Endometriosis & Immunity

Endometriosis UK
Spring 2013
Welcome to the first issue of 2013

In this edition we will be exploring the impacts of areas associated with endometriosis, from conditions that are similar to the wider impacts of having endometriosis. We hope that through this Endolink we can help to shed some light on a lesser known area of research into the condition, additional ways that may help to manage your symptoms and a lot of interesting information about what else is happening at the organisation.

Goodbyes

This issue also sees the team at Endometriosis UK saying a sad farewell to Liz Rickarby, our Support Network Manager. Liz was with the organisation for a year and a half and has been an incredible asset to Endometriosis UK.

We would like to say a huge thank you to her on behalf of the team and all the volunteers that she supported throughout her time at the charity. We also wish her the best of luck in all of her future endeavours.

A big thank you must also go to Joyce Amoah who worked at Endometriosis UK as Support Network Intern to help review the support services we offer. Her work was invaluable and we want to thank her for it. For more information on what she achieved please see page 13.

Awareness Week

Endometriosis is a condition that affects over 1.5 million women in the UK. With this in mind we wanted to make sure that as many people as possible were made aware of endometriosis and how it affects women, their families and their friends.

For more information on all the events that took place throughout Awareness Week including: local events run in Belfast, Guildford, Leeds, Edinburgh and many more; our two live online Q&A sessions where women were able to put their questions directly to endometriosis experts; and our EndoGallery, please visit our website – http://endometriosis-uk.org – or our new Facebook page – www.facebook.com/endometriosis.uk.org – or follow us on twitter @EndometriosisUK.

All the best,

Patrick Hinton

Words from the CEO

2013 is shaping up to be an exciting time for Endometriosis UK. With funding secured from the Dept. of Health through the HSCVF and the changes in the NHS, everyone at Endometriosis UK is working hard to try and improve the lives of women with endometriosis.

My own time has recently been spent (as noted below) in compiling responses to the Patients Association consultation on the NHS Constitution. We are also responding to the NHS Consultation on the treatment of severe endometriosis and attended the Unison Women’s Conference in February.

Additionally, we had the chance to add our voices to those of other small medical charities when the impact of the implementation of Clinical Commissioning Groups and the local commissioning of services was discussed at an NHS Joint Learning event. A future Endolink will pull these strands together and focus on the changes to the NHS structure and what this will mean to endometriosis patients.

I look forward to continuing to represent your views through similar opportunities in the future and I hope that together we will be able to make a significant difference.

Helen North
Endometriosis UK wins HSCVF grant

In November 2012 Endometriosis UK were awarded one of thirteen grants from the Health & Social Care Volunteer Fund (on behalf of the Department of Health). This grant, of up to £100,000, will be used to help increase the support services that we offer. We are also really excited that endometriosis has been recognised by the Department of Health as a condition that deserves this grant.

For more information on the proposed improvements to the support services Endometriosis UK offer, what it could all mean for you and how we intend to implement it over the next 15 months please turn to page 10.

Research

Although we are not in a position to fund our own research, we have been able to assist on a number of exciting projects that are aimed at improving the lives of endometriosis sufferers. Our primary role has been to connect researchers with the large group of sufferers we support, giving a vital insight into the lives of those who live with this condition.

We would like to say thank you to all of those who assisted by volunteering for these projects and improving the quality of the data collected.

We hope that over the next year we will be able to bring you the results from some of this research as well as use them to improve the information and support that we provide. We also hope to bring you news of many more research programmes and activities that you can become involved in.

Changes in the NHS

The NHS Constitution, which outlines what staff, patients and the public can expect from the National Health Service, is being reviewed. Following the release of this document we are working hard to make sure that all those who are affected by endometriosis have their needs represented as effectively as possible.

CEO Helen North has attended the House of Commons and given our findings to an APPG (All Party Parliamentary Group) to make sure that your voice is being heard across the NHS. The APPG is expected to release a report on their findings in May 2013. They hope that this can be used to positively influence the NHS constitution.

Thank you

Endometriosis UK would like to say a huge thank you to Antonia Boynton whose very generous donation to the charity will make a significant difference to our work over the next year. Antonia is a long term supporter of the organisation and is looking to set up an informal support group in Salisbury. If you are interested in attending please contact us.
Endometriosis & autoimmune diseases

In this section we will discuss the possible links between Endometriosis and autoimmune diseases. We will take a look at the medical reasoning and research behind why there is believed to be a connection and then explore the experience of a woman affected by endometriosis using antihistamines, that are often used to treat autoimmune diseases.

Endometriosis UK would like to thank Dr Haider Jan at the Royal Surrey County Hospital in Guildford for contributing to this article and to this edition of Endolink.

Introduction

The function of the immune system is to distinguish our body’s own cells with that of foreign agents like bacteria in an effort to fight them off and keep us free from disease. This is an extremely precise and balanced process and, when it goes wrong, can lead to our immune system thinking that our normal cells are foreign and destroying them. Diseases such as these are termed “autoimmune” and they include thyroid disease, rheumatoid arthritis and multiple sclerosis.

Endometriosis is seven times more likely to be found in relatives of affected individuals than in non-relatives. There is a particular association with chromosome numbers 7 and 10 but the specific genes have yet to be isolated.

In this article, we will explore the immune changes in endometriosis. To see whether it can be related to any of these conditions whilst possibly revealing new areas of research.

Does endometriosis fulfil the criteria of an autoimmune disease?

The presence of endometriosis in the body activates certain white blood cells known as B cells, which are used by the body to fight infections like endometriosis. However, in women with endometriosis B and T cells, also important in fighting diseases, may show some immunological abnormalities. These cells may be less effective in fighting the disease. In many ways, therefore, endometriosis behaves very much like an autoimmune disease because:

- There are increases in the number of cells that spontaneously destroy themselves with widespread tissue damage and multiple organ involvement.
- Women with relatives who suffer from endometriosis are more likely to have the condition.
- Sufferers of endometriosis have an increased likelihood of other autoimmune diseases.

Are there any specific antibodies related to endometriosis?

Antibodies are Y shaped proteins that are produced by B cells to neutralise invaders of the body such as bacteria and viruses. Occasionally, the body will fail to recognise cells as its own. The body may begin to produce auto-antibodies, which will start to attack its own cells. Research has found an increase in the number of...
auto-antibodies in women with endometriosis. There are a wide variety of auto-antibodies. There are specific auto-antibodies that work against the ovaries and any endometrium detected. One in particular, Anti-laminin-1 Abs, may be important in the development of pregnancy failures through its effect on events during early stages of pregnancy. It may affect:

- The implantation of early pregnancies
- The development of the placenta vessels
- The flow of nutrients

In future research, measurement of IgG anti-laminin-1 antibodies might be a useful marker for diagnosing reproductive failure.

Do the antibody levels predict disease and can they be used for monitoring?

Unfortunately, there is no correlation between endometrial antibody levels and the severity of endometriosis, or with the phase of a woman’s menstrual cycle. This means that it cannot be used to predict disease or monitor the effects of treatment. The simultaneous finding of antibodies in different parts of the body such as the ovary and some proteins in the nucleus gives credibility to the concept of endometriosis being a multiple antibody autoimmune condition.

What other diseases are associated with endometriosis?

There are several other autoimmune diseases that have been shown to have some association with endometriosis. Compared with published rates in the USA female population, one survey found women with endometriosis had higher rates of hypothyroidism, fibromyalgia, chronic fatigue syndrome, rheumatoid arthritis, systemic lupus erythematosus (SLE), Sjogrens syndrome and multiple sclerosis, but not diabetes.

Allergies and asthma were more common among women with endometriosis alone and highest in those with fibromyalgia or chronic fatigue syndrome. However, this has not been replicated in other studies and surveys tend to overestimate disease because of biases. The strongest association, with the most medical literature behind it, appears to be with inflammatory bowel diseases. One recent study of tens of thousands of women followed up for a combination of hundreds of thousands of years found a significantly increased risk of inflammatory bowel disease.

Can we treat it as an autoimmune disease?

Currently, the only medical therapies used in the treatment of endometriosis, apart from painkillers, involve the use of hormones or hormone manipulation. These include oestrogens, progesterones, danazol or gonadotropin-releasing hormone agonists. These medications shut down a woman’s hormones altogether, inducing a temporary menopause.

In the future, with further understanding, the immunology of endometriosis may help in developing non-hormonal medication. The ideal would be something that could inhibit the development of endometriosis and alleviate pain or infertility, without interfering with ovulation and menstruation. We hope that this avenue will be further investigated in years to come.
Personal Story: Elissa Bradley, age 27

“I was diagnosed as having endometriosis of the bladder and bowel in early 2011 shortly after my 25th birthday. This followed 11 years of false diagnoses, exploratory surgeries, painful and problem inducing treatments, and numerous specialist opinions, in both the UK and abroad. My diagnosis of endometriosis came about by, what some would probably call, a near death experience, but to me it proved to be life saving…

Following a ‘simple cystectomy’ - in a desperate attempt to rid me of an unidentified ‘burning’ pelvic and urethra pain and bloody urine - I found myself being rushed back to hospital with a ruptured bowel and life threatening peritonitis. During a long and complicated emergency operation I suffered a severe anaphylaxis shock and a cardiac arrest whilst open on the operating table – quick thinking and determined action from one particular doctor, Daniel, saved my life.

“Ironically, in a bid to protect me, my body’s natural defences were almost killing me.”

The surgeons and doctors couldn’t figure out why my body had gone into such a severe and life-threatening anaphylaxis;
anaphylaxis shock is an immediate high allergic response to something foreign introduced into the body. However, no drugs had been introduced into my system at the time of the arrest other than an antibiotic medication.

I was sent to an Immunology Specialist who after much confusion discovered that my body gave a high allergic response without a ‘true allergy’ being present. My body was firing high levels of histamine at non-threatening things such as water or saline solution. My body was producing a false allergic reaction in every case. It is suspected, therefore, that my endometriosis was caused by histamine receptors creating an internal ‘war zone’. Ironically, in a bid to protect me, my body’s natural defences were almost killing me.

Endometriosis is a disorder of both the reproductive and localised immune system; however the latter is often overlooked or dangerously eradicated from brief definitions of the condition. Various medications were and are still used to stop the condition worsening. The miracle for me, however, came in the simple form of a daily 10mg dose of anti-histamines. With this the intense ‘burning’ pain inside my pelvis and urethra area began to fade for the first time. I had been pain free for nearly two years until one month ago when the pain returned and left me with limited physical ability once more. When I was asked to write this article I was reminded of the great role my anti-histamines play in the control of my condition, so I doubled my dose of antihistamines for three days and the ‘burning’ pain was relieved once more, which is lucky as I have recently become a foster carer to two very demanding, but more than wonderful young girls!”

Although in Elissa’s case the use of antihistamines had a positive effect on her ability to cope with her endometriosis we have had reports of those who have experienced negative effects when using such medication.

Endometriosis UK does not advise self-medication and we always suggest you talk to your doctor or a medical professional before taking medication.
Psychosocial Impacts of Endometriosis

There has been, over the past 10 years, research into the impacts of the broader psychological and social (psychosocial) impacts of endometriosis on a woman’s life. Eleni Bourantani, who is affected by endometriosis, has researched endometriosis in an effort to understand what is happening to her. She has reviewed relevant scientific articles and collated their findings. The following is an extract from her full paper, which can be read online at http://endometriosis-uk.org/downloads/psychosocialarticle.pdf

Although this article may not give answers to the problems that it raises we know that there are a number of women interested in finding out more about the impacts of endometriosis. If you would like more information on ways of coping with the issues discussed then please visit the Endometriosis UK website. It is full of information and ways of getting the right support, including a list of help lines that can offer you support.

Psychological impacts

Endometriosis patients appear to be more introverted than other women and they present with depressive and anxiety symptoms. However, it is unclear whether endometriosis is the cause of these symptoms because of the stress and reduced quality of life of patients; or whether it may in fact be the result of psychological distress because stress disorders affect the immune system and make the patient more vulnerable to inflammatory diseases.

It also appears that:

- Women who develop endometriosis are apparently naturally anxious and thus may be more vulnerable to developing endometriosis inflammation.
- The low quality of life of endometriosis patients leads to further inflammation, thus perpetuating a vicious circle.

There is a general impression that depression is a symptom of endometriosis, but this has not been confirmed empirically. Although depressive symptoms may appear, clinical depression is rare. Women who find rational ways to cope with endometriosis handle its psychological impact better and manage to regain control over their social lives.

Beliefs about pain and the ways of coping appear to be a very integral part of the experience of pain and its emotional scarring. The interval between first symptoms and diagnosis should also be evaluated because the delay in diagnosis is very important to the patient’s emotional wellbeing.

Social Impacts: Relationships and sexual life

Dyspareunia (pain experienced before, during or after intercourse) affects 5% to 15% of women of reproductive age. Women with endometriosis
seem to suffer more from it. Endometriosis is often a cause of deep dyspareunia (within the pelvis), though women with endometriosis can experience superficial dyspareunia as well. It has been shown that after laparoscopy deep dyspareunia pain recedes and the quality of sex life improves.

Dyspareunia can be a cause of emotional distress and lead most women to limit sexual activity, and fewer to cease it, resulting in low self-esteem and problems with partners. Some women do continue sexual relations despite the pain because of a desire for pregnancy, while others find coping strategies to reduce pain.

From a male partner’s perspective, much like female patients, they have emotional responses to endometriosis akin to the stages of grieving, thus affecting their quality of life. Men and women whose relationships lasted through living with endometriosis claimed that they grew stronger than before, improving trust and communication. Women were admired for their courage and were viewed as strong, instead of dependent on the care of their partners.

**Work and Education**

Endometriosis can affect work performance, making full-time employment or education difficult. It can render a small percentage completely unable to work. Additionally abandoning work can cause feelings of guilt and may intensify the emotional burden of the patient. The main reason for absenteeism is pain, but medication side effects also have negative effects on work performance and increase absences.

Some bosses understand when explained to, but others might be reluctant to help, resulting in women even losing jobs. Many women do not disclose their problem, as their claims can be demeaned as women’s problems because of their gender-specific nature. From the employer’s perspective, endometriosis affects productivity and should be taken seriously. Good pain management, supportive employers, partners, family and GPs, as well as more flexible work arrangements can help a lot.

Women may find coping strategies, such as arranging periods so that they occur at weekends, but most often they suffer in silence while working. Being self-employed at home can be a quite flexible option, but not working means losing money. Information about endometriosis and self-management strategies (such as nutrition) may help patients regain control over their social and work lives, even if it means constant attention to their health habits.

*Many thanks to Eleni for producing this article. For the full version, including all the research papers that she references, please visit our website. If you would like to find out more about the issues discussed in this article then please visit the publications section of the website where there are a number of leaflets that can be downloaded.*
Endometriosis Awareness Week 2013

Awareness Week took place from the 4th to the 10th of March 2013 and the message was simple...

Endometriosis is a horrible condition that affects more than 1.5 million girls and women across the UK. This works out at nearly one in ten women of childbearing age. For many, it has a massive impact on their life and is something that can make every day difficult. People need to know about this impact and the only way that is going to happen is if people feel able to talk about how endometriosis affects them. Although, at times, this is hard, it is a vital step in helping to bring endometriosis, and what it means to you, into the public eye.

Throughout Awareness Week, under the strapline ‘Don’t take it lying down’, there were a number of exciting events organised by Endometriosis UK and our amazing volunteers:

- Our EndoGallery was designed to tell the world how endometriosis can affect you through words and photos. It was also a great opportunity to see that those affected by endometriosis are not alone. With hundreds of responses from women across the country it was a great chance to share experiences of endometriosis. To see the gallery go to http://endometriosis-uk.org/getinvolved/campaigning/awareness/endogallery.html

- Our Live Q & A sessions were an opportunity for women to put their questions directly to experts on both the medical aspects of the condition and ways of coping with it. To see the full transcripts of these sessions please go to http://endometriosis-uk.org/liveqanda

We would also like to thank everyone who ran events to support our Endometriosis Awareness Week. Connecting with people in local communities makes a huge difference to those who may be suffering in silence and don’t know where to turn.

Local events including a ‘wear red to work’ day in Oxford, running an information stand at the Royal Cornwall Hospital, art in Bradford (and a £1000 grant from the Mayor!), balloons in Belfast & Swansea, spreading the word via facebook and twitter and lots more.
Endometriosis Awareness Week 2013 took place from the 4th to the 10th of March 2013 and the message was simple... Endometriosis is a horrible condition that affects more than 1.5 million girls and women across the UK. This works out at nearly one in ten women of childbearing age. For many, it has a massive impact on their life and is something that can make every day difficult. People need to know about this impact and the only way that is going to happen is if people feel able to talk about how endometriosis affects them. Although, at times, this is hard, it is a vital step in helping to bring endometriosis, and what it means to you, into the public eye.

HSCVF Project

Volunteers for health and social care charities around the country have been boosted following the announcement by Care and Support Minister, Norman Lamb MP, of grants worth a total of £5.4 million.

The Health and Social Care Volunteering Fund grant will be used by Endometriosis UK over 15 months to develop a comprehensive support network delivered by volunteers focusing on locations in the south and south-east of England. The project will work with existing NHS services to enhance the information and support available to women and their families in these areas, and work to increase awareness of endometriosis.

Trevor Dahl, Chair of Endometriosis UK, said:

“This grant by the Health and Social Care Volunteering Fund gives a massive fillip to all involved at Endometriosis UK and will enable us to develop new and innovative ways of working with relevant organisations through our wonderful volunteers, many of whom suffer from this debilitating and often unpublicised condition.”

It is anticipated that the project will also aid healthcare providers to be able to respond to the needs of women in their community more effectively. Experience from this project will result in a model of good practice in volunteering and health promotion of endometriosis that can be replicated in other regions.
Support Network

Although we are very sad to see Liz leave, we wanted to take this opportunity to reassure all our members that we are still working incredibly hard to continue providing the excellent levels of support, information and guidance that those suffering from endometriosis have come to expect from us.

We are delighted to announce the appointment of Emma Bray as the Support Network Manager. Emma has previously been a fantastic Local Group Leader in London and Reading and we are sure she will be an asset to the team.

Following the award of the HSCVF grant we are also pleased to announce the appointment of Lynne Kuschel as Regional Volunteer Development Officer. In this role, Lynne will work closely with Emma to help recruit and train a number of local volunteers across the south and south-east.

New volunteers

We would like to welcome all of our new volunteers to the team here at Endometriosis UK. In October 2012 we had a great training day in London which they all attended and are now trained to work on our helpline, run a local group or support you online. We wish them the best of luck with their volunteering endeavours with Endometriosis UK.
Virtual Support Groups

Over the last year we have been running a number of support groups online, designed to provide support for women who have difficulty in accessing a locally run group. We believe that these are an excellent addition to our support services.

Much like a locally run support group, they are a place where women can talk about how endometriosis affects them, create a community and hopefully realise that there are others they can talk to. The Virtual Support Group covers a range of different topics associated with endometriosis and are held every one to two months. If you are interested in attending one of these sessions please visit our website for the dates and times of the next group meetings.

Helpline & Group Feedback

Once again we would all like to say a big thank you to Joyce Amoah. Without her help we would not have been able to undertake the evaluation assessment of the Helpline and Local Support groups that we offer. This was done to ensure that these services meet the needs of those who are affected by endometriosis. We have undertaken this survey, of those who have used our support services over the last year, in order to improve what we offer in the future.

In the near future we hope to share the results of this assessment and our proposal to address any issue that may have arisen from it with you.
Fundraising

Last year was a great success for the many fundraisers who got involved with our work. The previous edition of Endolink highlighted how your ongoing involvement is fundamental in ensuring that we are able to deliver our services across the UK.

2013 is set to be a very exciting year; we have 12 fabulous runners taking part in the British 10K and five extraordinary individuals participating in the Brighton Marathon. We have finalised the details of our forthcoming adventure to the Brecon Beacons. To find out more about Pink Pants 2013 please contact us today!

In this edition we wanted to introduce some of our fundraisers who are getting involved to support their patients and partners.

Meet Ertan...
Ertan is a Medical Trustee, head of our Medical Advisory Panel and in the final stages of preparation for the London Marathon in April. We met him on a frosty morning in Regent’s Park to find out about his motivations for running the marathon and how the all important training was going.

“In my daily practice I see women with endometriosis regularly and I would like to help Endometriosis UK to continue to support them.

A typical training day for me on a Sunday, for example, starts at eight o’clock; we go running for one to one and a half hours. When it’s pouring down with rain it makes it difficult to train over the weekends...I think perseverance is important, if you want to do something you have to work towards it. I feel healthier and fitter, the prospect of running the marathon is an exciting idea!”

Ertan’s fundraising target is £2500. You can sponsor him at http://uk.virginmoneygiving.com/ertansaridogan

Meet Edward...
“Last year I met a very special person, it so happens she has endometriosis. That encounter sparked the idea of running this year’s London Marathon for a related charity. I made a promise to fundraise for Endo UK after attending the information day last year.”

Eddy’s fundraising target is £500, and you can contribute at: justgiving.com/marathonmaneddy

The first ever London Marathon took place on 29 March 1981 when over 7,000 keen athletes took to the streets of London. Today, it is one of the most well known marathons in the world, renowned for its flat and fast route and charitable nature. Over 880,000 people have completed the course and more than 37,000 runners finished in 2012. We can’t wait to see Ertan and Edward cross the finish line on 21 April 2013.

Email fundraising@endometriosis-uk.org for a Supporters Pack if you would like to cheer on Ertan and Edward on the day.
We want to extend a tremendous thank you, to everyone who ran, walked, swam, climbed and jumped to support us in 2012. We know that for many of you fundraising represents a great personal achievement as well as an opportunity to get involved with the work that we do, this makes your successes all the more impressive.

Would you like to hold your own event to support us?

We have lots of information available to help you organise your own fundraising event. Contact us on fundraising@endometriosis-uk.org if you have any ideas or would like to talk about getting involved with the Pink Pants Challenges in 2013.

We are finalising some exciting new web pages where you can find out all about our current fundraisers. Keep an eye on our home page for more information about this and revised fundraising essentials factsheets, which provide invaluable information to help you on your way to fundraising success.

Thank you to everyone who pulled out all the stops to organise their own event, including...

- Hannah and the Belfast Support Group who organised a sponsored walk
- Amy who organised a music festival
- Kirsten and Katie who organised a film night at their university
- Kelly who held lots of fun family events throughout 2012
- Sara, Hannah and the Cornwall Support Group who held a wonderful fete
- Wendy who encouraged friends and family to donate instead of purchasing presents for her birthday
- Anna who organised a charity party
- Melissa who designed and sold awareness bracelets
- Michelle and Ruta who held a delicious fundraising lunch at work

Jon’s fundraising target is £1000, and you can contribute at: http://uk.virginmoneygiving.com/jonnyrae

Meet Jon...

Jon is the husband of one of our wonderful Support Network Group Leader, Anna. He is a really keen cyclist and when we secured a place in the prestigious Ride London 100 event he could not wait to get involved. Motivated by his wife’s wonderful successes running a local support group and her battle with endometriosis, Jon is keen to raise as much money as possible to support the work that we do.

“I am more nervous about the fundraising than I am about the event! I hope I can do Anna and all of Endometriosis UK’s members proud by raising lots of money. By August 2013 I will be in peak condition through racing and training and I’m really looking forward to the physical challenge as well as the fundraising opportunity that Ride London 100 represents”
There’s a support group near you...

**England (Midlands)**
- South Staffordshire
- Coventry & Warwickshire

**England (South-East)**
- East Berkshire
- Guildford
- North Surrey
- Southampton
- Sussex Coast

**England (South-West)**
- Bournemouth
- Bristol
- Cornwall
- Reading
- Taunton & Bridgwater

**England (East)**
- Hertfordshire
- Norwich

**London**
- Central London
- Enfield
- South London
- South-East London
- South-West London

**England (North)**
- Bootle
- Bradford, Leeds & Skipton
- Manchester
- Sheffield
- Teesside & Durham
- Warrington
- Widnes

**Northern Ireland**
- Belfast
- Londonderry / Derry

**Scotland**
- Lanarkshire
- Edinburgh
- Glasgow

**Wales**
- Cardiff/South Wales
- Oswestry/Wrexham

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**Endometriosis UK Helpline: 0808 808 2227**
(Opening times vary: please check the website or listen to the recorded message)