

The Ectopic Pregnancy Trust

Accounts for the Year Ending

31st March 2023

A NOTE FROM THE BOARD

UPDATE BY AND FOR BOARD

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.

A handwritten signature in black ink, appearing to be 'John Smith', written in a cursive style.

TRUSTEE
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

The Ectopic Pregnancy Trust - thank you so much this group has normalised ectopics and made me feel like I'm not alone.

The world needs to be more informed on ectopic pregnancy and this wonderful charity is the only one I've come across that does their part to do so, thank you EPT for being the voice of so many women.

I just wanted to say a huge thank you for hosting the support session today. I found it incredibly helpful to hear similar stories and discuss difficulties and feelings towards this experience with like-minded people!

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. We obtained training by LGBT Mummies (LGBT+ community) on how to support people from LGBTQ+ communities. Through social media messaging about this training, we received lived-experience story received from LGBT+ community. We also received training from MenCao on how to support people with learning disabilities and difficulties and autistic people. 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 next year.

We held the return of our annual Strategy day in May 2023. This was a welcome opportunity for the team to reconnect and meet new members as well as to plan for the forthcoming financial year.

As we have readjusted to life following repeated lockdowns, the team has continued to work incredibly hard to maintain a consistently high-standard of service 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 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 651,000 sessions on our website with top pages being symptoms of ectopic pregnancy and trying to conceive again.

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 are female with 35% male.

The new website was launched in June 2022 after extensive changes to its "look and feel" and all content was reviewed. We continue to invest in the website and upcoming projects include adding a search capability and updating the forum.

The ReachDeck toolbar has been installed since last financial year and 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.

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 11000 packs being sent out.

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 650 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 over 4000 during the financial year, an increase of 33%. 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 (eg 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 310,000 page views in the last report year. To improve search engine performance, our web developer performed an audit and cull of redundant and empty threads and so this fall on the last year's visits may be due to historic spam/bot visits previously. A volunteer with lived experience of ectopic pregnancy who is a website user experience 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. 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, Twitter, Instagram, 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.

On Facebook, we had open and closed discussion groups with over 5,500 providing peer support as well as a public page with over 18,900 followers (17,700 last financial year) centred on information. However, Facebook made changes to these public groups which resulted in lack of control over who could join and visibility of group/comments. Lack of control meant that anyone could see the posts within the group and could attempt to privately contact that member. The EPT closed the open discussion group as it was felt it no longer provided "safe space" and asked members to join the closed (private) Facebook group.

As of June 2022, The EPT has only the closed Facebook group 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 Facebook reach for this financial year is up 47.8% on the previous year.

The EPT's Instagram and Twitter accounts have over 9,500 and 3,800 followers respectively (8,400 and 3,600 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, we updated our profile in March 2022 to a "company" (there is no not for profit option) for a more professional appearance and at the end of this reporting period has 637 followers. We launched our TikTok account to reach the key 13+ demographic and since launch have over 1700 followers.

Our Treasured Tulips gardens on social media enables anyone visiting our website is able to request to "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. As at the end of this financial year, we had 1,368 dedications, with 171 completed and published garden patches.

We saw misinformation increasing in the wake of Roe v Wade ruling, conflating ectopic pregnancy treatment and termination of viable pregnancy. The EPT issued a response.

We obtained a grant for the Microsoft search engine, Bing. This will help us reach healthcare professionals whose IT systems are wedded to Microsoft.

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 aim to increase monthly sessions and include a mix of general and dedicated groups.

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.

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 70 during the report year. Our improved newsletter, e-topic, continues to be delivered electronically.

Strategic aim 2: Education and awareness

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 first ever Ectopic Pregnancy Awareness Day on 1 August. This date was selected as we have, over the last few years started the EPT 80 in 1 Challenge then. Having the Ectopic Pregnancy Awareness Day to coincide was a natural fit. With August being the eighth month, we were able to craft creative communications around the numbers 1 and 08.

Social media posts from The Ectopic Pregnancy Trust platforms reached a total of 520,834. #Ectopicpregnancyawarenessday had 388,000 impressions on TikTok. Social media reach is measured: (1) direct through our own social media channels; and (2) activity on our supporters' social media channels in which we are tagged. Therefore the total combined reach is almost 4.5 million.

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 is appointed one of the vice co-chairs of the Network 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 Lay Member for subsequent updates of what is now known as NG126. Ms Oza sits on the committee for the Women's and Reproductive Health Suite for NICE.

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 and assisted with the latest update published in July 2022.

Training talks

The EPT offers training talks to healthcare professionals and students which include lived experiences of ectopic pregnancy. We provided talks to North West London Integrated Urgent Care, midwife-led Health in Pregnancy Service team, emergency care nurses course, and charities. We also gave talks to the British Undergraduate Societies of Obstetricians and Gynaecologists and organised talks for university midwifery societies.

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

We participated 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 was involved in a webinar held by Peppy Health (employee health benefits specialising in fertility, having a baby, and women's and men's health) during Baby Loss Awareness Week which reached their employer client base which covers over one million employees. This was an important opportunity to educate workplaces about ectopic pregnancy.

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. In posting our image of our candle on our social media pages and encouraging people to share, we united with others across the world in honour of those babies who lit up lives for such a short time and in doing so our image reached over 163,000 people on Instagram and Facebook (150,000 last year). Posts from the charity reached over 500,000 people (450,000 last year). 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.

We were asked by the International Society of Ultrasonographers, Obstetricians, and Gynaecologists (ISUOG) to assist with planning BLAW communications and this demonstrates the relationship we have cultivated. We were asked to give a talk on pregnancy and baby loss to the British Undergraduate Societies of Obstetricians and Gynaecologists.

We were approached by a media outlet to assist with content to go out on their local radio stations across the country during BLAW and sent materials to shopping centres including W12, O2, and The Harpur Centre. BLAW social media channels promoted our EPT Walk of Remembrance for that Week.

"Baby Loss Awareness Week 2022" was searched for 14,000 times of which we captured almost 10% of visits and we were in the top ten for rankings including with the phrase "Baby Loss Awareness Week", competing with large charities who placed (paid) ads.

Small Charity Week: Small Charity Week takes place annually and is devoted to raising the profile of small charities. We participated in June 2022 highlighting the services we provide and the big impact they can have. Our posts reached over 26,000.

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 during the previous financial year. The Strategy was published in July 2022 which focuses on improvements for women's and girl's healthcare in England. Going forward, The EPT aims to work alongside the Department of Health and Social Care to further actions on early pregnancy loss care.

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. The November 2022 Association of Early Pregnancy Units conference was held in person which was the first once since the pandemic and was attended by our Director. 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.

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. Popular ITV Soap Coronation Street had a storyline on inconclusive scan and ectopic pregnancy and as a result our social media post had lots of engagement and website saw a spike in sessions. There was related online press-coverage some of which was not entirely accurate and referred to "phantom pregnancies" and we commented on the article to correct and remind symptomatic women/people to seek medical attention. Ms Oza was contacted by The Economist to contribute to a piece on Roe v Wade and concerns related to ectopic pregnancy.

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 were contacted by an account executive at a PR agency whom we had supported whose foundation sought to work with us for PR/marketing. We have put together a small PR team.

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 Christmas cards and pin badges which are excellent for increasing awareness about the condition. We added new design keepsakes and bobble hat in EPT colours which were popular. During the next financial year, we aim to launch new products for remembrance as we recognise that people appreciate a meaningful purchase.

In mid-December, we refreshed the look and feel of the shop. The shop now includes a donations button at the top. On sending the annual round-up newsletter soon after, we saw increased donations.

Shop sales for this financial year increased by 4% as compared with the previous financial year.

Fundraising

We receive no Government funding and exist through the goodwill of our fundraisers.

Our bespoke fundraising initiatives EPTea Party, EPT1000 Challenge, and EPT Mini Challenges continued to be popular. In particular, the Walk of Remembrance during Baby Loss Awareness Week (which has a modest donation to participate) was very successful with some participants engaging in extra fundraising. We signed up to Run4Charity which provides access to local runs covering distances from 5k to full marathons both across the UK and internationally. This is already proving popular as the platform offers variety and we should see the impact of the offering in the next financial year.

The London Marathon and Great North Run continue to draw significant interest from our fundraisers. For The GNR, we had 15 runners which is a good increase from the previous year's five. For LM, we had 12 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 virtual cookery course, live gaming, crocheting toys in memory of a loved one who lost her life to an ectopic pregnancy, swimming, biking, and walking challenges and skydives!

The EPT 80 in 1 where people cover 80 miles during the month of August (8th month) continues to be popular with over 300 participants and helps to raise awareness of the 1 in 80 pregnancies that are ectopic. This is now an annual event. The impact of these initiatives have meant that we have had a successful fundraising year.

Our Fundraising Coordinator continues to be supported by our press officer who assists fundraisers in getting press coverage, fundraising social media coordinator who looks after the EPT 1000 Challenge dedicated closed Facebook page for fundraisers to offer a space for mutual support and encouragement, and social media coordinator to promote activities and achievements.



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 Trust has been involved in supporting ground-breaking research with medical adviser and trustee Professor Andrew Horne of the University of Edinburgh on combining two drugs (methotrexate with gefitinib) to improve the effectiveness of medical treatment. Professor Horne's team ran the GEM3 trial, a multi-centre, double-blind, placebo-controlled randomised trial. The study sites were 50 centres across the UK which were publicised by the EPT, making it the largest study ever on ectopic pregnancy. The study was published in February 2023 and, while it showed no benefit in adding gefitinib with methotrexate treatment, it did gather data to further understanding about methotrexate treatment.

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 completes in May 2023 with the paper to follow thereafter.

The EPT assisted Monash University with research in ectopic pregnancy with the aim of standardising core outcomes in published papers. We provided feedback on the patient information leaflet and survey questions and helped to promote to gather participants. The paper was published online in February 2023.

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. We await the publishing of the report which is expected to take place during the next financial year.

We were approached 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 early this 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 were then prioritised in an international survey. The final stage involves 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.

We were also approached to work with 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.

We have been 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.

We were contacted 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.

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 Department of Health and Social Care, the Royal College of Nurses, the Royal College of Obstetricians and Gynaecologists, the International Society for Ultrasound in Obstetrics and Gynaecology, and the Health Care Safety Investigation Branch. 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 2023.

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); Mrs Shabana Masavi (Treasurer) Miss Julie Price; Prof. Tom Bourne; Prof. Andrew Horne; Mr Chris Woodward; 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)

Medical advisers: Cecilia Bottomley MB BCHir MRCOG; Fiona Bottomley, Superintendent Sonographer; 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; Suzanne Hollamby MB.BS, MRCOG CCST; Davor Jukovic PHD MD MRCOG; Emma Kirk BSc, MD, MRCOG; Marjorie McLean; Nick Raine-Fenning MRCOG, MBChB Ph.D; Jackie Ross MBBS MROCG; Prof. Siobhan Quenby; Rachel Small RGN, RM, FRCOG (Hon); Dirk Timmerman MD, Ph.D

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.

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.

The Charity changed from Excel Spreadsheets to the Xero Accounting package in 2022/23 so the accounts will be more useful in future years. As a result, the 2022/23 accounts are shown simply as 1 year rather than showing comparatives from the previous years.

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.

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.

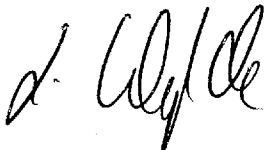
Basis of independent examiner's report

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: 31/01/2024

Profit and Loss - Detailed View

The Ectopic Pregnancy Trust
For the year ended 31 March 2023

2023

Turnover

201 - Corporate Donations	540.00
270 - Interest Income	817.59
206 - Fundraising Activities	141,072.43
209 - Merchandise Sales	5,695.23
204 - Other Fundraising Platforms	23,725.23
200 - Personal Donations	12,767.36
Total Turnover	184,617.84

Gross Profit

184,617.84

Administrative Costs

404 - Bank Fees	234.00
478 - Admin Costs	9,561.16
401 - Helpline Consultants	670.00

Leaflets

400 - Leaflets	21,451.08
400b - Storage for Leaflets	1,153.61
Total Leaflets	22,604.69

Management Costs

420 - Management Costs: General	13,023.32
Total Management Costs	13,023.32

437 - Payroll Costs	42,218.66
482 - Pensions Costs	2,684.15
477 - Salaries	61,044.07

Shop Costs

412 - Shop Merchandise Costs	1,420.82
Total Shop Costs	1,420.82

429 - Sundry Expenses	906.48
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Support Group Costs

453 - Support Group Costs: Email	7,625.34
451 - Support Group Costs: Forum	6,900.00
452 - Support Group Costs: Helpline	11,378.99
454 - Support Group Costs: Zoom	1,560.75
Total Support Group Costs	27,465.08

489 - Telephone & Internet	799.60
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425 - Website & Digital Marketing	33,929.45
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Fundraising Costs

300 - Fundraising Costs: General	17,100.31
301 - Fundraising Costs: London Marathon	6,907.20
Total Fundraising Costs	24,007.51

Project Costs

350 - Design Print & Post	13,090.60
Total Project Costs	13,090.60

Total Administrative Costs	253,659.59
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Operating Profit	(89,041.75)
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Profit on Ordinary Activities Before Taxation	(89,041.75)
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Profit after Taxation	(89,041.75)
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Balance Sheet

The Ectopic Pregnancy Trust
As at 31 March 2023

31 Mar 2023

Current Assets

Cash at bank and in hand

CAF Cash	13,634.21
CAF Gold	95,329.88
Total Cash at bank and in hand	108,964.09

Total Current Assets

108,964.09

Creditors: amounts falling due within one year

Suspense	(1,864.00)
Total Creditors: amounts falling due within one year	(1,864.00)

Net Current Assets (Liabilities)

110,828.09

Total Assets less Current Liabilities

110,828.09

Net Assets

110,828.09

Capital and Reserves

Accumulated Funds	179,869.84
Current Year Earnings	(69,041.75)
Total Capital and Reserves	110,828.09

Notes to the accounts

1. Accounting policies

Basis of preparation of accounts

These accounts have been prepared on the basis of historic cost in accordance with Accounting and Reporting by Charities - Statement of Recommended Practice (SORP 2006) and with Financial Reporting Standards for Smaller Enterprises (FRSSE) and with the Charities Act 1993.

The accounts are prepared on a going concern basis under the historic cost convention.

Incoming resources

Incoming resources are accounted for on a receivable basis.

Investment income

Bank interest is included on an actual receipts basis.

Deferred income

In accordance with the Statement of Recommended Practice (SORP 2006), grants received in advance and specified by the donor as relating to specific accounting periods or alternatively which are subject to conditions which are still to be met, and which are outside the control of the charity or where it is uncertain whether the conditions can or will be met, are deferred on an accruals basis to the period to which they relate. Such deferrals are shown in the notes in the accounts and the sums involved are shown as creditors in the accounts.

Recognition of liabilities

Liabilities are recognised on the accruals basis in accordance with normal accounting principles, modified where necessary in accordance with the guidance in the Statement of Recommended Practice (SORP 2006).

Resources expended

All resources expended relate to marketing and administration of fundraising activities.

Fixed assets and depreciation

All tangible fixed assets, except buildings and freehold land, are stated at cost less depreciation. Items of less than £500 are not capitalised. Depreciation has been provided for at the following rates in order to write off the assets (less their estimated residual value) over their estimated useful economic lives.

Fixtures and fittings: 25% straight line

Computers: 25% straight line

Capital Gains

The Board of Trustees consider that, in order to comply with the Statement of Recommended Practice (SORP 2006), gifts or tangible fixed assets or grants of a capital nature given for specific purposes and fully utilised in the furtherance of the objects of the charity should be credited to the relevant fixed asset fund after the sums have been properly expended on the restricted purpose. The related asset is shown in the balance sheet at the cost of acquisition or subsequent revaluation.

If the related assets are subject to restrictions by the grant making organisation or on their use and disposal, then these restrictions are noted in the fixed asset section of these accounts. In such circumstances, the fixed asset fund created is treated as a restricted fixed asset fund. As the related assets are depreciated, then a transfer is made from restricted fixed asset funds to unrestricted revenue reserves to reflect the diminution in the asset subject to the restriction. In this year there were no restricted funds.

If the related assets are not subject to restriction by the grant making organisation on their use, then the fixed asset fund created is treated as a designated fixed asset fund. As the related assets are depreciated, then a transfer is made from designated fixed asset funds to unrestricted revenue reserves to reflect the diminution in the asset in the year.

Any residual liability to the donor arising from, for example, the assets future sale, is disclosed as a contingent liability unless the event that would trigger repayment of the grant becomes probable in which case a liability for repayment is recognised.

Taxation

As a registered charity, The Ectopic Pregnancy Trust is exempt from income and corporation tax to the extent that its income and gains are applicable to charitable purposes only. Value Added Tax is not recoverable by the charity and is therefore included in the relevant costs in the Statement of Financial Activities.

Funds structure policy

The charity maintains a general unrestricted fund which represent funds which are expendable at the discretion of the Trustees in furtherance of the objects of the charity. Such funds may be held in order to finance both working capital and capital investment.

Restricted funds have been provided to the charity for particular purposes and it is the policy of the Board to carefully monitor the application of those funds in accordance with the restrictions placed upon them.

2. Winding up or dissolution of the charity

If upon winding up or dissolution of the charity there remain any assets, after the satisfaction of all debts and liabilities, the assets represented by the accumulated fund shall be transferred to some other charitable body or bodies having similar objects to the charity.