



The Ectopic Pregnancy Trust

Accounts for the Year Ending

31st March 2024

A NOTE FROM THE BOARD

Alex Peace-Gadsby stepped down from the position of Chair and was replaced by fellow Trustee, Chris Woodward in December 2023.

This year has again been another challenging one. We continued to see the impacts of the Covid-19 crisis including within hospitals, the treatment of ectopic pregnancy and creating additional emotional stress on people during one of the toughest experiences of their lives. The Ectopic Pregnancy Trust has continued to be there to support those in need through this traumatic time through all the various lockdowns.

The condition remains the leading cause of death in the first trimester of pregnancy and has a devastating physical and emotional impact. People must come to terms with the risk of life to the woman/pregnant person, the experience of major invasive treatment or surgery, often performed in emergency circumstances, and a loss of part or all of the woman/person's natural fertility, at the same time as coming to terms with losing their baby. All of this happens in a short period of time, often in circumstances where the people affected have never heard of the condition until it happens, and leaves people vulnerable to emotional difficulties in the months and sometimes years after the loss.

The Ectopic Pregnancy Trust remains a niche charity with limited resources but big ambitions. We provide exceptional support on a large scale and work tirelessly with key stakeholders, such as healthcare professionals and government, to improve diagnosis, treatment and raise awareness. We are successfully positioned and respected as key influencers in affecting change.

These great outcomes are achieved thanks to an amazing team of employees, consultants and volunteers who really care and give their time and support for nothing or nominal financial amounts. Without the dedication of team members, volunteers, fundraisers, trustees, medical advisers and ambassadors, we would not be able to provide our vital services that make such a huge difference at such a difficult time. The success of the Trust over this financial year is testament to everyone's efforts and I thank everyone for their kind contribution.

Being a small charity, every penny of income is really made to count. No money is ever spent on advertising for donations. Instead, many who support us have used our services historically and understand first-hand the importance we play in helping people through this devastating experience, others have great sympathy for the cause. Thanks to everyone's generosity and goodwill, we will continue to invest in our support services and work to make the hospital experience the best it can be in the difficult circumstances.

No one should ever die from an ectopic pregnancy and, for anyone affected by the condition, the quality of their hospital experience and emotional support should be excellent.



Chair, The Ectopic Pregnancy Trust

OUR PURPOSE AND STRATEGIC AIMS

Our Purpose

Ectopic pregnancy is a common, life-threatening condition that is the leading cause of maternal death in the first trimester of early pregnancy. The condition affects around 1 in 80 pregnancies in the UK and occurs when an embryo grows outside of the womb. The pregnancy can never be saved. A variety of treatments are available depending on the presenting symptoms and speed of diagnosis.

Ectopic pregnancies have an incidence of approximately 11 per 1,000 pregnancies which means that nearly 12,000 women have ectopic pregnancies diagnosed each year [Source: Confidential Enquiry into Maternal Deaths and Morbidity 2009-14, December 2016]. However, from anecdotal evidence, this may be closer to more than 30,000 admissions in the UK alone, as some instances may not be diagnosed as an ectopic pregnancy but instead as a miscarriage and undergo expectant management. Unfortunately, women can still die from an ectopic pregnancy. The 2019 MBRRACE-UK Maternal Deaths and Morbidity Report 2015-17 states that six women died from early pregnancy problems, five of whom had ectopic pregnancies. All five women with ectopic pregnancies died within 48 hours of presentation and three of the six women who died were from Black or other ethnic minority groups. [Source: Confidential Enquiry into Maternal Deaths and Morbidity 2015-17, November 2019]. According to the 2022 MBRRACE-UK Report, 8 women died in the report period between 2018-2020, which is an increase from the previous report [Source: Confidential Enquiry into Maternal Deaths and Morbidity 2018-20, November 2022]. In the 21st century, no woman or pregnant person should die of an ectopic pregnancy.

The legacy of suffering an ectopic pregnancy can be far-reaching for women/people, couples and wider family and friends. Women and people who suffer have to endure the physical trauma of invasive treatment and face their own mortality, the impact on their future fertility and the sad loss of losing their baby all very quickly. This can be a very frightening and distressing experience. The impact can be long-lasting and many people require ongoing support many months and even years after the experience. We also provide support when people are ready to try for another baby; whether they are struggling to conceive, are trying naturally or through assisted conception routes as well as those who do go on to conceive successfully. Given the increased risk of a subsequent ectopic pregnancy, early pregnancy post-ectopic is also a traumatic time for many people. The Trust also provides its services to medical professionals who treat early pregnancy complications.

We are a small, niche UK-based charity with an extensive reach. We have the support and guidance from world-class health care professionals as our medical advisers and trustees. Our team members are driven to help others through their own experiences and empathise with our service users since many have experienced pregnancy loss and difficulties of their own. We operate with the assistance of our committed team members, volunteers and fundraisers (many of whom have suffered an ectopic pregnancy and used our services historically) and are grateful for the support of our ambassadors.

Our services have been in demand now more than ever due to the challenges that the Covid-19 pandemic brought and its ongoing impacts. We continue to rise to that need.

Our Vision

The Ectopic Pregnancy Trust believes:

- no woman or person should die from an ectopic pregnancy;
- any woman or person capable of conceiving of childbearing age, who is sexually active or undergoing assisted reproductive technology (ART) treatment, having ectopic pregnancy symptoms, should be considered to be pregnant until proven otherwise to maximise the speed of diagnosis; anyone diagnosed with an ectopic pregnancy should receive as many treatment options as the stability of their medical condition allows; this includes conservative management, medical treatment with methotrexate, and surgical treatment;
- it should be universally recognised that early diagnosis enables treatment choice, preserves fertility and enables a person to feel a greater degree of control over her medical condition. This commonly reduces the emotional impact of the ectopic pregnancy;
- it should be universally recognised that the emotional effects of losing a baby can far outweigh the physical condition even in the early stages of pregnancy; and
- anyone who has suffered an early pregnancy loss should have access to all of the information and support they need to aid their physical and emotional recovery.

Our Aims

Our strategic aims are:

- to provide **information** and **support** to all persons affected by ectopic pregnancy and other early pregnancy complications and the healthcare professionals who care for them;
- to advance **education** and to promote **awareness** of ectopic pregnancy and other early pregnancy complications among the medical profession and wider public; and
- to support **research** into ectopic pregnancy and other early pregnancy conditions.



Strategic aim 1: Information and support

Just a quick message to say a huge thank you for the [group Zoom] session yesterday and for creating such a warm, encouraging space.

The Ectopic Pregnancy Trust has made a huge difference in my life the past month, I especially loved having the opportunity to dedicate a tulip to my baby.

I have found a lot of solace and hope and really good information on your websites and forums lately that's really helped. It's nice to know I'm not alone. I sent my story in recently via email hoping it may help others. The work you do is amazing. X

We play a key role in disseminating information and supporting anyone who experiences the condition during diagnosis, treatment and recovery from the condition. Our medical advisers continue to support us to ensure we provide current and accurate information.

We provide training so that the team can gain insights into lived experience for the range of people who can be impacted by ectopic pregnancy. The Director completed two sets of training for safeguarding provided by NSPCC – *child protection for governors and trustees* and *safeguarding 16-25 year olds* and sent the link for latter to support team highlighting the excellent training. These sessions help the charity to reflect the diverse range of relationships and people that can be impacted by ectopic pregnancy. We aim to produce an easy read guide to ectopic pregnancy if funding is secured.

Our annual Strategy day planned for May 2023 was held online via Teams due to rail strikes and the venue booking has been moved to 2024. This was a welcome opportunity for the team to reconnect as well as to plan for the forthcoming financial year. We also held our first team Reflective Practice session in June 2023 and plan to hold further sessions, aiming for twice a year. In March 2024, The EPT became a registered charity in Scotland.

The team has continued to work incredibly hard to maintain a consistently high-standard of service. A new team member joined in January 2024 providing administrative support and continuing to support on Facebook fundraising groups and, over the last financial year, we have achieved the following:

Information disseminated via our website

We believe that equipping people with information about the condition at such a challenging time helps to process what is happening to them. Empowering people in this way results in an increase in their personal knowledge (particularly on the assessment and treatment processes and expected outcomes) and thus reduces the degree of stress and confusion, helping the healing process.

The EPT was awarded the Patient Information Forum tick as a trusted information creator. This is a UK-wide quality mark for healthcare information. Through PIF Tick membership, we have made connections with providers of information to professionals and the EPT's information is accessible to them through those platforms.

Our website provides a valuable resource for women and their families who are being diagnosed or treated for ectopic pregnancy, with sections covering the definition of ectopic pregnancy, diagnosis and treatment, physical and emotional recovery and trying to conceive again as well as information for partners and medical professionals. The information is relevant, accurate, accessible, peer-reviewed and up-to-date. We had over 860,500 users on our website and forum (increase from over 651,000 users in previous financial year) with top pages again being symptoms of ectopic pregnancy and trying to conceive again. Most website users find us through organic searches.

88% of users accessed the site via tablet/phone. This is consistent with previous years and reasons for such intense mobile-usage could include increased privacy or people accessing information at the point of need, such as while at hospital. Broadly consistent with the previous financial year, 65% of visitors to the website are female with 35% male (forum being 68% female and 32% male).

We continue to invest in the website and a recent project involved adding a search capability and we plan to update the forum in the next financial year. The website also has new content on scans and IUDs. The ReachDeck toolbar continues to be used regularly, It has various accessibility tools to reduce barriers including being able to translate the website into 100 languages, reading aloud in 40 languages, screen-masking, and reducing distracting content. We now have animations on symptoms of ectopic pregnancy in English, Welsh, Bengali, Chinese, Somali, Portuguese, and Polish.

Information disseminated through hospitals

We distribute a suite of free patient information leaflets to hospitals across the UK. These are then disseminated to patients on diagnosis or when leaving hospital which means that people have access to information quickly and are signposted to our services at the point of need. This information suite was Highly Commended at the BMA Patient Information Awards 2019 and shortlisted for the overall BMA Patient Information Award 2019.

We produce three specialist leaflets on treatment routes for ectopic pregnancy (Surgical, Medical and Expectant Management) as well as one on Pregnancy of Unknown Location. The relevant leaflet is inserted into the back pocket of EPT-branded A5 wallets which have inserts covering general information on ectopic pregnancy and FAQs. This means that the information is tailored to the patient's individual treatment need. The look and feel of the leaflets and wallets are welcoming yet thoroughly professional in tone and content.

We also have produced EPT-branded gestation wheels with a reminder to hospital staff to reorder leaflets. The number of treatment packs sent over the reporting period exceeded last year's record number with over 12707 packs being sent out, which is a 6% increase on the previous year. We have also sent out 7245 leaflets on pregnancy of unknown location.

We arranged for the general information and individual leaflets to be translated into seven languages and produced an accessible print version. The languages are: Arabic, Bengali, Chinese, Polish, Portuguese, Somali, and Welsh. These have been uploaded to a dedicated section on our website and each treatment pack includes an A5 leaflet signposting to the various language versions in the corresponding language and English. This is so that healthcare professionals can advise their patients' about the language versions and native speakers can also locate them.

We sent out over 869 EPT-branded posters which is again an expected increase following the fall during the previous financial year. These raise awareness of the symptoms and emotional impact of ectopic pregnancy and are disseminated free of charge to hospitals. We also encourage supporters of the charity to disseminate these across GP surgeries, clinics, pharmacies and Urgent Care Centres. Our "symptoms" poster informs the general public of the signs of ectopic pregnancy with the aim of educating communities so that anyone experiencing symptoms seek the care that they need as soon as possible. The "emotions" poster reassures people that their feelings are common. Both posters include the EPT's contact details and website address.

We produced simple, wallet-sized contact cards and sent out 3700 during the financial year. These are useful not only for people to keep in their purses and wallets over time in case of future need but also helps healthcare professionals with an added printed resource. These are especially helpful for hospitals who do not distribute our leaflets and give out their own (e.g. due to Trust policies) and can instead include these cards with their own materials.

Key support services

Equipping people with information goes hand-in-hand with our providing more personalised support services.

We offer emotional support and information in a number of ways: via support line, email exchange, Zoom group sessions, text exchange, social media direct messaging and through our online forum. Topics range from experiencing symptoms, going through diagnosis of ectopic pregnancy, to information on trying to conceive successfully again. We also frequently help those who need us after a number of years of heartbreak. The information we provide is medically moderated and overseen by trained staff and team members. Our support team members are exceptional in their care for anyone suffering the aftermath of an ectopic pregnancy. We are known among healthcare professionals for providing empathic support and evidence-based information and are approached by them with suggested ideas and content. For instance, a leading clinician contacted us to offer training to help us support women and people who experience caesarean section scar ectopic pregnancy and we discussed what more we could be doing for this type of ectopic pregnancy. The team aims to provide a dedicated space for women and people who experience caesarean section scar ectopic pregnancy.

Support line: Support calls provide in-depth opportunities for callers to discuss events, their emotions and ask any questions. Our support line functionality in moving to a call-back service continues to be highly effective. By encouraging callers to leave contact details on voicemail, we are able to communicate quickly via email/text message to arrange a call at a time that suits best which can include evenings or weekends. We aim to respond via text message/email within an hour or two of the message being left so that callers receive acknowledgement fast at an anxious time and strive to ensure calls take place within 24 hours of the original request or accommodate alternative times to suit individuals. To break down barriers, we have put in place interpreting services with two specialist suppliers to enable people whose first language is not English and British Sign Language to use our support line without hindrance.

Emails: We respond to over 300 emails per month requesting specific help and support during or after treatment for ectopic pregnancy. We continue to recruit and train additional team members who are supervised by senior staff. In addition, we also exchange emails and other forms of communication with medical professionals, journalists and supporters, resulting in over 5,000 email exchanges a year. Due to demand, we recruited a further trained team member to respond to emails.

Forum: Our message boards provide peer support but are moderated and contributed to by trained team members. They can be found via our website and are 'live', thereby offering virtually instant information and support for those in need. We had over 486,000 page views in the last report year (over 310,000 last report year). 92% of users access the forum via tablet/phone.. A volunteer with lived experience of ectopic pregnancy who is a website user experience (UX) student has kindly assisted with suggestions on how to improve the forum and we hope to upgrade to an improved, more user-friendly platform next financial year. We are planning to secure grant funding for this. We will look into alternative, more user-friendly forum platforms, gather user experiences, and web developer will perform a review and report on phpBB performance and tracking to inform the process and select the most effective for our audience's needs. For every person who has the confidence to post on the boards, there are many more who take their comfort from reading the messages of others. Our Forum Moderators continue to monitor the boards on a daily basis and aim to respond to posters within 24 hours; this is so that no person is waiting for more than a day for a reply at an anxious time in their lives.

Social media: We have solid, active presence on social media platforms, namely Facebook, X (formerly known as Twitter), Instagram, TikTok, Threads and LinkedIn accounts. Some direct message via these social media sites for support and many others read and take comfort. Some people comment and find support on our posts from others who have been through similar experiences.

The EPT follower growth across all platforms has increased by 14%, with over 41,000 followers at the end of this financial period. Our engagement rate was 4.39% (Anything between 1% and 3.5% is considered an average engagement rate, with a higher engagement rate represented by anything over 3.5%).

On Facebook, we have a public page with over 21,000 followers (18,900 last financial year) centred on information. However, Facebook made changes to public groups which resulted in lack of control over who could join and visibility of group/comments.

The EPT has a closed Facebook group with over 1.6k members and it provides a virtual community enabling those who have experienced ectopic pregnancy to reach out to others going through a similar experience and facilitate our directing users to sources of accurate information on our website and other support services. Some of our top performing posts reach over a quarter of a million people.

The EPT's Instagram and X accounts have over 11,300 and 3,900 followers respectively (9,500 and 3,800 respectively last financial year). The EPT's reach on Instagram for this financial year shows an increase of 291.9% compared with last year. Instagram is our fastest growing platform and the use of reels and stories is increasing our reach and Ectopic Pregnancy Awareness Day had a big impact.

For LinkedIn, since updating our profile in March 2022 to a "company" (there is no not for profit option) for a more professional appearance, at the end of this reporting period has 819 followers. Increasing reach on LinkedIn will be a focus for the coming financial year.

Our TikTok account is primarily used to reach the key 13+ demographic and since launch have over 2500 followers.

Our Treasured Tulips gardens on social media enables anyone visiting our website the ability to request a "plant" and dedicate a tulip which they can choose to personalise. People are provided with the option to donate so there are no barriers to remembrance. During this financial year, we had 670 tulips, with 83 completed and published garden patches. At year end this increased our total patches to 279 since July 2021.

February saw the launch, in England, of certificates for pregnancies and babies lost before the 24th week of pregnancy. This is optional and can be a way to remember your baby. The certification includes ectopic pregnancy, miscarriages, and termination at any gestation before 24 weeks. This subject quickly became one of our top performing posts across social media.

During this year's Baby Loss Awareness Week, our social media posts were seen half a million times, with that number still increasing daily since the end of the Week. Every share allows our content to reach those who may need our support and resources. Our symptoms animation video was viewed over 27,000 times, with many of the community sharing to help others identify symptoms.

Marking 25 years of The EPT, we chose a respectful acknowledgement across social media with an accompanying blog with stand out achievements chosen by The EPT team. This was met with a very powerful response of support from our community with comments such as 'Thank you for everything you do. It really is so important for not only educating people but also for helping those who, like myself, find themselves all of a sudden in this scary situation suffering an ectopic, needing support & trying to make some sense of everything.' being shared across social media.

As of end of April, linked Shopify with Instagram and Facebook channels to make purchasing easier particularly after shop posts and already seeing impact.

Face-to-face support: As a very small charity, we do not have the resources for regular face-to-face support across the country. However, harnessing the power of technology and the appetite for using video calling etc, we offer remote face-to-face support now using Zoom. This can be requested on an individual, couples or group basis. We hold monthly sessions and include a mix of general and dedicated groups for those who have experienced more than one ectopic pregnancy, non-tubal ectopic pregnancy, and partners.

Live Chat: We offer a Live Chat service using the Skype platform to accommodate anyone who prefers to type and receive replies in real-time. This is currently operated on a requested basis due to resourcing constraints.

Support for healthcare professionals: At the recent AEPU conference, we started conversations with The Miscarriage Association about support for healthcare professionals working in early pregnancy following a workshop. Our organisations started collaborating to create a space dedicated to facilitating peer support for staff in early pregnancy.

The support services process involves recruitment, training, and on-going support and pastoral care. The support is medically overseen and moderated. The support team is very collaborative and are able to refer to each other seamlessly. For example, someone having a one-to-one phone call may then wish to participate in a group Zoom session or vice versa and relevant team members liaise direct to organise. The team works efficiently and each support route has at least two dedicated team members. This is so that no one person is overly burdened by emails/calls/messages which are intense in content, there is shared learning and peer-to-peer support among these team members, and we have means for cover during absences.

Our Project Support Team (members help with a variety of administrative tasks on an ad hoc basis) grew to 80 during the report year. Our improved newsletter, e-topic, continues to be delivered electronically.

Strategic aim 2: Education and awareness

Brilliant works you guys are creating !!
Creating awareness is outstanding, but what will make it even more amazing is .. as you so confidently and beautifully stated... women and families need to know there are places of support and The Ectopic Pregnancy Trust is at the top tier for information, support and just all round sisterhood !!!

The Trust seeks to raise awareness among the medical profession and public at large so that earlier diagnosis can be achieved. To facilitate this over the last year, we have:

Ectopic Pregnancy Awareness Day

The EPT held the second Ectopic Pregnancy Awareness Day on 1 August 2023.

Ectopic Pregnancy Awareness Day saw our engagement rate average 6.91% across all channels, and the hashtag #ectopicpregnancyawarenessday has over 732k views on TikTok. Social media influencers such as Becca Maberly (AMotherPlace) and Alicia Burnett (BlackBabyLossAwareness) shared their own experiences of ectopic pregnancy and supported the day with posts and signposts. Charlotte Crosby shared the symptoms of an ectopic pregnancy, although from a different account's content rather than our own.

Collaborations

Pregnancy & Baby Charities Network: The EPT is a member of this Network which represents UK charities whose focus includes improving care throughout the path to parenthood before, during and after pregnancy and after losing a baby or pregnancy. The group collaborates to influence the Government and the NHS to improve care for parents. The EPT strives to ensure that people who experience early pregnancy losses are represented. The Director of the EPT was formerly one of the vice co-chairs of the Network (and previously to that its secretary) and is instrumental in governance, oversight, and strategy.

All-Party Parliamentary Group: We are members of the All-Party Parliamentary Group on Baby Loss which brings together MPs and Peers from across parties to work on this vital issue. The EPT has been a part of the Group from inception in 2016. The APPG's overall aims are to develop policy that supports families dealing with the grief and loss of a baby and to raise awareness of what more can be done by the government, Parliament or other agencies to help those affected. By participating in discussions, The EPT constantly ensures that ectopic pregnancy and early pregnancy loss remain within the Government's agenda.

NICE Guideline: Following representation as a stakeholder on the introduction of a NICE Guideline for Pain and Bleeding in Early Pregnancy in 2013, we registered as stakeholder for updating the clinical guideline on CG154 Ectopic pregnancy and miscarriage: diagnosis and initial management. EPT director Munira Oza continues to be a Lay Member for subsequent updates and participates in the NICE Women and Reproductive Health Suite committee. Ms Oza has been part of the committee for the Women's and

Reproductive Health Suite for NICE since March 2023 and was contacted to contribute to a blog post for International Women's Day 2024 as lay member. She participated in a recent update published in August 2023 concerning NG126 Ectopic Pregnancy and Miscarriage; *medical management of miscarriage*.

Maternal Mental Health Alliance; The EPT joined the Maternal Mental Health Alliance in December 2023 and The EPT and MMHA are planning to collaborate on content.

National Bereavement Care Pathway: The EPT worked in collaboration with other charities and with the support of the Department of Health and the APPG on Baby Loss to produce a National Bereavement Care Pathway. We reviewed the Pathway on Miscarriage, Ectopic Pregnancy and Molar Pregnancy Pathway to ensure that information on ectopic pregnancy is up to date and clear so that all bereaved parents are offered the same high standard of parent-centred, empathic and safe care when a baby or pregnancy is lost through the condition. The EPT continues to support the Pathway.

Training talks

The EPT offers training talks to healthcare professionals and students which include lived experiences of ectopic pregnancy. We provided talks to healthcare professionals across the NHS, medical courses, government departments, and charities.

Other key collaborations:

We along with 12 other pregnancy/baby/parenting charities designated Core Participant status for the UK's Covid Inquiry (healthcare module).

The Director joined Women's Voices Advisory Group for Miscarriage Care and various Patient and Public Involvement (PPI) groups joined into a collective, formally named as the Women's Advisory Group Tommy's National Centre for Maternity Improvement.

Campaigning and Policy

Think Ectopic campaign: We progressed our Think Ectopic campaign focused on raising awareness among primary, urgent, emergency, and out of hours care. At the heart of the project is a biocard on ectopic pregnancy which reminds healthcare professionals about ectopic pregnancy. There are also supporting materials which include patient safety netting pro forma and clinical handover template. All materials for the Think Ectopic campaign were co-created with health professionals and we launched the pilot in September 2023. The feedback from these pilot sites was highly positive. 100% of clinical staff surveyed had used the biocards. 78% of respondents felt that it had increased their knowledge about ectopic pregnancy symptoms and 68% stated that their knowledge of how to refer someone with symptoms had increased. Rather than a second phase of the pilot as originally intended, due to the incredibly positive feedback, we planned to go straight to launch. Launch will entail enlisting staff in early pregnancy units to become Think Ectopic champions at their hospitals and disseminating copies among their colleagues in accident and emergency, paramedics, and midwifery thereby raising awareness in those specialist units.

We continue to participate in three focused campaigns: Baby Loss Awareness Week; Small Charity Week and Volunteers' Week as opportunities for our voice to be part of a powerful, collective message. Through campaigning, we are able to shine a spotlight on ectopic pregnancy and early pregnancy loss and seek to influence policy and action change.

Baby Loss Awareness Week: Baby Loss Awareness Week takes place annually from 9 to 15 October and is an opportunity for bereaved parents and their loved ones to acknowledge and remember their losses. It is also a chance to raise awareness of the emotional impact of pregnancy and infant loss, and the scale of the tragedy, which affects up to one in five families in the UK. Baby Loss Awareness Week is a collaboration of a number of charities united in their support for families who experience the death of a baby including Bliss, Child Bereavement UK, The Miscarriage Association and Tommy's as well as the EPT. We have participated since inception and this year was the 20TH anniversary. Today, the EPT continues to drive the Week forward extensively alongside other charities as the EPT Director sits on the core Working Group and social media coordinator sits on the group for Marketing and Communications.

The EPT were contacted by an internationally known company to assist with early pregnancy loss support for employees, providing talks in the workplace and sharing circle with another charity. The EPT also secured a case study for BBC Radio London during Baby Loss Awareness Week and Director, Munira Oza spoke on the Shay Kaur Grewal show.

As part of the BLAW campaign, we sold special Baby Loss Awareness pins and used social media to reach out to our followers, particularly on Facebook. On 15 October, as in previous years, the week closed with the Global 'Wave of Light' where candles were lit across the globe as part of the international Pregnancy and Infant Loss Awareness Day. During this year's Baby Loss Awareness Week, our social media posts were seen half a million times, with that number still increasing daily since the end of the Week. Every share allows our content to reach those who may need our support and resources. Our symptoms animation video was viewed over 27,000 times, with many of the community sharing to help others identify symptoms.

Collectively across the participating charities, the number of families reached will have reached into the many hundreds of thousands. As well as participating in Baby Loss Awareness Week on an annual basis, this group shares best practice and identifies potential joint opportunities.

Small Charity Week: Small Charity Week takes place annually and is devoted to raising the profile of small charities. Held between 24 and 28 June, we reached over 45000 (up from 26000 last report year), largely down to a post focused on symptoms ("Five things you should know about symptoms of an ectopic pregnancy").

Volunteers' Week: The first week of June sees Volunteers' Week and, was a valuable opportunity to highlight our valued volunteers for their support and publicly thank.

Women's Health Strategy: The charity had submitted evidence for the government's Women Health Strategy and it published in July 2022, with focus on improvements for women's and girl's healthcare in

England. The EPT continues to work alongside the Department of Health and Social Care to further actions on early pregnancy loss care and Pregnancy Loss Review recommendations.

Conferences

We frequently participate in external conferences focusing on early pregnancy. The Director sits on the Board of the Association of Early Pregnancy Units (AEPU) offering the patient's voice. Our Director represents the Trust at AEPU meetings and attends the annual conference.. Our Director also usually presents at in-house hospital seminars and meetings and we often provide EPT materials for displays which largely ceased during the pandemic.

We attended the SEPN conference and this was a valuable opportunity, having three sessions in the day with focus on ectopic pregnancy as well as other important topics like supporting transgender patients in early pregnancy.

We attended the Primary Care Conference where we introduced the Think Ectopic project and concept of the ectopic pregnancy biocard, gathering valuable feedback on our ideas. We presented the idea of an ectopic pregnancy biocard and received very positive feedback on our plans. We will build on this feedback to develop a strategy, including co-creating materials with healthcare professionals and piloting the campaign. This work will be a key part of the charity's activities in the next financial year.

We attended a Pregnancy and Baby Loss Awareness event at Boots HQ.

Media

We continued to assist a number of media outlets covering print, on-line and television/radio formats. We received wide ranging exposure in print newspapers and magazines. Coverage included a headline article on The Guardian website about ectopic pregnancy contributed to by the director and a case study, referenced by ITV's This Morning as a source of support, assisting an article in The Telegraph, and articles in the Daily Mail and The Sun, the former of which signposted to our support and latter needed some corrections to article for which we contacted the journalist. We were asked to review magazine articles and a script for a well-known BBC TV programme.

Our dedicated team of volunteer fundraisers continue to spread the word through interviews such as with BBC local radio stations and local press, which often include the Trust's contact details.

We are fortunate to have the continued support of a PR agency through someone we had supported and the agency's foundation sought to work with us for PR/marketing.

Merchandise

Our on-line shop stocks a range of branded merchandise that promotes the Trust. By purchasing and using our products, awareness about ectopic pregnancy and the Trust's name and website get increased exposure among the general public.

Our biggest sellers continue to be our pin badges which are excellent for increasing awareness about the condition. Our second most popular item this financial year has been a new product, a branded scented candle, which was received extremely well. We added a new design 25 year Christmas bauble and 25 year EPT badge which have been popular too. Shop sales for this financial year increased by 17% as compared with the previous financial year. During the next financial year, we aim to launch new products for remembrance as we recognise that people appreciate a meaningful purchase and plan to introduce four new items.

Fundraising

We receive no Government funding and exist through the goodwill of our fundraisers. Through the dedication and energies of our fundraisers, we have had another successful year.

Our bespoke fundraising initiatives EPT80in1, EPT1000 Challenge, and EPT Mini Challenges continued to be popular. We continue our successful partnership with Run4Charity which provides access to local runs covering distances from 5k to full marathons both across the UK and internationally.

The London Marathon and Great North Run continue to draw significant interest from our fundraisers. For The GNR, we had 15 runners. For LM, we had 15 runners. During this financial period, we had a mixture of events; these included race nights, being nominated for charity of the year, golf days, wedding favours, raffles, runs including 5 -10ks, half and full marathons in the UK and Paris, a dinner dance (in memory of a friend who died of ectopic pregnancy), swimming, biking, and walking challenges and skydives!

The EPT 80 in 1 challenge, where people cover 80 miles during the month of August (8th month), continues to be popular. This financial year had 223 participants who helped to raise awareness of the 1 in 80 pregnancies that are ectopic. This is now an annual event.

Our Fundraising Coordinator continues to be supported by our press officer who assists fundraisers in getting press coverage, fundraising supports who looks after the EPT 1000 Challenge dedicated closed Facebook page for fundraisers to offer a space for mutual support and encouragement, running and LM groups amongst other activities and closely with our social media coordinator to promote activities, achievements and works closely with creating campaigns and digital support.

Strategic aim 3: Supporting research

Ectopic pregnancy is still the commonest cause of death in early pregnancy and, even if not fatal, the effects are distressing and far-reaching. Women can suffer from long term psychological problems and it can impact on their future fertility.

If an ectopic pregnancy is diagnosed early, it is likely it can be treated effectively and perhaps avoiding the need for invasive surgery. That's why it's important that there is more research like our trial into ways that we can improve the medical management of the condition.

- Professor Andrew Horne, University of Edinburgh

The EPT continues to seek to effect change by improving speed of diagnosis, treatment choice and levels of care. Over the last year, we have participated in the following to support this objective:

Improving treatment choice

The EPT supports research into biological processes that may be connected to ectopic pregnancy. The Trust sponsors a PhD student at The University of Edinburgh who is researching the causes of ectopic pregnancy. This involves examining cellular changes in the lining the Fallopian tube with may result in ectopic embryo implantation. This work was supported by a joint Medical Research Council/Ectopic Pregnancy Trust PhD Fellowship. This research was briefly paused during the pandemic but was restarted in Autumn 2021 and final third year pledge was advanced. The research completed and the paper is to follow soon.

The EPT worked with Sands, The Miscarriage Association, and Antenatal Results and Choices on audit questions concerning bereavement care in early pregnancy/gynaecology units and participated in the Pregnancy Loss Review on whether the law should be changed to allow registration of pregnancy losses before 24 weeks. The report was published in July 2023 and The EPT remains part of the steering group regarding implementation of recommendations. A key recommendation involved the implementation of a certification process for pregnancy losses prior to 24 weeks which was launched in February 2024.

We continue to work on a Priority Setting Partnership for Ectopic Pregnancy. The project is a collaboration between the Cochrane Gynaecology and Fertility Group, the University of Monash, University College London, and The EPT and commenced the previous financial year. It aims to identify the top ten priorities for future research in ectopic pregnancy. The first stage brought together people from across the world who suggested their top five 'unanswered' research questions, which to then prioritised in an international survey. The final stage involved refining the interim list to the top ten research questions. Ms Oza is a key lead in the project and sits on the Scientific Steering Committee and attended ESHRE for PSP this year, to finalise the list. It is anticipated that the paper will be published in the next financial year.

We assisted Kings College London on a study on early pregnancy loss during the Covid-19 pandemic (along with the baby loss counselling charity Petals). The study is part of wider research entitled PUDDLES (Parents who suffer pregnancy loss and whose babies die during the pandemic) and is a global collaboration between

the UK, Australia, Brazil, Canada, India, Italy, and New Zealand to understand the experiences of bereaved parents during the COVID-19 pandemic using qualitative interviews and analyses. This specific collaboration with The EPT and Petals investigates women's experiences of early pregnancy loss and care during the COVID-19 pandemic. The EPT requested participants for the study which was quickly oversubscribed due to huge interest in those wishing to take part. The paper is expected to be published next financial year. In connection with our work on PUDDLES, we reviewed a consensus statement on post-pandemic perinatal mental health,

Last year we were contacted by the Aberdeen Centre for Women's Health Research to assist with Public and Patient Involvement to explore the impact of existing medical treatment, priorities for new medical treatments and acceptability of mifepristone as an experimental treatment. We assisted with gathering participants for PPI engagement and participating in meetings to gather insights into whether women thought this would be a beneficial study. Entitled the AMETHYST trial (Adding Mifepristone to mETHotrexate for ectopic pregnancy Study), the stage 1 bid was submitted to the National Institute for Health and Care Research (NIHR).

We were contacted last financial year by University College Hospital to assist with a research study investigating the psychological impact of being diagnosed and managed for a caesarean scar ectopic pregnancy. We were contacted in December 2023 by UCL for the development of a core outcome set for treatment of caesarean scar ectopic pregnancies - COSCAR. We continue to progress COSCAR

We were invited by Sergio Silverio to join regular Lifecourse Analysis of Women's Mental Health Research group meetings. The EPT were also asked by Sergio Silverio to be involved in a new study to look at early pregnancy loss and complications in the post-pandemic era. This is a follow-on study from VESPA and PUDDLES.

We were contacted by the Royal College of Midwives to assist on a priority setting partnership for maternity and midwifery care. We joined as project partner alongside other organisations including The Miscarriage Association, Antenatal Results and Choices, and Birmingham Women and Children's Hospital.

We supported research through UCL including sharing a survey on patient experiences of early pregnancy units which seeks to look into ways to improve care and participated in a symposium regarding linguistic challenges in pregnancy loss communication alongside Tommys, Sands, and ARC.

Representing lived experiences of ectopic pregnancy

Exactly 21 years ago for me. No support whatsoever, just expected to brush it off and carry on. People around me didn't like it when I fell to pieces. Thank you for bringing this out into the open.

The Trust has forged key relationships with a number of similar focused organisations and inform the debate through lived experiences and best practice. These include other charities and groups such as:

The Association of Early Pregnancy Units: The Trust has a representative on the executive board of the AEPU which develops best practice to managing ectopic pregnancy and other early pregnancy complications, participating in regular meetings and the AEPU strategy day.

Professional/governmental organisations: These include NHS Direct, the National Institute for Health and Care Excellence, the Department of Health and Social Care, the Royal College of Nurses, the Royal College of Obstetricians and Gynaecologists, the Royal College of General Practitioners, the Healthcare Services Safety Investigation Body, the Maternity and Newborn Safety Investigations programme, and the International Society for Ultrasound in Obstetrics and Gynaecology. This ensures that the condition and lived experiences are well represented and included in the development of best practice.

The Ectopic Pregnancy Trust

The report of the trustees for the year ended 31 March 2023⁴.

Charity name: The Ectopic Pregnancy Trust

Registered charity number: 1071811

Date of registration: 2 October 1998

Principal address: 483 Green Lanes, London, N13 4BS

Telephone: Admin - 020 7096 1838; Helpline - 0207 733 2653

Trustees: Mrs Alex Peace-Gadsby (Chair until December 2023); Mrs Shabana Masavi (Treasurer) Miss Julie Price; Prof. Tom Bourne; Prof. Andrew Horne; Mr Chris Woodward (Chair from December 2023); Rachel Small; Michael Wood-Williams

Staff/Team members: Munira Oza (Director); Jill Ansell (Fundraising coordinator); Sonal Colvin (Shop and donations coordinator); Sam Page (Hospital leaflets coordinator); Kerri Stedman (Social Media Coordinator); Helen Corsi-Cadmore (Projects coordinator); Lois Rowland (Fundraising support coordinator); Tara Moverley (Volunteer support coordinator/Administration); Natalie Max (Press officer); Karen Donovan (Support Team); Michele Fugiel Gartner (Support Team); Joanne Cadle-Junor (Support Team); Gita Noren (Support Team); Katharine Christopher (Support Team); Beth Pidd (Support Team); Sophie Ashby-Clarke (Support Team); Katie Lewis (Support Team); Mary Hall (Administrative support)

Medical advisers: Cecilia Bottomley MB BChir MRCOG; Prof. Tom Bourne PHD MD MRCOG; Sonal Colvin BSc; Professor Colin Duncan BSc(hons), MBChB(hons), MD, FRCOG; Janine Elson MD FRCOG; Prof Andrew Horne Ph.D, MRCOG; Davor Jukovic PHD MD MRCOG; Emma Kirk BSc, MD, MRCOG; Nick Raine-Fenning MRCOG, MBChB Ph.D; Jackie Ross MBBS MRCOG; Prof. Siobhan Quenby; Rachel Small RGN, RM, FRCOG(Hon); Lisa Starrs BSc (Hons) RN RM

Ambassadors: Michelle Gayle (Actress and Singer); Susan Penhaligon (Actress); Amanda Redman MBE (Actress); Philip Cairns (Actor); Charlotte Crosby (TV Personality)

Volunteers

Volunteers continue to be an essential resource in ensuring that the charity is able to deliver its objectives. They are typically people who have been affected by the condition and want to give something back to the charity, such as by answering helpline enquiries, facilitating the message boards, becoming a buddy through to administrative tasks. The charity has strict policies and procedures for vetting, training and supervision.

The charity ensures that no person applying for employment or for admission as a volunteer to the charity will be treated less favourably on the grounds of their sex, race, class, colour, racial group, ethnicity, marital status, sexual orientation, age, trade union membership or otherwise, religious belief or physical or mental disability.

Decision making

The Trustees are responsible for strategic decisions with appropriate consultation with the staff. Where medical information is required, the Medical Advisors are consulted. The staff have the authority to make operational decisions without prior Trustee consultation.

Records maintenance

The charity's records are maintained and annual accounts are prepared by the treasurer.

Type of governing document

Trust deed.

How the charity is constituted

The charity is constituted as a Trust.

Charity Trustee selection methods

The Charity has a clear policy and procedure for the recruitment, selection and induction of Trustees, which runs alongside our equal opportunities policy.

Policy on reserves

The charity holds two bank accounts with Charities Aid Foundation, a cash account and a Gold account. The Treasurer takes responsibility for ensuring that excess funds are moved into the Gold account to ensure that the potential for interest is maximised.

The trustees have set a reserves policy which requires that the reserves be maintained at a level that ensures that the charity's core activity continue during the period of unforeseen difficulty. The calculation of the level is an integral part of the organisation's planning, budget and forecast cycle and takes into account risks associated with each stream of income and expenditure being different from that budgeted, the planned activity level and the organisation's commitments.

Further financial review details

The 2024 accounts continue the improvement in income generation shown in the 2023 results. During the year the Trustees spending on charitable activities increased by over £10k from 2023 This was as a result of the Trustees' active decision to seek out areas where reserves built up over the last 5+ years could be effectively used. A key area was work to upgrade the website.

The Trustees will continue to monitor the situation to ensure the Charity is in a position to enable it to continue to meet its objectives for the foreseeable future and continue to grow.

Availability and adequacy of funds

The board of trustees is satisfied that the charity's assets in each fund are available and adequate to fulfil the obligations in respect of each fund.

Statement of Trustees Responsibilities

Charity Law requires the Board to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity as at the end of the financial year and of the surplus or deficit of the charity. In preparing those financial statements, the Board is required to;

1. select suitable accounting methods and then apply them consistently;
2. make estimates and judgements which are prudent;
3. prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.
4. state whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements.

The trustees are also responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which are sufficient to show and explain the charity's transactions and enable them to ensure that the financial statements comply with regulations made under the Charities Act. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are also responsible for the contents of the trustees' report.

Signature

A handwritten signature in black ink, appearing to be 'Chris Woodward', written over a horizontal line.

Chris Woodward

Acting Treasurer

Independent examiner's report to the trustees of The Ectopic Pregnancy Trust

I report on the accounts of the Trust for the year ended 31 March 2024.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under Section 43(2) of the Charities Act 1993 (the 1993 Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 43 of the 1993 Act;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 43(7)(b) of the 1993 Act; and
- to state whether particular matters have come to my attention.

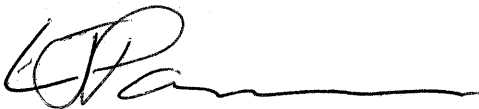
Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention which gives me reasonable cause to believe that in any material respect the requirements to keep accounting records in accordance with section 41 of the 1993 Act and to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 1993 Act have not been met or to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Signature



Date: 22.01.2025

Profit and Loss - Detailed View

The Ectopic Pregnancy Trust

For the year ended 31 March 2024

	2024	2023
Turnover		
201 - Corporate Donations	9,047.36	540.00
270 - Interest Income	667.18	817.59
206 - Fundraising Activities	53,066.53	141,072.43
209 - Merchandise Sales	7,354.37	5,695.23
203 - Other Donations	20,087.52	-
204 - Other Fundraising Platforms	10,832.78	23,725.23
200 - Personal Donations	111,143.67	12,767.36
Total Turnover	212,199.41	184,617.84
Cost of Sales		
1001 - Shop Merchandise Costs	6,046.03	1,420.82
402 - Management Costs: AEPU	906.00	-
505 - Support Group Costs: Forum	7,221.24	6,900.00
400 - Leaflets	22,217.22	25,726.08
502 - PAYE	9,427.04	-
506 - Support Group Costs: Helpline	13,508.54	11,378.99
901 - Project Costs: Think Ectopic	9,715.00	-
501 - Net Salaries	65,482.33	63,793.23
503 - Pensions Costs	-	2,684.15
504 - Support Group Costs: Email	3,425.00	7,625.34
Total Cost of Sales	137,948.40	119,528.61
Gross Profit	74,251.01	65,089.23
Administrative Costs		
101 - Bank Fees	206.00	234.00
478 - Admin Costs	-	9,561.16
401 - Helpline Consultants	-	670.00
Leaflets		
400b - Storage for Leaflets	872.80	1,153.61
Total Leaflets	872.80	1,153.61
Management Costs		
512 - Management Costs: General	14,851.04	13,611.32
403 - Management Costs: Strategy Day	2,865.25	-
Total Management Costs	17,716.29	13,611.32
108 - Payroll Costs	33,658.59	42,218.66
461 - Postage & Stationery	439.16	-
Shop Costs		
1003 - Storage: Shop	1,075.61	-
Total Shop Costs	1,075.61	-
106 - Sundry Expenses	1,173.78	1,337.72
Support Group Costs		
507 - Support Group Costs: Zoom	1,632.79	1,560.75
Total Support Group Costs	1,632.79	1,560.75
704 - Telephone & Internet	381.20	979.60
105 - Training & Welfare	-	318.00
493 - Travel & Subsistence	916.16	-
425 - Website & Digital Marketing	56,718.19	35,568.81
Fundraising Costs		
300 - Fundraising Costs: Supporting fundraisers	19,094.97	17,105.11
301 - Fundraising Costs: London Marathon	5,553.60	6,907.20
Total Fundraising Costs	24,648.57	24,012.31
Project Costs		
350 - Design Print & Post	529.08	13,090.60
Total Project Costs	529.08	13,090.60
Total Administrative Costs	139,968.22	144,316.54
Operating Profit	(65,717.21)	(79,227.31)
Profit on Ordinary Activities Before Taxation	(65,717.21)	(79,227.31)
Profit after Taxation	(65,717.21)	(79,227.31)