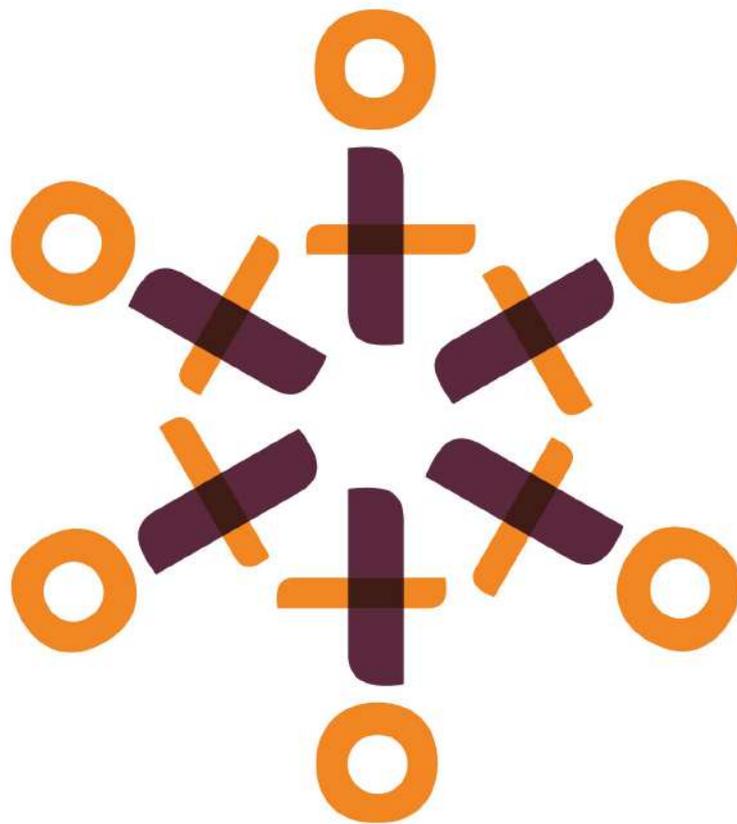


**Endometriosis
Association of Ireland**

**Annual Report
2015**



Chairperson's Foreword 2015

In 2015, we welcomed a rise in membership, an increase in social media engagement and as a result increased media awareness and activity. We held our largest information day to date, which was attended by over 120 women and their partners, families and friends. The keynote speaker of the day was Heather Guidone, Surgical Program Director at the Center for Endometriosis care in Atlanta. Heather's tireless work with both the CEC and Endometriosis Research

Center is recognised worldwide. She is a leading advocate, educator and a woman who truly empowers everyone she is in contact with. It was a privilege to welcome her to Ireland and to the EAI 2015 Information Day. Heather's talk was one of the most well received on the day, her unique mix of personal and professional experience with endometriosis brought a fresh and unique approach to this familiar subject.

January 2015, I was invited to give a talk entitled "Despicable EndoMEtriosis" to the Donegal Clinical Society alongside Dr David Hunter (Belfast). I thank Dr Matt McKernan (Chairman of the Donegal Clinical Society) for this opportunity. I believe that the discussions that followed both talks stimulated some deeper thinking and awareness of endometriosis. I urged all doctors present to consider endometriosis in young women presenting with severe pain that was interrupting their lives and to refer them where appropriate. I also gave information on the EAI and the valuable work that we do in educating and empowering women.

Endometriosis Awareness Month in March is always a busy month, and our information day this year kept up on our toes. We welcomed Heather Guidone (CEC, Atlanta), Dr John Kennedy (SIMS Dublin), Ms Aoibhinn McGreal (Pelvic Physiotherapist), Ms Shelagh Wright (Pain Management), Ms Margaret Dunne (Psychosexual Counsellor) and Mr Mo'iad Alazzam (UPMB Beacon) to give talks to our attendees. We also welcomed Zareen Ahmed from Gift Wellness to talk about her company and our own member Aisling Carroll to talk about her experience with endometriosis and how becoming a member has benefitted her. Our day was supplemented by exhibitors and practitioners to bring balance to the day.

If you did not manage to attend, the videos are available on www.endometriosis.ie/info2015

One of the strongest awareness pieces in March came from our member Noelle Carew who bravely put her story into print for the Irish Independent. Noelle's story of her journey through surgeries and fertility treatments reached women worldwide. We received messages from many women after this article and were able to provide information and support. Her article is online at <http://www.independent.ie/life/health-wellbeing/health-features/endometriosis-id-be-vomiting-and-passing-out-with-the-pain-but-doctors-said-i-was-just-attention-seeking-31034089.html>. This was followed by a piece by Patricia Scanlan who talks about endometriosis in her new book, she praised the work of the Endometriosis Association of Ireland in her piece.

Following the Information day, it was on to further awareness with 2 radio interviews - Spin Talk and 92.5 Phoenix FM Dublin. I spoke with the Spin Talk presenters live on air and gave the facts and figures for endometriosis in Ireland. They then took calls from women who were living with endometriosis. It was a very popular piece and we received positive feedback. In April, I travelled to Dublin to the 92.5 Phoenix FM studios for the Access All Areas programme. I was met by the presenters and researchers Conor and Stephen who were well read up on endometriosis. Their main disbelief was the lack of public awareness and the delay to diagnosis. We went live on air and discussed the topic, with our member Noelle Carew joining by phone to the studio. This interview was also distributed online bringing us further positive feedback and members for our online support group. September 2015, The Guardian (UK) newspaper ran an excellent series of articles on endometriosis. This brought about a flurry of activity online with many publications quoting parts of the series. This series was a great example of where good research into a topic paid off. The Guardian worked with patient advocates, charities and individuals to allow them to tell their stories. It was an excellent opportunity for the EAI to quote and share these articles and allowed us to bring more women into our online support group.

In October the awareness continued with Shawna from Sex Siopa ran an interview piece endometriosis with another member Jeanne Sutton, her blog is well written and helped us reach out to a wider audience. November was back to the airwaves with our member Lily speaking to Sean O'Rourke on RTE Radio 1 about endometriosis as part of her fertility journey. The interview focused on the impact of endometriosis on fertility and Lily's decision to use assisted reproductive techniques to enable her to conceive and carry her child. It was a moving piece as the journey was not easy, Lily now has her child and helps to raise awareness of endometriosis, the use of donors in fertility treatments, and single women choosing to conceive.

With all the activities the EAI ran in 2015 from support meetings to interviews to the information day, fundraising is an essential component of our year. We were very fortunate that we have dedicated members who renew their membership annually and those who make regular donations. The VHI Women's Mini Marathon is an important fundraiser for the EAI but unfortunately this year we had only one member take part and fundraise on our behalf. Our text number was also a convenient way for women to make a small donation and to share with friends and family. See our poster at the back of this report for more information.

2015 ended on a positive, we reflected on all the awareness, education and support we provided during the year and used this to plan for 2016 and beyond. Endometriosis still remains a little-known condition, shrouded in taboo, secrecy and shame. In Ireland, we estimate up to 155,000 women are living with endometriosis. The EAI has less than 1% of this figure as members. When we reach women through media coverage or via our social media they are delighted to find support and accurate information. The Endometriosis Association of Ireland is approaching it's 30th year in existence. It would be nice to build the membership to a level where the EAI could act on the same level as some of the bigger health charities. We know that the instance of endometriosis is similar to asthma and diabetes, yet very few people have heard of it, let alone describe its impact. With your help we can reach more women, educate more young girls and help those suffering in silence.

On behalf of the board of the Endometriosis Association of Ireland, I thank you all personally for your support. This is YOUR association, without your support the charity would not exist. We look forward to the challenges of 2016 and beyond into our 30th year.

Kathleen King

Chairperson of the EAI

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 September 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.

In 2011 following a series of strategic planning workshops we finalised our vision and mission statements.

Vision statement

All women in Ireland will have ready access to a timely diagnosis and receive appropriate treatment, care and support, enabling them to enjoy happy, fulfilled, healthy lives with their family and friends.

Mission Statement

The EAI is committed to providing support and raising awareness of endometriosis, its symptoms, effects and treatment options among women and the medical profession in Ireland. Its aim is to achieve this through education, information, facilitating research and advocacy.

Our community:

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

Traditionally, around 10% of women in their reproductive years are thought to have endometriosis - approximately 100,000 women in Ireland. However ESHRE, the European Society for Human Reproduction and Embryology, estimates that between 2 and 10% of women within the general population have endometriosis. This could mean the figure is over 155,000 women in Ireland alone.

Unfortunately, many will never receive a diagnosis, or may only find out when being investigated for unexplained infertility. 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 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 meetings and social media, 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 endometriosis community.

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 Carmichael House telephone number is 01-8735702 (messages only)

The Association has a website www.endometriosis.ie and is emailable on 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, as well as Pinterest and Google+.

Following the 2015 AGM, the Board was:

Kathleen King, Chairperson
Bébhinn NicLiam, Secretary (resigned & reelected)
Shauna Heslin, Treasurer (resigned & reelected)
Mary Heslin, Director
Charlie Barr, Director
Laura Kearns, Director

Governance

The Governance Code

The Governance Code for Community, Voluntary and Charitable organisations is an important step forward for the charity sector in Ireland. It was developed by the sector, for the sector. It is there to help us to become more effective, with good leadership and financial controls, to be open and transparent.

This voluntary Code was launched in June 2012 and we were amongst the first charities to sign up officially to the Code. We are classified as a Type B organisation, as an incorporated body, so our requirements are much more stringent despite our small size and lack of staff. As resident members, we take part in the Governance Code peer support group in the Carmichael Centre which are held quarterly. Our membership of the Wheel is also very helpful. The process is on-going and is reviewed fully every 3 years. We are on the journey to becoming compliant with the Code.

Charities Regulatory Authority

The Charities Regulator is Ireland's national statutory regulator for charitable organisations. The Charities Regulator is an independent authority and was established on the 16th of October 2014 under the Charities Act 2009. The Regulator has the power to conduct statutory investigations into any organisation believed to be non-compliant with the charities acts.

The key functions of the Regulator are to establish and maintain a public register of charitable organisations operating in Ireland and ensure their compliance with the Charities Acts.

The Endometriosis Association started the registration process with the Charities Regulatory Authority, helped by their 13 page user guide.

Memorandum & Articles of Association

Last year it was agreed that work on updating our Memorandum & Articles of Association (M&As) was to be a key focus for 2015. As so many changes were required to bring the M&A into compliance with the most recent changes in company and charity laws and regulations, we turned to A&L Goodbody to help us through this process. They were able to do this work for us on a no-fee basis. This was a major piece of work for the association.

We were able to present the updated M&As - now referred to as a Constitution - to the members of the association at the 2015 Annual General Meeting in November where it was passed. The Constitution will now be sent by A&L Goodbody on to the Revenue Commissioners and the Charity Regulator, as their approval is required before we can officially adopt it.

Strategic Planning

The 6 strategic aims developed by the board going forward into 2014 were as follows:

- Aim 1: To support all people effected by endometriosis and allied conditions, in Ireland
- Aim 2: To comply with the Governance Code
- Aim 3: To increase awareness of endometriosis and allied conditions
- Aim 4: To lobby and advocate on behalf of all those effected by endometriosis and allied conditions
- Aim 5: To secure resources to carry out the aims of the association
- Aim 6: To support research in endometriosis and allied conditions

The rebranding of the association was part of the strategic planning for 2015, to develop a logo which reflected the ethos of the association, and what we have to offer, and would stand out and work well for us across all media and materials, at different sizes. On top of that we looked for something that would also stand the test of time and not date too easily.

Financial Governance

The association's accounts are audited by McCloskey & Co., Chartered Accountants & Registered Auditor, Apex Business Centre, Blackthorn Road, Sandyford, Dublin 18.

The following is the financial summary for 2015, as approved by our Auditor:

The Endometriosis Association of Ireland				
(A Company Limited by Guarantee and not having a Share Capital)				
Detailed income and expenditure account				
for the year ended 31 December 2014				
	2015		2014	
	€	€	€	€
Income				
Memberships	2,044		1,518	
Fundraising	2,300		204	
Donations and grants	442		11,114	
		4,786		12,836
Expenditure				
Events	3,143		2,238	
Training	750		-	
Rent payable	583		618	
Insurance	197		195	
Printing, postage and stationery	100		256	
Media, social media & promotions	1,209		252	
Telephone	-		-	
Website development costs	68		990	
Meeting costs	-		361	
Audit	369		369	
Bank charges	20		-	
General expenses	249		38	
Subscriptions	25		25	
		6,713		5,342
Surplus for the year		<u>(1,927)</u>		<u>7,494</u>

Association Activities

2015 Endometriosis Information Day

The Information Day is a red letter day on the the endometriosis calender. It's our biggest annual event, where speakers, activists, experts (and that includes the endometriosis patient), members, volunteers, supportive family members and partners all come together to find out about latest treatments and research and discuss how best to manage this condition. This year it took place in the Lucan Spa Hotel on Saturday 21 March.

Ms Heather Guidone, the Surgical Program Director of the internationally reknowned Centre for Endometriosis Care flew in from Atlanta, Georgia. Heather spoke about the importance of a patient centred multi disciplinary approach to the treatment of endometriosis.



Heather Guidone, Surgical Program Director, CRC, Atlanta, USA

Mr. Mo'iad Alazzam, Endometriosis Specialist Gynaecologist at the Beacon Hospital Dublin spoke about the challenges in surgical management for endometriosis, the risks and benefits.



Dr. John Kennedy, SIMS Clinic, Dublin

Dr. John Kennedy, Obstetrician and Gynaecologist at the SIMS Clinic, gave valuable information on the ART (Assisted Reproductive Technology) journey for endometriosis patients.

Ms Shelagh Wright PhD who is the Facilitator of Pain Management & Pyscho-Oncology Education, and author of Pain Management in Nursing Practice guided the attendees through exercises to help reduce stress and break the cycle of chronic stress in the body.



Aoibhín McGreal, Clinical Specialist Physiotherapist



Margaret Dunne, PsyAchosexual Counsellor



Kathleen King, Chairperson of EAI



Mr. Mo'iad Alazzam, Beacon Hospital, Dublin



Shelagh Wright, Pain Management Specialist



The calm just before the doors open to everyone attending the 2015 Information Day

“30 years ago, the Endometriosis Association of Ireland opened its doors to provide education and support for individuals living with endometriosis as well as to raise critical awareness. Those doors remain open today, with the volunteer-based organization leading the way in disease progress; their altruistic efforts run by and for those with endometriosis and living up their motto, “strength through support.” I had the absolute privilege of joining them in Dublin for their Annual Information Day in 2015 and witnessed first-hand how dedicated the Association is to their mission – and to those with endometriosis.

I have taken part in countless endometriosis meetings and conferences over the past 25 years, but have never seen such a well-run, empowering, uplifting and edifying event as EAI’s Information Day. With a common goal of bridging gaps and making strides, speakers ranged from endometriosis specialists to psychotherapists to pain management practitioners to physiotherapists, addressing the many facets of endometriosis, its treatments and coping mechanisms. It was so gratifying - and such a true honor - to be a part of the selfless camaraderie, support, encouragement and expertise that is sometimes difficult to come by; this unique event is a must-attend for anyone who treats, cares for or lives with endometriosis.”

– Heather C. Guidone, Surgical Program Director, Center for Endometriosis Care, Atlanta, GA USA



John, Heather and Aoibhín taking questions

Ms Aoibhín McGreal, Clinical Specialist Physiotherapist introduced us to the benefits of pelvic physiotherapy.

Ms Margaret Dunne, Specialist Pyschotherapist gave her Endometriosis and Sex talk

Zareen Ahmed, CEO of Gift Wellness, told us about how her charity work and experiences led to the creation of Gift Wellness. Zareen supports women worldwide.

Aisling Carroll spoke about her own experience with endometriosis and how being a member of the association benefitted her.

Along with the speakers,



Laura making everyone welcome on the day



Aisling Carroll, spoke about her endometriosis experience



The board of the Endometriosis Association of Ireland (L-R): Laura Kearnes, Kathleen King, Mary Heslin, Bébhinn NicLiam, Shauna Heslin, Charlie Barr.



Shane and Noelle Moylan, a great EAI volunteer and ambassador

there were exhibitors and complementary health practitioners to give attendees an insight into a range of treatments and products available.

The success of the event was helped hugely by supporters who volunteered their services, ensuring everything was running smoothly, so everyone could get the most out of the day

Support Meetings

Support meetings were held in Tallaght and Letterkenny during 2015. The Support Meeting in Tallaght Library was attended by a small number of people.

The Letterkenny Support Meeting was held December, in the grounds of Letterkenny hospital. It was really well attended with 18 people who had travelled from as far as Mayo. 4 apologies were also received



Reaching out to the Medical profession

The Endometriosis Association of Ireland was invited by the Royal College of Surgeons Ireland (RCSI) to talk to medical students in May 2015. The opportunity to explain to the doctors, the GPs, the gynaecologists of the future what it means to live with endometriosis is very much appreciated.

Bébhinn spoke to a large group of students about the challenges of having a condition which is so prevalent but remains stubbornly under recognised, with the delays in diagnosis leading to years of untreated symptoms.

Kathleen gave a talk "Why the Delay?" to health care professionals in Dublin, in an event organised jointly by TCD, the Coombe Hospital for Women and St. James Hospital, based on an analysis of the information collected in the survey we conducted in 2014.



Bébhinn talking to medical students



Kathleen's talk at St. James Hospital



Annual General Meeting

The AGM took place in November 2015, in Dublin. This is an annual meeting which gives members the opportunity to put themselves forward for the board, to approve the appointment of auditors, to vote in any election or on any resolution proposed. It is important, and is a legal requirement. All are welcome, but only members can vote. We do try to encourage attendance, but it can be difficult to convince members of the importance of the AGM.

Fundraising

The association is not in receipt of a regular income, and depends entirely on membership fees, one-off grant applications, donations and fundraisers. Membership fees are the bread and butter but unfortunately do not cover our costs. We have to pay for our registered offices, audited accounts, public liability insurance and other legal requirements, before we can consider postage, printing, room hire or anything else. Fundraising, whether organised by the association or our supporters, is absolutely vital for the work of association.

VHI Women's Mini Marathon

Every year the mini marathon is a great source of donations, made possible by caring, 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 2015 just one woman took part wearing Endometriosis Association of Ireland T-shirt. She raised substantial funds for the association, but income from this event was far down compared to other years. This event needs to be utilised better in future, both as a fundraiser and for raising awareness.



Text to Donate

We set up a service with LikeCharity to enable people to donate to the association via mobile phone texts. By texting the keyword ENDO to 50300 people can donate €4. Some service providers apply VAT which means we receive a minimum of €3.26. Towards the end of 2015 LikeCharity introduced a charge for the keyword, but we decided although the cost was substantial, the service was worthwhile continuing.

Giving Tuesday

#GivingTuesday is a worldwide movement of charity "giving" on the first Tuesday of December each year. It is in its 5th year worldwide

and is brought to Ireland for the first time in 2014 by

mycharity.ie. "Giving" can obviously be financial support through a donation, but it can also be time by volunteering, support by fundraising, advocacy by promotion on social media. It is up to anyone to "give" on giving Tuesday by whatever means they desire.

#GIVING TUESDAY

Our members and followers took part by submitting "unselfie" images in support of the EAI; they were encouraged to donate time or funds to their chosen charity. It was a powerful campaign and is gaining momentum year on year. It raised the profile of the EAI.



International Activities

World Endometriosis Society (WES)

In 2015 we renewed our 3 year membership of the World Endometriosis Society . WES advances evidence-based standards and innovations for education, advocacy, clinical care, and research in endometriosis and related disorders, in collaboration with its stakeholders and global partners to improve the lives of all affected women and their families. WES organises, every third year, the World Congress on Endometriosis. We attended the WCE2011 in Montpellier, France but could not afford to travel to WCE2014 in Sao Paulo. We hope to be at the next one in 2017. WES also organises a consensus meeting alongside the Congress, to establish research priorities in endometriosis. EAI took an active role in Montpellier (the first time patient organisations were asked to join) and the subsequent work of the group afterward.

EndoWhat educational film

Film maker Sharon Cohn is making a documentary about endometriosis, aimed at the general public as well as health care professionals. The board, having seen the trailer, decided to donate €500 to the film makers in recognition of the importance the film will have as an educational resource.

Because of donation EAI will receive 25 educational licences. We started looking at suitable launch venues in 2015 for the Irish debut.



Worldwide EndoMarch

The Worldwide EndoMarch has its third outing, having been first announced in 2013. This global initiative was instigated by the Nezhath family, all doctors specialising in women's health and endometriosis in particular. The goals are:

1) Worldwide Awareness of Endometriosis We hope endometriosis becomes as recognized by the general population as is diabetes and hypertension, which will help reduce diagnostics delays.

2) Endometriosis Education in Public Schools and Universities Endometriosis is a disease of adolescence. As such, we have worked hard to recruit & train nationwide and international teams of Education Ambassadors & Community Partners, who are now establishing education programs in schools and universities across the U.S. and throughout the world, using curriculum created by our team of endometriosis experts.

3) Discovery of a non-invasive test to diagnose endometriosis

4) Research into potential preventive measures

5) Collaboration with medical schools and societies to bring advanced training to the forefront of their curriculums

6) And finally, discovery of a cure for endometriosis

In 2015 EndoMarch said "We are on our way toward making impressive changes regarding endometriosis awareness, as is evident by the recent uptick in media attention. Endometriosis affects young girls and women of all ethnicities and we are starting to hear more about the global impact of this disease. As such, we'll continue expanding globally so that there can be chapters around the world, led by passionate advocates who are dedicated to making a difference. Toward this end, we now have on board EndoMarch representatives from China, the most populous country in the world, who have held



three EndoMarch events and educational symposiums this year alone, and are in the process of planning their forth one for the 2015 year. Cyprus has also just recently joined the EndoMarch, and in the U.S.A., a steady stream of individuals, medical professionals, schools, universities, and organizations join the cause daily, so that we can all work together to bring the needed attention to this perplexing disease that has devastated so many people's lives.

Concerning collaboration with medical schools and societies, we are very excited to announce that the Society of Laparoendoscopic Surgeons (SLS), the largest, multi-disciplinary minimally invasive surgery society in the world, has for the first time ever, established a fellowship program specifically for endometriosis, to train the future generation of specialists. (Since endometriosis affects so many different organs and tissues of the body, the multi-disciplinary nature of this fellowship will really begin to make a difference)."

What makes EndoMarch special is that anyone, anywhere can take part, in whatever way they are able to. It can be as simple as wearing a yellow T-shirt, or holding up a sign. By sharing the photos online, all these individual or group actions become something so much larger. Here in Ireland, Kathleen King became the "country captain" and from the get-go put all her experience and enthusiasm into developing the EndoMarch campaign

International Pelvic Pain Partnership (IPPP)

The first ever workshop of what was to become the International Pelvic Pain Partnership (IPPP) took place in London in 2012. The IPPP is a patient alliance and meets via teleconferences, which allows greater participation from the States as well as the Netherlands, France, Spain, Britain, Iceland and Ireland. The IPPP looked towards the first ever World Congress on Abdominal and Pelvic Pain (WCAPP) which was held in Amsterdam in 2013, to see how the patient's perspective could be introduced.

The IPPP negotiated with the congress organisers to hold a workshop at WCAPP, attended by patient organisations, medics, researchers etc, where gaps in research could be identified. This led to WCAPP issuing an invitation to IPPP to address the main body of the congress, on the role patient organisations can play in helping healthcare professionals. Judy Birch of the Pelvic Pain Support Network (PPSN) and Francoise Wattel of Cystite Interstitielle France gave an excellent presentation to a packed international audience. Because of the success of the workshop and presentation, the IPPP were then invited to participate in WCAPP2015.

The IPPP is proving to be an international collaboration which is achieving real results, and leading the way in collaborative working with the medical profession

2nd World Congress on Abdominal and Pelvic Pain

The second World Congress on Abdominal & Pelvic Pain (WCAPP) was held in Nice, France and attended by our two delegates, Shauna and Mary Heslin. It was organised by Convergences in PelviPerineal Pain (Convergences PP), a federation of different French scientific societies concerned with chronic pelvic perineal pain, in collaboration with the Abdominal and Pelvic Pain (AAP) special interest group (SIG) of the International Association for the Study of Pain (IASP), the International Pelvic Pain Society (IPPS). The International Pelvic Pain Partnership (IPPP), also participated and organized a parallel patient workshop on one day of the conference, along with many French patient organizations.

The theme of the conference was to try to understand how patients can suffer often extreme levels of pain with no visible abnormalities on the basis of standard tests (clinical, bacteriological, endoscopic



imaging) or with minor lesions that are disproportionate to the symptoms and to examine how this pain can be legitimately treated with no available evidence base, in relation to interstitial cystitis/bladder pain syndrome, chronic prostatitis, endometriosis, pelvic congestion, vulvodynia, irritable bowel syndrome, proctalgia fugax, adhesions, chronic pelvic pain, pudendal nerve pain, musculoskeletal dysfunction, low back pain and the issue of central sensitisation.

Key messages that echoed throughout the conference were:

1. The need for a multidisciplinary approach;
2. Look at the whole patient, holistic approach, while at the same time phenotyping;
3. The need for personalized treatment, as every patient is different;
4. The aim of treatment is to improve quality of life for the patient.



top: participants from the Patient Open Day at WCAPP, our delegates Shauna (left) and Mary (right), below presentations at the congress:

A key question heard throughout this meeting was: why do a few patients have only one pain syndrome, while other may have multiple pain disorders? What makes these patients different?

Patient workshop

A workshop was held for patients all day on Friday 12 June on the theme of patient and professional perspectives of chronic pelvic pain. The aim was to facilitate discussion between chronic pelvic pain patients and support groups representatives and health professionals specialising in chronic pelvic pain. The main focus of this year's workshop was to explore outcomes for chronic pelvic pain in treatment and self-management, but also for research. The day concluded with two presentations on standardisation and classification of chronic pelvic pain, emphasising how important it is for patient advocates and support groups to get involved in standardisation and guideline committees and all decision-making in the field of terminology, definitions and criteria..

(NB Key notes of Congress taken from Review written by Jane Meijlink, used with grateful thanks)

Other international contacts

The association is a member of the Pain Alliance Europe (PAE) since the launch 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

PAE wants Chronic Pain recognised as a disease, to raise awareness of Chronic Pain, to educate - Chronic Pain education should be part of basic training in medical schools, and to stimulate Research & Data Collection. You can read more about this on www.pae-eu.eu

We also highlighted the ISAL Day Against Pain which took place in October.

Contact with our community

Our membership numbers are still relatively low. In 2015 we had a total of 90 members, This compares to 86 (2014), 41 (2013), 39 (2012), 52 (2011), and 73 (2010) The membership fees are crucial to the continuing existence of the association, in helping us meet our legal obligations such as the cost of a registered office, auditing of annual accounts, insurance etc. It also helps fund our website which is the way people find us, and get the information they very much need. The association would like to have 1,000 members in order to become a robust, proactive, thriving organisation.

We held 2 support meetings during the year, in Tallaght and Letterkenny. The Endometriosis Information Day was attended by approximately 90? people..

It's important to remember that the association does not have any staff. All tasks take much longer as a result because we rely entirely on passionate volunteers who donate their spare time, knowledge and skills to the association.

Media coverage

The well known author Patricia Scanlon was featured during March in the Irish Independent, with an excellent article on the impact endometriosis has had on her.

In August the Irish Times ran a piece featuring Lisa Diamond, giving a first hand account of what living with endometriosis was like for her.

The Guardian newspaper, a British publication, made endometriosis a major theme in September with a huge online impact.

July saw Kathleen and Noelle raising awareness of Endometriosis on Access All Areas on 92.5 Phoenix FM Podcast, great interview and a fantastic team on Access all Areas.

Spin Talk covered Endometriosis on Tuesday 18 August, Kathleen gave another great interview and it was followed up with our members giving their experiences. The discussion was well received and emails followed.

My hormones won the battle for my ovaries, but I won the war against endometriosis

A disease that was once dismissed by doctors as simple period pain can affect up to 10 per cent of women

It's told by doctors: It's osomatic have a low old of pai a baby et

and we'll get to the bottom of it. The doctor said, and that was what kept me going. He didn't think I was imagining this illness, whatever it was. And so the tests for conditions continued. The excruciating pain of infertile, and the possibility of a well, one is about a as, as his new from his body isn't really and is a former adware with Lisa A. Love

the guardian

home UK world politics sport all

headlines

Endometriosis: the hidden suffering of millions of women revealed

20 things every woman (and every doctor) should know

The pain is paralysing 30 women describe living with endometriosis

A visual guide What is endometriosis?

Postal & telephone enquiries through the Carmichael Centre

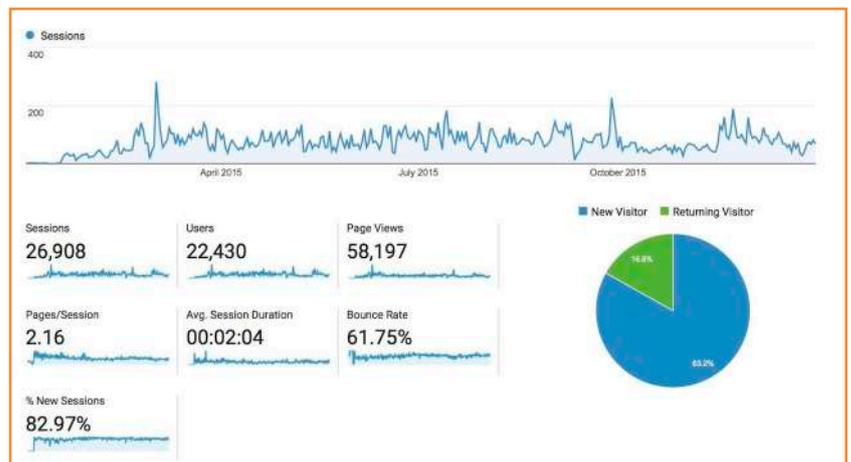
Approximately 100-150 items come to us every year through our registered address at Carmichael House. This includes personal telephone enquiries taken down by reception staff, that need to be responded to, as well as everything from invoices to membership renewals.

Our website www.endometriosis.ie

Over the course of 2015 we had 58,187 page views and 22,430 users. In 2014 we had 28,500 pageviews of our new website, which was still in the process of having information added. On our old www.endo.ie website we recorded 681,682 page views in 2013, which was an unexplainable one-off. Putting this into context we had a total of 145,410 page views over the 2011 and in 2012 this had dipped slightly to 131,506.

The website 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 pelvic pain, 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.

The information given is accurate, up to date and peer reviewed, important in an environment where false information and myths still hold sway. Our information is based on the ESHRE (European Society of Human Reproduction & Embryology) latest publication.



Our Email info@endo.ie

We had an unprecedented 190 personal email enquiries in 2015. This is a huge increase, and while we welcome every opportunity to inform and support women, it is also a huge pressure on our team.

We received 56 personal emails in 2014, 83 in 2013, 65 in 2012, 65 in 2011 and 96 in 2010. 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.

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 developments are quickly shared.

Facebook

The number of fans of www.facebook.com/Endoireland rose from 1,585 to 2,635 'likes' for our page. We only had 516 at the start of 2013, and it had taken a lot of effort to reach the 500 milestone. The strategy of linking up with reputable endometriosis organisations worldwide and ensuring all information put out was accurate and up to date was proving correct. The majority of 'likes' are from Ireland, with many also in the USA and UK.

In line with the publicity we generate in March during international Endometriosis Awareness month, there is a peak in new 'likes' in March.

The 'reach' of our posts shows how many people can be reached, through sharing etc. In July 2015 this peaked to a total of just under 9,000 people.

Secret Facebook Support Group

In contrast to our public page on Facebook, we also host a Secret Support Group. This is a group which is not visible to the outside world and cannot be searched for, and so maintaining confidentiality and ensuring a safe environment for women taking part. Group members are added only after they send a joining request to info@endo.ie. It is a growing community of mutual support, monitored to ensure respect, compassion and accuracy of information. There is another closed group on Facebook called "Endoireland" which, confusingly, is not connected to the association but is run by concerned individuals.

Twitter: @endo_ireland

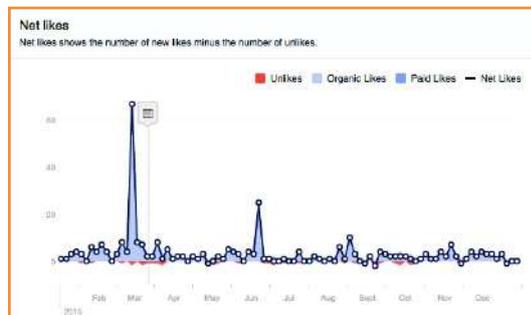
By the end of 2015 we had a cumulative total of 5,251 tweets and 1,395 followers on our <http://twitter.com/endo-ireland> twitter account.

Twitter impressions (the equivalent of Facebook 'reach') varied between 9,000 and 57,000 people in March. Some statistics, such as 'mentions' only started being counted in August. We were recorded as receiving 7 to 28 @endo_ireland mentions each month

Twitter remains a very useful way of sharing information, and is used by many medical professionals, journalists and patient organisations.

We set up pages on Google+, Pinterest, LinkedIn and YouTube to increase our possibilities of interacting with a much wider endometriosis community, including professionals.

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

2015 was another very challenging year for the Endometriosis Association of Ireland. There is always a fine balance between organising activities and ensuring enough time is devoted to governance issues. We were helped by a small number of volunteers coming to the aid of the board, by fundraising, helping out at the Information Day or taking part in radio interviews.

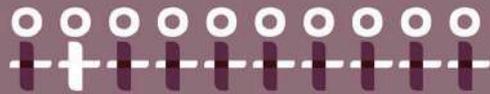
Although the issue of long term funding was not resolved it was highlighted. The association spent more money in 2015 than it took in as income, which is not sustainable. Memberships are vital to the stability of the association, and the issue of non-renewals has come up again. A lot of energy is put into recruiting new members every year, and we need to find out why existing members (beyond a small core of very dedicated people) are not continuing their support. The new website may hold the key in helping members in renewing their annual membership, if it's a matter of convenience.

The association is very dependent on the goodwill of people effected by endometriosis, and we owe it to the 155,000 plus women in Ireland with endometriosis - whether diagnosed or not - to make sure that awareness is out there, along with access to accurate information and timely, appropriate treatment.

A big thank you to all our members, volunteers and supporters!

**Text ENDO
to 50300**
to donate €4 to the
Endometriosis
Association of Ireland

100% of text cost goes to the Endometriosis Association of Ireland across most network providers. Some providers apply VAT which means that a minimum of €3.26 will go to the Endometriosis Association of Ireland.
Service Provider: LIKECHARITY.
Helpline: 01 4433890



for more info:
www.endometriosis.ie   