



topic



The Ectopic
Pregnancy Trust

Information

Education

Support

A warm welcome to our new Trustees, Professor Tom Bourne and Kevin Walker

Tom Bourne has given valuable assistance to the Trust for many years as a medical advisor and we are delighted that he is now giving us further support as a Trustee. He has recently been instrumental in establishing our very successful education programme where his knowledge and specific expertise in the field of early pregnancy and its complications have been of immense value.

“A well respected specialist, Tom works principally at Queen Charlottes and Chelsea Hospital, Imperial College, London . He also works at the Katholieke University in Leuven, Belgium. He has edited six books, published over 150 papers in international journals and is a Board member of the Association of Early Pregnancy Units, the International Society for Ultrasound in Obstetrics and Gynaecology and is on the steering committee of the International Pregnancy

of Unknown Location Analysis trials. He has a wealth of experience in the use of ultrasound in gynaecology and early pregnancy. His current research interests include the management of early pregnancy complications, implantation and early pregnancy embryonic growth.”

Kevin Walker is founder and owner/director of Camille Lingerie and his appointment as Trustee will bring valuable business expertise to the Trust. In only ten years, Kevin has built up a highly successful enterprise developing the Camille brand with quality and value for money as the goal of the company. The business has grown impressively and currently operates 19 stores throughout the UK and the Republic of Ireland, together with approximately 75 concession outlets and a strong Internet presence.

We look forward to the benefits we will gain from Kevin’s business acumen and strategic thinking.



Tom Bourne



Kevin Walker

Mumsnet leads to meeting at Department of Health

Contributions and chat on the social networking site, Mumsnet, have highlighted the inadequacies which are often experienced by women in early pregnancy despite the many guidelines currently in place. This has led to demands that the Department of Health implements a new Early Pregnancy Code of Practice.

In response, the DoH set up a meeting in February which I attended together with representatives of the DoH and various user groups, such as the Miscarriage Association, the Stillbirth and Neonatal Death charity (Sands) and the Association of Early Pregnancy Units. Chaired by Dame Christine Beasley, the Department’s Chief Nursing Officer, the services provided during early pregnancy care were reviewed and various suggestions discussed. These included better communication and information

systems, shorter waiting times, improved access to scanning facilities and better staff training in the psychological effects of early pregnancy loss. It was agreed that these simple changes would make a massive difference to those experiencing the trauma that early pregnancy loss brings.

It became clear from the meeting that the guidelines need to be stronger and better implemented and, as a result, the DoH has given a firm commitment to change.

We see this as a very positive step forward while also demonstrating how the voices of ordinary women using a social networking site can make a very real difference in leading to improved services. We will keep in touch with the DoH to check on the implementation of the strengthened guidelines.

Another 'sell out' conference!

Following the success of our first medical conference in April last year, we held a second one on The Management of Early Pregnancy Complications on October 15, again at the Royal Society in London. This enabled us to offer the opportunity to attend to a further 60 people who could not previously be accommodated. This level of demand for places demonstrates both the need for the training we are offering and the high regard in which our last conference is held.

We used the same format for both conferences, with workshop based sessions and case study discussion, enabling the participants to be very interactive and to learn from different experiences and to share knowledge.

The date coincided with the annual International Pregnancy and Infant Loss Awareness Day. The EPT is part of the The Baby Loss Awareness Campaign, which promotes this special day in the UK, exists to promote awareness and understanding of the impact of pregnancy and baby loss among health and social care workers and the community at large. Babyloss Awareness also gives bereaved parents, their families and friends the opportunity to commemorate the brief lives of their babies. The aims and ours have much in common and each delegate left our conference with a candle to mark the day.

Planning for the next conference, scheduled for 18 June, is well underway and we are expecting another great turn-out.



Tom Bourne at the Conference



Conference Attendees

Our volunteers – where would we be without them?

All charities rely heavily on the time and generosity of their volunteers and the Trust is no exception. We are fortunate in having an excellent group of people willing to assist us in many different ways and below we focus on the work that just some of our volunteers undertake. As this year our focus is on support, we would like to highlight the important roles our support volunteers provide.

Buddy service

This is essentially a 'listening' service offered to women who need longer term one-to-one support following their loss to ectopic pregnancy. A dedicated volunteer is assigned to a woman so that she can freely express her grief and any other difficulties and problems she may be encountering. This can be done either over the telephone or by email, depending on what the



sufferer is most comfortable with.

The Trust provides buddies with full training over several months and makes every attempt to ensure that buddy and person requiring help are matched appropriately to give the best possible level of support.

Helpline service

This service provides telephone information and support to callers and is available on normal working weekdays from 10.00 am to 4.00 pm. There is a message answering service outside these hours and volunteers respond as soon as possible.

Volunteers who assist with the helpline are trained to ensure that the service is always delivered to a high level and is appropriate to the individual caller, who may be the woman herself, her husband or partner or, on occasions, another relative or close friend. Needs are many and varied, ranging from a sympathetic and understanding ear to

requests for advice in a particular situation.

The helpline also deals with questions from professionals, members of the press and other contacts of the charity.

Forum moderators

Moderators are crucial to ensure that the message board operates effectively at all times. They also check what appears on it, both for accuracy and to ensure that no inappropriate items are posted.

The message board enables people to ask questions, share experiences and to support each other. It welcomes visitors from all over the world and is open all day every day.

We are always looking for more volunteers to help us provide our valuable services, so if any of the above roles are of interest to you, please contact:

ept@ectopic.org.uk



Patients, carers and families to benefit from new essential standards of care

New essential standards of quality and safety are being introduced gradually from April 2010 across all health and adult social care services in England. The Care Quality Commission (CQC), the new independent regulator of health and adult social care, will license providers once they meet essential standards and will constantly monitor them as part of a new, more dynamic system of regulation which places the views and experiences of people who use these services at its centre.

NHS trusts were the first to come into the new system which started on 1 April this year. They will be followed in October by all providers of social care for people over 18 years of age and by providers of independent

healthcare. Over the coming two years the system will cover all those involved in primary care, including dentists.

The new system means that care and treatment should meet essential standards of quality and safety for individuals, while also respecting their dignity and rights. The most significant change from earlier systems of regulation is that each standard is based on an actual outcome for people rather than on a policy or target. Providers will have to demonstrate that people in their care have a quality experience across all aspects of their treatment, care and/or support.

For more information go to:
www.cqc.org.uk.

AEPU LOGO?

About the AEPU

The AEPU is an independent organisation providing information to help patient choice and facilitating access to local early pregnancy units (EPUs) when needed. In addition, guidelines (2004 and 2007) have been drawn up to harmonise care in EPUs throughout the UK and to set standards for patient care. The AEPU believes that all women with early pregnancy problems should have prompt access to a dedicated EPU that provides efficient management of early pregnancy complications as well as adequate counselling and appropriate treatment whenever necessary.

Their conference is held annually in November and attended by healthcare professionals working in early pregnancy.

Our director, Helen Wilkinson, is an executive on the AEPU board.

Raising awareness of the Trust at AEPU Conference

The Trust was given space for a stand in the main hall at the Association of Early Pregnancy Units (AEPU) Conference held last November in Glasgow and attended by approximately 200 people.

Our stand was well visited by delegates and our director, Helen Wilkinson, was invited to give a talk about the work and activities of the Trust which was well received. She explained the Trust's mission and the ways in which it offers support to sufferers as well as its role of providing information and education on all aspects of ectopic pregnancy through the hospital membership programme.

Helen's talk, together with the information provided at the stand, generated a great deal of interest and we were delighted to welcome several new hospital members as a result. This will help both to strengthen our profile and continue our aim of increasing awareness of the complexities of the condition.

New Projects

New project targets 16 to 24 year-olds

This new and exciting project to raise awareness of ectopic pregnancy among young men and women is run by Ruth Kirkpatrick for the Trust. It is in the early stages of development but we have already recruited several volunteers with experience in relevant fields, including youth work, social work, paediatric nursing, education, the music industry and Connexions (an information and advice service for 13 to 19 year olds).

To find out more about the project, we put a few questions to Ruth.

Who specifically makes up your target group?

Young men and women in the UK aged between 16 and 24. This group tends to be marginalised in terms of access to information and support, and yet they are the most vulnerable to sexually transmitted infection which is one of the preventable causes of ectopic pregnancy.

What are the project's basic aims and messages?

Our aim is to deliver information and support services to this vulnerable group which will ultimately result in the prevention of ectopic pregnancy for young families in the future...

To achieve this, we plan to research, explore and, where possible, design appropriate information and support services tailored to the needs of this age group. We also plan to identify activities in which the Trust can engage to help raise awareness and understanding of the links between chlamydia and ectopic pregnancy and infertility to empower this group to prevent infection and problems in the future.

By what means are you raising awareness?

It's very early days! We are initially identifying and making contact with UK organisations that provide resources, support, education and information to young people in the target age group in order to raise awareness both with the organisations themselves and with the young people who use their services.

Are you currently receiving help from any other bodies?

We have recently succeeded in securing a very welcome grant of £300 from Leeds University RAG. We will be using the money to cover the postage costs of sending information to student welfare offices of higher education centres throughout the UK. The information will consist of a leaflet on chlamydia and ectopic pregnancy and a brochure about the Trust – who we are and what we do – together with a letter from the 16-24 project team. In doing this, we hope to raise awareness of ectopic pregnancy and its link with chlamydia in this vulnerable group, while also directing student welfare officers to the support services available for students who experience ectopic pregnancy.

National chlamydia screening discussed on BBC Radio 4

Following National Audit Office claims of failings within the chlamydia screening programme, Peter Greenhouse, one of the Trust's medical advisors and consultant in sexual health at the Bristol Royal Infirmary, was invited to participate in a Woman's Hour broadcast last November to discuss the issues raised. Pointing out that chlamydia is the main preventable cause of ectopic pregnancy and infertility, he stressed that early diagnosis of the condition and rapid treatment are critical in avoiding future problems for women.

Aware that a screening programme in Sweden had been very successful, and knowing that sending letters out to people often doesn't work, Peter lobbied back in 1998 for an effective screening programme to reach those most at risk of the disease. This so-called opportunistic screening included targeting schools, prisons and army barracks.

Peter pointed out that chlamydia is very widespread, with an estimated half of the population infected by the age of 30. This has made doctors and nurses

very aware of the problem and helped to reduce the stigma associated with the disease in the general population. It has also led to a greater awareness amongst men that they could be putting their partners at risk, leading them to seek screening.

The broadcast was part of a wider debate on the NAO's allegation of duplication and inefficiency within the NHS chlamydia screening programme. Peter was joined by Dr Nicola Low, Senior Lecturer in Epidemiology and Public Health at the University of Berne in Switzerland, who called for more cost effective randomised clinical trials. Peter agreed that more robust data is needed, in particular the rate of chlamydia per year per age group on ectopic pregnancy to determine its link to infertility and ectopic pregnancy.

On an optimistic note, Peter mentioned that recent research on genetic markers has revealed that a majority of women are not at risk of tubal damage from chlamydia.

Researchers call for more frequent chlamydia tests

In a recent broadcast on Radio 4, Professor Pippa Oakeshott, study leader of a group of researchers from St George's Hospital in London, also raised the issue of chlamydia and its link to ectopic pregnancy and infertility.

The group recruited sexually active female students between the ages of 16 to 27 from 20 universities and colleges in London and found that most cases of pelvic inflammatory disease occurred in women who tested negative for chlamydia when initially tested. The findings, published in the British Medical Journal, suggest that the women may have become infected in the 12 months after screening. This has led the researchers to recommend that women should be tested for chlamydia every time they have a new sexual partner to identify the condition rapidly.

Professor Oakeshott added that testing needs to be more accessible to young people, with kits being given out in colleges and youth clubs.

For more information on chlamydia and ectopic pregnancy, go to:

http://www.ectopic.org.uk/medical_information/chlamydia_professionals.htm

Ruth Kirkpatrick

Ruth is a fantastic asset to the Trust. She is a buddy, mentors new volunteers, manages the 16-24 Project and undertakes various administration tasks. She also works on the Helpline and we asked her to share with us her experience of this aspect of her work.



Ruth Kirkpatrick

How long have you been involved with the helpline? I've been a volunteer with the trust since 2004 and started on the helpline in 2007.

How much of your time does it take up and how often do you take calls? I spend one day a week on the helpline, taking calls and briefly logging each contact for our records. I have received up to nine or ten phone calls during a session, although this would be quite unusual, so planning any other work can be difficult! Very occasionally, the phone doesn't ring at all. Between calls, I work on policy and practice development and, more recently, I have been involved in the website rewrite.

I work from home, so I have no travelling time, other than from my desk to the fridge!

Real Life

Do you mainly offer a sympathetic ear and emotional support or do you offer some help and practical advice? Both.

The aim of the helpline is the same as that of all our services, and that is to provide information, education and support to people who are affected by ectopic pregnancy and to those who care for them. Some callers start with a specific question, but after talking for a while they feel able to open up and talk about how they are feeling emotionally. Some callers need to talk through their experiences, many have medical questions, and some are seeking advice on advocacy, while others are looking for support with new pregnancies. Some are in hospital with an urgent need for information, while others are several years post-treatment for ectopic pregnancy. Not all staff and volunteers who operate the helpline are medically qualified but we do all have access to up-to-date medical information and there is always a Trust medical advisor available for telephone consultation if necessary.

The helpline number is the main number for the Trust, so in addition to calls from people who have experienced an ectopic pregnancy, I receive calls from, for example, hospitals requiring leaflets, from fundraisers, volunteers and supporters, and from colleagues working with other agencies. I also talk to doctors and other medics who may have specific questions relating to a patient.

Each call is unique and I never know what's going to happen when the phone rings. We have some regular callers but most people I speak to are calling for the first time.

What inspired you to take on this role?

I had my ectopic pregnancy in May 2003. I remember plucking up the courage to phone the helpline several times, then bottling out after dialling the number because I was

too afraid to talk out loud about how I felt. Eventually I did make contact, and just having someone there who had been through the same thing was a fantastic help to me.

When I had been volunteering for a while with the Trust, I talked to Izzie about assisting her with the helpline service and it all took off from there. I had previous helpline experience in an organisation advocating for young people and I have many years' professional experience of supporting people in crisis, so although it was daunting at first, it didn't take long for me to feel settled in the role.

What personal qualities do you feel are needed to fulfil the role? I think you need to be able to listen actively and be comfortable with other people's emotions and silences. You need to have healed emotionally to an extent where it's possible to provide an independent listening ear to someone who has been through a similar, but unique, experience. It's important to be able to say "I don't know, but I can find out." You must be able to commit adequate time without interruption and be happy working in isolation, but also happy to seek advice and supervision from the Trust's supportive team following a tricky call, or one that pushes the buttons or opens up old wounds.

From a purely personal point of view, I think it's important that people on the helpline have direct experience of ectopic pregnancy. Although I rarely talk about my

own experience to callers, if people ask me, I do share some details when appropriate and callers have fed back that it has been helpful to talk to someone who 'gets it'.

What support does the Trust give you as a volunteer? If I am not able to answer a specific medical query with confidence, I know that I will be able to talk to a professional quickly and get back to the caller with the information they need, usually the same day. I am very proud that we are able to provide such an efficient and reliable service.

I completed a volunteers' training programme, which was crucial preparation for working on the helpline, and since then I have received regular supervision and appraisal. I also attend team meetings and support events organised by the Trust.

How many other people are involved on the helpline? Izzie and I are the regulars operating the helpline. We also have some trained volunteers on standby who are able to do occasional shifts or deal with any outstanding calls if we have periods when we are very busy.

What do you feel you gain from your role? A huge amount of satisfaction, knowing that I'm part of a small team of very dedicated people making a massive difference. I have also gained a great deal of knowledge and insight into a subject I knew absolutely nothing about seven years ago.

How do you relax? I can often be found with a large glass of New Zealand Sauvignon Blanc in my hand. I love walking in the hills and fields where I live, going to the cinema and the theatre, laughing raucously with my naughty friends and thinking about exercise. I am currently thinking about starting training for the Adidas Women's Challenge in September – just thinking about it is exhausting!

Some reflections on the London Marathon

After pounding the streets of London to raise valuable funds for the Trust, some of the participants tell us a little of their experience, their thoughts and their emotions.

We are always extraordinarily fortunate in the number of people willing to don their running shoes for the Trust to take part in this annual event. This year marks a spectacular new record for us with an amazing 16 runners having participated. We are very grateful to all of the following for their magnificent efforts:

- Amanda Barsby
- Julia Bennett
- Elizabeth Daborn
- Lucy Day
- Penelope Graveney
- William Hennessy
- Catherine Hudson
- Alan Hulme
- Rebecca Hunter
- Mark Johnson
- Leon Jones
- Ben Lane
- Gillian Law
- Sally Silver
- Tom Wilkinson
- Jonathan Zeffert

Fundraising



Alan Hulme running the London Marathon



Elizabeth Daborn: On 15 May, I will also be taking part in the Moonwalk in London but before then the ballot opens for the London Marathon 2011. I have already been asked whether my name will be in that ballot again. I can say absolutely one million per cent, yes!! It was an awesome day and everyone I know had an amazing time.

I am grateful to everyone who gave me constant support, making this a truly amazing experience. It has meant a massive amount to me and the Trust.

Catherine Hudson: The first few miles were brilliant, the crowds were amazing and friends and family were there to cheer me on. Everything went quickly with everyone encouraging one another but miles 19 to 22 were hard. However, I knew my legs could still run!

My biggest concerns were my 'Lucozade moments', when I nearly choked on the drink and when I squirted it into my eye, followed by the mathematical calculation of how much I could run near the end without taking on so much water I would need to disappear to the toilets – yet again!

In a way, I'm really sad it's over. The support of everyone has been overwhelming and massively appreciated.

Alan Hulme: Stuck in Stockholm due to the volcanic ash, an alternative earlier marathon began! I had to hire a car to ensure I got home in time, driving 1,100 miles over 18 hours through six countries. Getting lost in Belgium in the middle of the night was not helpful! I finally arrived in Calais at 4:30 in the morning to find no hotel availability, so I queued up for the ferry at 6:00 am and got the last ticket for a sailing that morning. And then the real Marathon began...

Mark Johnson: The marathon was a truly amazing and fantastic experience – something I will never forget. But it was also very emotional and both physically and mentally challenging. I found the last few miles very tough and after 18 miles I could hardly walk let alone run! But with the unbelievable support of the crowd and knowing that whatever pain I was enduring was nothing compared to what my wife and countless other women have suffered owing to ectopic pregnancy kept me going and I finished just under my target of five hours.

Jonathan Zeffert: I tried to break the record as the fastest children's TV character by dressing as Tinky Winky, receiving lots of press coverage, including making an appearance on BBC's One Show.



Event Calendar

Take a look at our website www.ectopic.org.uk/fundraising where you will find a calendar of events listing a variety of events suitable for all levels of fitness. So why not get fit and also raise some valuable funds for the Trust?

A special thank you goes to Lorna and Davie Docherty from Kirkintilloch in Scotland who raised over £3,000 towards the funding of last year's conference. Accompanied by their nephew, Matthew Grant, the couple hiked the 95 mile-long West Highland Way from Milngavnie to Fort William over four days in June 2009 in remembrance of the baby they lost the previous year. The route passes through a wide range of different terrains, ranging from lowland moors, dense woodland and rolling hills to high mountainous regions. They held a race night and a

gala information day to help with their fundraising efforts and awareness raising.

Lorna experienced an ectopic pregnancy in the autumn of 2008. Her life was saved when she arrived in the operating theatre just as her fallopian tube was starting to rupture. Having experienced such a devastating and life-threatening event, they wanted to raise vital funds for the Trust while also raising awareness of the condition and how dangerous it can be.



Fundraisers:

We would like to say a huge thank you to all of you who have fundraised on behalf of the EPT we really are so grateful for the money you raise, it really is vital to ensure that we continue to offer the services which we do.

Here are some of our recent fundraisers, who I would like to take the opportunity of thinking:-

- Pete Thain for completing the 'Toughguy' challenge on 31st January
- Helen Tedman for skydiving for us on 27th February
- Kath Jones and Ceri Hornsby for taking part in the Cardiff to Calais event in February
- Jo Longbottom for running the Adidas Silverstone Half Marathon
- Jonathan Dennis for running the Reading Half Marathon on 21st March.
- Matt Raven for running the Paris marathon on 11th April
- Andrew Kwaan for running the Brighton marathon on 18th April
- John Colvin for running the Stratford marathon on 25th April
- Michael Blake for running the Edinburgh half marathon on 18th April
- Luke and Hannah Byrne for running the Chester half marathon on 16th May
- And Paula Reid, Sandra Canning, Jodie Pelc, Lauren Greeves and Neil Brown who all took part in the Yorkshire Three Peaks Challenge on 15th May.



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