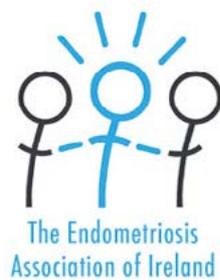


 **ANNUAL**  
**REPORT**  
THE ENDOMETRIOSIS  
ASSOCIATION OF  
 **IRELAND**  **2012**





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## INTRODUCTION

### About us

We are a non-profit and non-governmental patient organisation, striving to provide support and information for sufferers of endometriosis and to promote research into this disease. We also aim 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 major financial outlay, but 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:

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

Around 10% of women are thought to have endometriosis - approximately 100,000 women in Ireland. For every woman with endometriosis there are many more whose personal lives have also been impacted by this disease: the partners and husbands, family members, and children will all have been caught up in its often negative influence.

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.

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## 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).

We are also represented on Facebook by our official page [facebook.com/EndoIreland](https://www.facebook.com/EndoIreland) and on Twitter [http://twitter.com/endo\\_ireland](http://twitter.com/endo_ireland)

Following the 2012 AGM , the management board was:

Clodagh Lynam, Chairperson

Bébhinn NicLiam, Secretary

Shauna Whelan, Treasurer

Adrienne Egan, Director

with Special Advisor Kathleen King



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## OVERVIEW OF 2012

The association was very active during the year, but much was “behind the scenes” and actually curtailed our usual output of newsletters and organising of support meetings throughout the year.

Charities have found it very difficult since the economic crisis, and the association is no exception. We are particularly vulnerable because we are very dependent on membership fees, we do not have the fundraising clout of a larger charity. We now have a concessionary membership rate that people do avail of, but have struggled to find a way to keep members.

As an official charity, we are obliged to have a registered office address, and we also need to provide revenue with audited accounts. These are both large expenses for a low-income charity but are necessary for us to continue to exist. On top of this are the costs of providing a support service and of raising awareness of endometriosis

### Governance

The association attended the launch of the Governance Code for Charities and Voluntary Sector in June 2012. This initiative is to create more transparency in how charities operate and to bring policies and procedures up to a standard which will become the norm. We signed up for the Governance Code which is the start of a journey, looking at all aspects of how we operate as an organisation. We participate in the Governance Code peer support group in the Carmichael Centre and have had special meetings to go through check lists and identify areas in which action needs to be taken. The Governance Code will become a very important standard for all charities, big and small, in Ireland.

We also attended a seminar on Data Protection & Freedom of Information facilitated by the Bar Council Law Library, and another seminar on the Role of the Company Secretary.

We also initiated a meeting with legal advisors on updating our “Memorandum & Articles of Association” in order to bring them into compliance with current regulations. The legal firm are assisting us on a “pro bono” basis, that is, as part of their charitable outreach.

We are also glad to announce that Adrienne Egan joined the board in an official capacity as Director in 2012. Adrienne’s skill sets and experience go a long way in strengthening the abilities of the board, and will help to meet the governance and organisational challenges ahead..

## ASSOCIATION ACTIVITIES

### Support Meetings

We held a support meeting in February 2012 in Kilkenny, intending it to be the first of four over the year. Although we had positive feedback from those there, it was not very well attended despite advertising it on our website, Facebook, and a mass email to all on our notifications list.

## Flora Women's Mini Marathon

Every year the mini marathon is a great source of donations, made possible by motivated women. Often they are not even members, or even effected themselves but have seen friends or family members struggling to cope with endometriosis.

In 2012 eight women took part wearing Endometriosis Association of Ireland T-shirts, and raised over €1,000 for the association.



2012 was not a great summer but the sun shone down for the Marathoners on the day!



## 2012 Endometriosis Information Day

This important annual event organised by the association took place in the Lucan Spa Hotel on Saturday 10 March. It was well attended by women and their partners or family members, from all over Ireland. Dr. Hugh O'Connor was the keynote speaker along with Dr. Moya McMeniman a colleague of Dr Mary Wingfield. Speaking from the patient perspective were Netanya Curtis and Bébhinn NicLiam. The success of the event was helped hugely by supporters who volunteered their services, looking after registrations, ensuring the IT and audio visual equipment was all working smoothly, putting up signs and all the many jobs that have to be done on the day

Some of the volunteers went one further and afterwards joined the organising committee for the 2013 Information Day.



International Endometriosis Awareness Week 2012

# endometriosis information day

**Saturday 10 March 2pm - 5pm**  
in the Lucan Spa Hotel, Co. Dublin (N4 junction 4A)

**endometriosis treatments and research**  
Speakers include **Dr. Hugh O'Connor** and **Dr. Moya McMenamin**

the AGM of the Endometriosis Association of Ireland will take place beforehand at 1.30pm - all welcome

Further details from [www.endo.ie](http://www.endo.ie), [info@endo.ie](mailto:info@endo.ie) or 086-3203855 (messages) follow us on [facebook.com/EndoIreland](https://www.facebook.com/EndoIreland) and [twitter.com/endo\\_ireland](https://twitter.com/endo_ireland)

The Endometriosis Association of Ireland is a registered charity (C19693), registered in Ireland No. 140289  
Charitable Centre for Voluntary Groups, Carmichael House, 4 North Brunswick Street, Dublin 7

**Ni Neart go cur le Caille - Strength through Support**

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## Other activities

The Endometriosis Association of Ireland was invited by the Royal College of Surgeons Ireland (RCSI) to talk to medical students. It is really fantastic to be given the opportunity to explain to the doctors, the GPs, the gynaecologists of the future what it means to live with endometriosis.

We attended the Endometriosis Education Day in Galway, organised by Dr. Mo'iad Alazzam which included a presentations by Lone Hummelshoj of the World Endometriosis Society.



At the Royal College of Surgeons Ireland

We met with other doctors too, to see if we could establish ways of working together and if we could participate in GPs further education.

We are based at the Carmichael Centre for Voluntary Groups (CCVG) as are around 50 other charities. CCVG provides opportunities for networking with other groups, both informally and formally such as through the Governance Code peer support meetings. CCVG are a source of much of our information and knowledge on areas such as the Charities Act, strategic planning etc. and we try to participate in CCVG events as much as possible.

## INTERNATIONAL CONTACTS

### WCE Consensus Meeting

At the World Congress on Endometriosis in 2011, the Endometriosis Association of Ireland was one of 15 patient organisations who attended the Consensus Meeting. The aim of that meeting was to rigorously analyse current research and treatments of endometriosis in scientific terms. It was attended by endometriosis specialists, researchers and patient organisations. The work was not completed at that first meeting, and continued by email throughout 2012. It was a formidable piece of work, looking at treatments on the strength of available evidence to come to agreement on each, by consensus.

### International Pelvic Pain Partnership (IPPP)

The International Association of Patient Organisations (IAPO) Congress took place in London during March. As many endometriosis or pelvic pain organisations were in attendance, the opportunity was used to get together to find common ground. It was the first workshop of what was to become the International Pelvic Pain Partnership (IPPP) an informal network. The IPPP looked towards the first ever World Congress on Abdominal and Pelvic Pain (WCAPP) which was being planned for Amsterdam in 2013, and how to introduce the patient's perspective to it. After the initial workshop, the IPPP met via teleconferences, which allowed greater participation.

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## Other international contacts

The Pain Alliance Europe (PAE) was launched in November 2011. PAE was created by a number of organisations coming together, to create a stronger voice in Europe for those who have to live with chronic pain. The association attended two General Assemblies of the PAE.

The 3rd European Symposium on Societal Impact of Pain (SIP) took place in May, in Copenhagen. Workshops on different themes took place, with the results being presented to the general assembly on the final day. The association was one of the endorsing organisations, and also gave a presentation about the need for patient involvement in treatments, on behalf of Judy Birch of the Pelvic Pain Support Network, who could not attend.

The association attended the Endometriosis Conference organised by the Endometriosis Association of Iceland held in Reykjavik in September. New research on genetics was presented to the conference, and it was very interesting to meet members of the Nordic Alliance who share many of the same problems faced by Irish endometriosis patients.



**SIP workshop in May**



**The Endometriosis Conference in September**

**The PAE General Assembly in November**

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## CONTACT WITH OUR COMMUNITY

We were not able to produce any newsletters in 2012 after the one which went out in the New Year, as the board's time was concentrated on reviewing and improving governance. This was unfortunate, but unavoidable, as the association has to ensure that we are in compliance with Company Law, the new Charities Act and with the regulations of the Governance Code.

Similarly our target of 4 support meetings a year on top of the Information Day was not achievable. We held one support meeting, in Kilkenny, and a very successful Information Day.

We took a decision that our website needed to be reviewed and upgraded, and that this project needed to take priority. The current website is dated and increasingly difficult to use. It does not fulfill its potential as a real resource for both members and first time users.

It's important to remember that the association does not have any staff. All the work done is done by a small number of volunteers - who have to find time to do it, along side work and family commitments and managing their own health, hospital appointments and operations!

### Our mobile phone 086 320 3855

We have not recorded the number of personal queries by telephone, which we use as a message service. We have noticed the number of messages we need to respond to has fallen, possibly as more people have adopted social media such as Facebook. It is still an invaluable asset to the association, especially when dealing with enquiries and registrations for the Information Day etc. Credit is purchased when needed, so it is very economical.

### Postal & telephone enquiries through the Carmichael Centre

Approximately 100-150 items come to us every year through our registered address at Carmichael House. This includes personal telephone enquiries taken down by reception staff, that need to be responded to, as well as everything from invoices to membership renewals.

### Our Website [www.endo.ie](http://www.endo.ie)

In 2011 we had a total of 145,410 page views over the year. In 2012 this had dipped slightly to 131,506. The website - even as it is now - is of immense importance to the association, and to the people who are looking for support and information. It is a 24 hour a day, open every day portal. It comes up during internet searches for endometriosis and is often the first indication to women that they are not alone in dealing with this illness. We also know that many people who join our Facebook page do so because they've come across the link on our website.

Yearly Stats	
Year	Page Views
2006	 (60422)
2007	 (86919)
2008	 (129702)
2009	 (131338)
2010	 (151963)
2011	 (145410)
2012	 (131506)

### Our Email [info@endo.ie](mailto:info@endo.ie)

Email conversations peak in 2010 at 96, to 65 in 2011 and again 65 in 2012. These refer to personal queries from individuals who have been diagnosed with endometriosis or seeking a diagnosis, and can involve multiple responses over longer periods of time.

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## Our Presence on Social Media

We continued with a high level of activity on social media platforms, by posting activities, events, research and sharing information on endometriosis blogs and advice on living with a chronic illness. This has helped make the association much more visible. The majority of people and groups we interact with are based in Ireland, but it has also led to very beneficial international contacts. The endometriosis community worldwide is much more linked up than ever before, and any progress

The number of fans of **www.facebook.com/Endoireland** rose from 216 to 516 by year end. It was a big milestone getting over the 500 mark. Growth is quite slow on an official Facebook Page, (compared to personal profiles) and not helped by changes to viewing our page posts on people's newsfeeds. 516 fans meant potential exposure to the 182,066 friends of fans.

Our Facebook personal profile "Endometriosis Assoc-Ireland" was set up in parallel with our official Page, and the same items are posted. It's a good way to keep in touch with people who don't want to physically go to a Page and "like" it, and also with the many endometriosis groups and individual activists who prefer to operate using a personal profile.

The number of followers on Twitter rose from 198 to 357 by year end. **<http://twitter.com/endo-ireland>** has become a very useful way of sharing information, and is used by many medical professionals, journalists and patient organisations.

To have an effective presence on these platforms requires a regular input, and posts which are of interest to both patients and healthcare professionals. Time is involved but it also means that the association is seen to be active and contactable.

## CONCLUSION

2012 was a very challenging year for the Endometriosis Association of Ireland. It faced another year of falling membership, limited resources and increased demands. The board had to limit activities in some areas in order to concentrate on improving governance, drafting a brief for a new website, and organising our priority awareness raising event, the Endometriosis Information Day.

Although the issue of funding was not resolved it was highlighted. The association is very dependent on the goodwill of people affected by endometriosis, in terms of memberships, fund-raising through events such as the mini marathon, and the time people are willing to volunteer.

We were able to consolidate the volunteers by providing a structure, and that has strengthened the association by widening the skills and abilities it can call upon. At a time when financial resources are under great pressure, it is a very welcome sign that we are developing our very important human resources, our volunteer base.