the structure alone and the committee were not able to complete it in 2010. Quotes were received for a new website, but a decision still has to be made as to if it is feasible to attach the forum, which holds much information, to the new website.

### **Contact with Endometriosis Sufferers**

As outlined in the previous section, the number of personal queries is increasing all the time – 95 were received by email alone in 2010. That is just under two per week, and each one requires a considered reply or research to be done. Answering just one can take a few hours. And there is the postal correspondence and telephone messages and so on to deal with. It is a very good thing that endo sufferers in Ireland do have someone to contact, but we do not always have the resources to deal with this fully. Some phone calls and emails do not always get a response, or there can be a substantial delay. A permanent help-line would be an ideal and direct way of being accessible to women when they most need support and advice. However there are no resources for this at present. When someone is in pain or distressed any delays must be avoided as much as possible. And responses must be sensitive to and sympathetic with the person who needs help.

The committee, as fellow endo sufferers, do not want to fail even a single sufferer seeking help or advice. However, the more awareness there is out there about endometriosis and the more women are receiving that diagnosis we can only expect more enquiries to come to us.

The committee have identified this a major challenge to overcome. It may require more people dealing with enquiries or re-allocating tasks within the committee. We should not rule out the prospect of finding a suitable person to work for the Association in a salaried position, subject to funding, even in these financially hard times.

# Conclusion

2010 was a difficult year for many people in Ireland, and the financial constraints were felt strongly in the charity sector. The Endometriosis Association of Ireland managed to register an increase in members (this has unfortunately not continued into 2011), which stabilised our finances. We met our targets for the year, in organising a successful Information Day and other events during International Endometriosis Awareness Week, hosting four support group meetings and producing a quarterly newsletter for our members. We also managed to field many enquiries and requests, whether personal, from journalists, hospitals, researchers etc, more than in any other year.

Women with endo actively participated in furthering the aims of the Association by fundraising, making donations, attending support group meetings and sharing their experiences, organising awareness raising events themselves and contributing to the 'ideas fund' of the Association.

The committee learnt a lot over the year. Mistakes were reviewed with a view to improving from them. The process of identifying the challenges to our longer term goals was begun, which is a crucial piece of work. There is a huge need to make more women, and medical professionals, aware of endometriosis and all it entails. Ideally, every woman would get a timely diagnosis and access to the best specialist care. As a small organisation run entirely by volunteers, with funding drawn from membership subscriptions, we are already now feeling the pressure from a slightly raised awareness of endometriosis. To prepare for the future, to be an organisation that is a strong focal point and advocate for endometriosis sufferers in Ireland needs adequate resources and strategic planning.

The continued support from members is invaluable to us. We need to encourage more people to join, to strengthen our voice and support our work in reaching out to the wider endo community. We need to find additional ways of funding our activities. Channelling the energy, time and goodwill of our supporters needs to be done in a sustainable, optimal way. All the successes, disappointments, problems and challenges of 2010 will feed into and aid the Association's planning for 2011 and beyond.

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- Ní neart go cur le Chéile - Strength through Support -

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