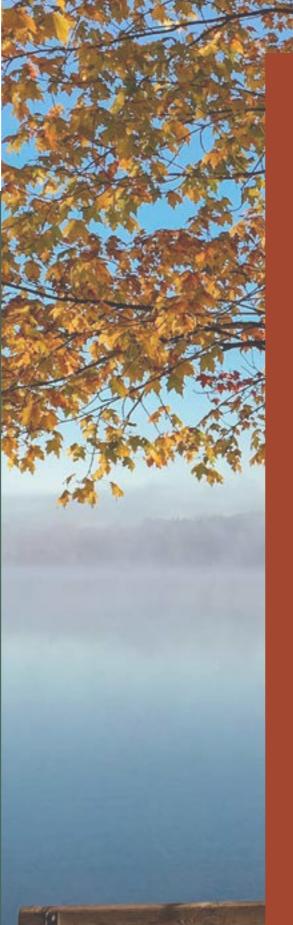
# AFFINITY



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Hello and welcome to the winter edition of Affinity.

This issue is published to coincide with the charity's annual National Fertility Awareness Week, this year 1st November - 5th November. The aims of the week are threefold: changing perceptions and raising awareness of fertility issues; providing vital support for the 3.5 million people affected by fertility problems and finally, raising much needed funds to continue the charity's work.

#YouAreNotAlone is our core message. During National Fertility Awareness Week, we challenge the taboos and myths around infertility and highlight the devastating impact fertility problems cause - physically, emotionally, financially, and socially. It is a chance to highlight where to find help, and what kinds of support are available.

Be part of something special! This is a fantastic opportunity to gather the community together - sharing stories and experiences - we are stronger together and really *can* make a difference. Why not get involved? You can find out more information about each day (and the themes we will cover) within this issue of Affinity.

Over the last few months, we have continued to provide and increase our support groups, health and wellbeing programmes and webinar series. We were joined by two fantastic speakers, Debbie Evans, director of nursing & clinical services, Herts & Essex fertility centre and Ephia Yasmin, consultant gynaecologist and fertility specialist at University College London hospital who spoke about the 'two-week wait'. We know this can be one of the most difficult times when you're going through treatment. You can watch any

of our webinars on our website.

We have started a new Fertility Weight Loss group for those affected by fertility issues and, who are trying to lose weight to be able to progress with their fertility treatment pathway. If you have been told by a clinician to reduce your BMI (body mass index), are feeling a bit lost, under pressure or generally feel like you have a mountain to climb, this is a fertility group who will really understand. Peer support can be a great help to anyone facing these issues. No judgment, no pressure. Just motivation and support. A group to help you reach your goals and improve your overall wellbeing. To find out more please email alice@ fertilitynetworkuk.org

Lastly, our heartfelt congratulations to comedian Rhod Gilbert on his documentary focusing on male infertility: Stand Up To Infertility, which has been nominated for Best Single Documentary at this year's BAFTA Cymru Awards. We are proud to have supported Rhod in making this important documentary and its legacy continues in our work with Rhod and the HIMfertility campaign.

Remember, we are your charity, we are here for you. If you would like to share your story or share anything else, please contact info@fertilitynetworkuk.org.

Very best wishes, Gwenda



# Return to the fold by Dr Catherine Hill, Communications Manager

# Diane's silver anniversary

Former fertility nurse Diane runs the charity's Support Line and is celebrating an amazing 25 years with the charity.



It's nearly seven years since I first began working in communications for Fertility Network UK. Back then, I was still bruised from my own fertility journey - being told I was probably infertile days before my 21st birthday because of blocked fallopian tubes and then, when I finally met the right man in my thirties, struggling and failing to become a mum for over half a decade.

Multiple surgeries, miscarriages, and many thousands of pounds later, I was finally successful, and I will be forever grateful, but the experience left a scar. I didn't think that could ever be a positive thing. I was wrong. As soon as I started working for Fertility Network, I found having personal experience of infertility was enormously helpful. I could empathise emotionally and knew on a literal basis what people were experiencing. It was a revelation: fertility became my second family.

#### **Coming home**

I left just over two years ago to join another charity in the field, Progress Educational Trust. While there I created and led the #ExtendTheLimit campaign to change the restrictive 10-year storage limit for eggs frozen for social reasons. I'm happy to say that we were successful in this, with the Government recently announcing plans to extend the storage limit for eggs, sperm and embryos to 55 years, pending parliamentary approval. It was time to come home.

I am so happy and proud to be back in the fold at Fertility Network. I'm back working with old friends and making new ones too. The charity is going from strength to strength and is a powerhouse for change: campaigning for fair access to NHS-funded fertility treatment for all clinically eligible patients irrespective of their postcode, race or sexuality and leading work encouraging more men to speak up about their experiences of male infertility or being the partner of someone experiencing fertility problems.

#### **Our work**

It is wonderful to see how Fertility Network's reach is extending. There are so many more support groups for people struggling - not just regional ones, but specialist groups too. There is the single women's group, the Black women's group, HIMfertility for men, the Asian women's group, the over 40s group, the LGBT+ group, the moving on from treatment group, the pregnancy loss group and many more. There is support whatever stage of your journey you are at.

A core part of my role is raising awareness of fertility issues with the public and part of the way that I do that is to work with the media, encouraging them to run articles investigating different aspects of fertility, especially ones which tackle the many myths around the, often taboo, topic. But in order to do this, I need to find brave people with experience of infertility who are happy to share their story with the press. If you would like to be a Fertility Network volunteer, get in touch at media@fertilitynetworkuk.org

I am a scientist and journalist by background. Infertility has taken me to some different places, including writing a book about the vagina, Raising the Skirt: the Unsung Power of the Vagina. Being infertile wasn't part of my plan but it has had some unexpected benefits and being part of Fertility Network is certainly one of them.

My goodness, 25 years! That soon flew by!

I have had the pleasure of working with several Fertility Network chief executives, all of which have been, and still are, approachable and very professional in their manner. Many staff have come and gone - and come back again! All of which I see as my 'Fertility Family'.

Having worked in critical trauma care for many years, dashing around working with teams helping to save lives, my knees started to creak. So I decided to move on to another adventure, doing courses in fertility, which led me to running Fertility Network's Support Line.

I also administrate the Health Unlocked Forum which offers all those who post a reply and the support they are looking for.

#### **Treasured memories**

I have been privileged to talk with ladies, gents and couples from across the UK, about all aspects of fertility treatment and the support they need.

Years ago, I used to receive photos of many successes which are kept in my albums here in Birmingham. No names are printed, but I can honestly say I remember how most of them were conceived. I even have a photo of two embryos one lady asked me to keep - the nearest she got to having a baby.

Treatment has changed. Previously, we didn't have the expertise to grow embryos to day five blastocysts. Single embryo transfers were another step forward, as was ICSI; I feel this is one of the most amazing treatment options for sperm problems, allowing many

men to become a genetic father, without the need of a sperm donor. One couple sent me a photo each year, for many years, of their son who was conceived in this way.

Many people who contacted me did become regular callers, so we developed a friendship and trust as I followed them through their fertility journeys. Never meeting any of the clients I spoke with, except one!

I recently had a cataract operation and was waiting, strategically spaced, with the nursing sister (pandemic rules) who had sat down to talk me through my eye drops. She repeated my name three times and began to cry!

#### **Celebrity status**

Well, I couldn't give her a hug, so trying to comfort her the best I could, she said: 'I feel like I'm sitting by a celebrity!'

She had recognised my voice and told me how I had supported herself and her husband for four years! She proudly stood up and showed me her 29 weeks' bump how humbling was that?

Other work has involved helping the BBC with soap scripts when they needed fertility story lines. I remember watching them some months later, thinking: 'I helped with that!'

Well, now I sit here in my conservatory working for the charity that I love so much and hope I can serve them for a bit longer. The staff are my second family, that have stood by me too, during some grim times. I am here for them and all of you if needed.



# Could you be an egg or sperm donor?

A lack of gamete donors is behind the campaign in Scotland to increase the number of people donating.

68% of people in Scotland believe egg or sperm donation is a kind thing to do 27% of those who would donate feel they don't know enough it, or wouldn't know how to donate

49% of people in Scotland would consider donating their eggs or sperm to people who need help to conceive

With the COVID pandemic causing a great deal of issues for fertility treatments in general, one area that has become a focus is the lack of eggs and sperm available from donors. There is now a significant need for egg and sperm donors to come forward in all countries in the UK.

In recognition of this, on the 10 June 2021, the Scottish Government and NHS Scotland launched the first national campaign of its kind to encourage people to become egg and sperm donors, within the four NHS tertiary fertility centres in Scotland (Aberdeen, Dundee, Edinburgh, and Glasgow).

Hundreds of people in Scotland need the help of egg or sperm donors to give them the chance to become parents, providing them with the gift of starting a family. The demand for egg and sperm donations is high, and they are needed for some of the one in six couples who experience fertility problems, as well as same-sex couples.

Minister for Public Health, Women's Health, and Sport, Maree Todd said:

Donating your eggs or sperm is an important decision and this campaign aims to highlight the options available to people who have carefully considered doing so. Demand for egg and sperm donations through the NHS remains high - altruistic donations provide the potential to give the joy of starting a family to others.

Julie and Natalie conceived their son, Thomas, through the use of donor sperm. The couple, who live in the Borders and underwent fertility treatment at NHS Lothian said:

We cannot thank the NHS, the staff at the Edinburgh Fertility Centre, and the generous man that donated his sperm, enough. Without the combination of all three we would not have our amazing little boy, Thomas.

There are no words to explain how grateful we are to the donor, and everyone involved in this journey, and we count our blessings every day. Without the donor our little boy would not be who he is. Our donor helped make us a family. He gave us the best job in the world, being parents. Off the back of this process, my wife is going to become an egg donor in the hope that she can provide another family with the opportunity to feel the way we do.

Raising awareness about the need for donors is vital and whether you know someone who has had a personal struggle to conceive, or you just want to help others, becoming a sperm or egg donor for the NHS is an incredible act of generosity.

To find out more about becoming a donor, visit www.eggsandsperm.scot

### National Fertility Awareness Week



Catherine Hill, Fertility Network's Communications Manager, gives us a heads up on what to look out for and how to get involved.

This year's National Fertility Awareness Week (1 - 5 November) promises to be our biggest and best yet. This is your week, the fertility community's week, so please get involved: watch a webinar, share your story, or hold a Fertili-Tea with friends, families or colleagues.

Make sure to catch these highlights, including three exclusive surveys revealing:

- The national picture on access to NHS-funded fertility services
- What it's like to juggle IVF and employment
- The impact of COVID-19 on fertility patients and treatment

#### **Raising awareness**

This week is the best opportunity to raise awareness of how fertility issues impact so many people and show everyone affected that they are not alone. There is strength in numbers, and 3.5 million people in the UK are facing fertility issues.

Not being able to have the family you yearn for can be an incredibly isolating experience. Far too often people struggle in silence with fertility issues but together - sharing stories and experiences - we can change perceptions, signpost support and raise funds to help others.

The key message of National Fertility Awareness Week is #YouAreNotAlone. We are stronger together. This week is a chance to challenge the taboos and myths around infertility and raise awareness of the devastating physical, emotional and social impact fertility problems wreak.

That's why this year we aim to:

Change perceptions of fertility and infertility

Signpost support across all stages of fertility journeys

Raise funds to enable Fertility Network UK to continue helping all facing fertility issues

National Fertility Awareness Week: changing perceptions, signposting support and raising funds. Download more info and assets here:





Every article in the media, every time someone shares our posts or hashtags on social media, every radio interview given, every time someone talks about what they are doing and why: every story shared helps our community.

By sharing your story, you help us to promote the importance of fertility education by increasing young people's awareness of the facts about fertility, dispelling myths, and equipping a new generation with information which can help them make informed decisions about their futures.

You can help someone struggling with fertility issues to feel less alone and isolated, and to find a community where others understand and can empathise and share.

You can help someone to understand what their friend partner, family member or work colleague is going through.

If you would like to share your story with the media during Fertility Week, or contribute a blog (500 word max) or short video (less than 1min), please email: media@fertilitynetworkuk.org



Brew like you've never brewed before. Everything seems better after a cup of tea, so we're asking patients, the public and fertility clinics to host a face-to-face or virtual Fertili-Tea during the awareness week, selling tea and fertility-themed cakes to friends, family and colleagues. You can play our Fertili-Tea Quiz too.

Download the quiz and Fertili-Tea assets at: https://fertilitynetworkuk.org/fertilitea



#### **Monday 1 Nov #FertilityFairness**

We want to see fair access to NHS-funded fertility treatment for all eligible patients regardless of postcode, race or sexuality. Look out for our survey on access to NHS-funded IVF, info on fertility treatment and success rates for Black, Asian and other ethnic minority fertility patients and hear the experiences of the LGBTQ+ community. Join our #FertilityFairness webinar at 18.30, hosted by Dr Raj Mathur, Chair of the British Fertility Society.

#### **Tuesday 2 Nov #DonorDay**

On #DonorDay we'll highlight the work of the national donor recruitment campaign in Scotland, raise awareness of the need for ethnic minority gamete and embryo donors, and encourage donation. Learn more and share your experiences at our #DonorDay webinar at 18.30, hosted by Nina Barnsley, Director of the Donor Conception Network.

#### Wednesday 3 Nov #HIMfertility

#HIMFertility is all about male fertility. Men are half of the fertility equation and their experiences, thoughts and feelings matter equally. Look out for lots of male voices throughout the day, including comedian Rhod Gilbert, founder of the HIMfertilty campaign. Find out more at our male-only #HIMfertility webinar at 18.30.

#### **Thursday 4 Nov #FertilityEd**

Fertility education is the focus on Thursday and we highlight why it's vital - both in education and in the workforce. We shine a spotlight on our education initiatives: Your Future Fertility which aims to educate young people about the factors that can affect fertility; and Fertility in the Workplace which encourages a supportive work environment and helps employees to know their rights. We will share the results of a Fertility Network and Fertifa survey looking at the experience of fertility patients juggling treatment with work. Join our #FertilityEd webinar at 18.30, hosted by Professor Joyce Harper, Co-founder of the British Fertility Society's Fertility Education Initiative.

#### Friday 5 Nov #TalkFertility

Friday's #TalkFertility is all about celebrating patient voices and highlighting coping strategies for both current fertility patients, anyone thinking of moving on from treatment or considering adoption or surrogacy, and people who are childless not by choice. We will be signposting where to find help, and sharing the results of a Fertility Network survey looking at the effects of the COVID-19 pandemic on fertility patients and their treatment.

# A marathon city effort

Tony Suckling, aka @thehopefulfather on Instagram, tells us about his latest challenge raising funds for Fertility Network. Do let us know about any challenges and fundraising efforts you are involved in.





On Saturday 18 September, I walked from my home in North West London and covered 30 miles - a walking marathon - visiting all the fertility clinics in the city, and finally my workplace, before heading back home again.

This was a massive challenge for me as I have never covered 30 miles in one day and I am used to walking in the countryside or up mountains. My calves began to give way after about 15 miles due to the constant hard pavements, but I pushed forward, struggling towards the end. It was a massive relief to find a warm bath ready when I got home!

It was great to see all the fertility clinics and I met some lovely people along the way. In contrast to my previous preparation for Everest Base Camp, this was a bit of a different challenge. However, it was one that I really wanted to do to raise awareness of just how many clinics are here in London to choose from.

I did my walking city marathon alone, which for me sums up the male fertility journey: doing it all alone until you realise your friends or colleagues are there to help you... or in this case, fill me with tea and biscuits at the end of the day.

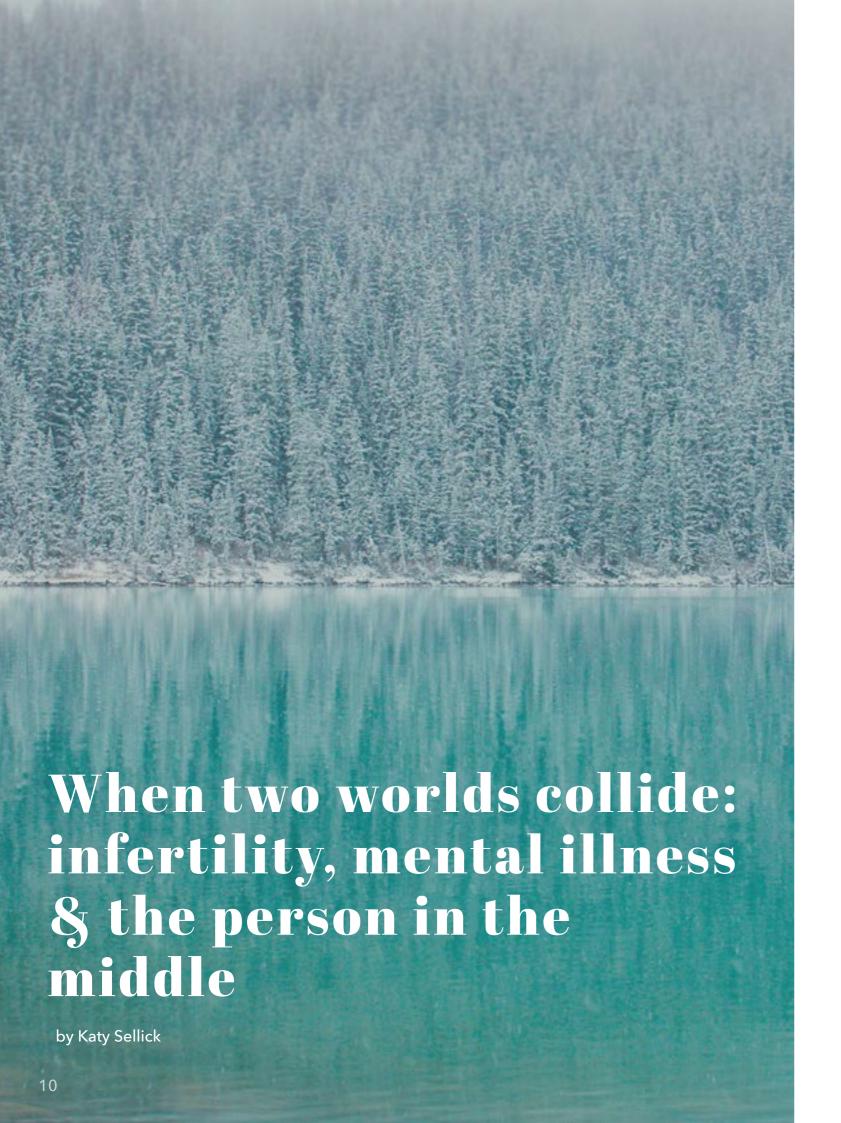
Tony is a member of the team trekking to Everest Base Camp in March 2022 to raise funds for Fertility Network. In preparation for this, Tony is aiming to climb a "mountain" every month, sometimes up actual mountains, other times walking and climbing the distance wherever he is.

Please do donate to Tony's fundraising appeal and help Fertility Network continue to support anyone experiencing fertility problems. You can donate at: www.justgiving.com/crowdfunding/everestforfertility2022

A special thanks to Tony, the Everest Base Camp team, the Fertility Fairies, and everyone else who organised brilliant fundraisers for our charity this year.



week using the hashtags **#DonorDay #HIMfertility** 



1 in 4 people will experience a mental illness.

1 in 6 couples will experience infertility.

I am 1 in 4. I am 1 in 6.

So why, does it feel like you are in 1 in 4, 1 in 6 million?

I am a part of two worlds. I am in recovery for anorexia nervosa, a mental illness that tore my life into pieces. I'm also a member of the worst club in the world, the world of infertility. Both statistically 'common', but I wonder as I walk the streets, where are you all? If common, then why does it feel like you're walking a war alone: suffering in silence, ashamed of my failing body and my mental health.

Why, in 2021, are people still pretending their hearts and minds aren't broken? Because mine is, and statistically, I'm not the only one.

So, this piece is for anybody who knows infertility, mental illness, and the pain when worlds collide, yet you are somewhere quietly lost in between. Lost between knowing you need help for your mental health, but being scared, for if this affects your chances of receiving the help you need to conceive. Scared of the judgment and stigma, surrounding your fertility, your body and your mind.

#### My journey

Four years ago, having been through unsuccessful fertility treatments and traumatic life events, I was diagnosed with anorexia.

When I needed something to control, when the lines wouldn't appear on a stick, I based my self-worth on a number on a scale instead, plugged with hormones, going to scans hearing that my body still hadn't cooperated, life felt wildly out of control, and for somebody vulnerable to mental illness, it was a final catalyst. I punished, hated and neglected my body for failing me.

As a woman, even with help, I couldn't do what others seem to do so easily, but I also felt deep shame, because I was fuelling the infertility fire by restricting my food, pushing my body to breaking point and internally, self-destructing. How could I possibly admit to having an eating disorder, people would think I didn't want or deserve to be a mum.

I know the world tells people to be kind, but ultimately there is a stigma attached to mental illness that I was afraid of.

I left my consultant's office four years ago, advised to gain some weight, then come back. My world fell apart and four weeks later I was admitted to an inpatient eating disorder unit, a place where I have spent more of the last four years in that I would care to admit, but also the place I accepted help, and in doing so, worked with the most incredible, kind and supportive staff, and finally, opened my eyes to recovery.

I started to contemplate a life other than the darkness that I had become accustomed to. It has been, it is, an incredibly difficult road to walk. I have worked closely with dieticians and staff who have helped me to heal my relationship with food, my body and work towards getting back to a place where physically I can try again to have a chance at being a mum.

So, in 2021 as I sat back in the consultant's office, the same office that I left four years ago, I looked around, breathed a deep breath, and told them I was 'ready' to try again.

What followed: appointments, injections, scans, hope, crushing disappointment, negative tests, was the familiar feeling of failure. I couldn't quite grasp it. What do you mean, it isn't working, the world I let back in, the routines I accepted. Four years of striving forwards, yet I never stopped to contemplate it not working once I got here.

The toll it has taken on my mental health has been huge. I knew it was always going to be a risk. Physically, it was a risk. I mean, if you know you know right? The bloating: physically, it was a difficult process to move through. I used to grab my stomach, tell myself I was fat, disgusting, the worst excuse of a human that ever existed, now I must grab my stomach to inject it. Am I 'hormonally induced bloated', or am I everything anorexia

has told me I am for so long?

It was an incredibly confusing time to muster through with my recovery teetering alongside. Just keep going, I would whisper to myself, you want to be a mum, this is how you get there, you don't have room for anorexia, you don't have room to be mentally ill. Even writing that, I feel sad, sad that I thought I had to choose.

#### **Healing difficult relationships**

I knew that fertility treatment put me at risk of relapse, but I think I forgot the pain that infertility brings, the crushing heaviness of feeling broken, the sheer level of loneliness and complete lack of understanding that anybody seems to offer you. I've just spent four years trying to heal my relationship with myself and my body, yet the resentment, frustration and self-blame is as fresh as ever. Infertility is that isn't it. Constantly feeling broken and like you are doing something everything - wrong.

I feel as a society, we women walk around

apart. I scroll through forums and see women describing how inadequate they feel, how much they hate their bodies for failing, was it something they did wrong? Did we eat the wrong thing?

I found my old nemesis; self-blame, quilt, and despair. But these women all feel the same, so perhaps it's ok to feel like this? It must be normal to feel like this.

But is it really ok? Is it ok that we belittle ourselves after already putting ourselves through these horrendous treatments, let alone the emotional turmoil? Research has shown that infertile couples experience significant anxiety and emotional distress when treatment is unsuccessful, there has also been a link between certain hormone therapy having a mental health impact. So why is there not more support, a dialogue that ensures you don't suffer in silence?

As somebody trying to re-learn what a healthy relationship with food is, to see food as equal, not 'good' or 'bad', to not use food as punishment, not over analyse my diet,

calories, weight or exercise. All of a sudden, I with the weight of the world crushing our hearts and minds, with a smile plastered on am back among a world of people speaking our faces. Until behind closed doors, we fall about what to avoid, which food helps implantation, which thicken the uterus lining.

As I stand in a supermarket, I see another checking calories on different sandwiches, and I think to myself, are you struggling with numbers too? Or are you wondering which would be the better option to thicken their lining? Maybe you are neither, but how does anybody get through this?

#### How do I heal my relationship with food, not restrict my diet, but make sure I am doing everything 'right'?

People post pictures of themselves with fries after embryo transfer, but I am afraid of fast food because I struggle to eat fried fast foods; does this mean I want to be a mum any less than somebody eating fries? No - but does it give me another reason to feel like a failure, an undeserving failure? Yes. Mental illness has you feeling like a freak, infertility has you feeling 700 emotions at once. I feel like my head is going to explode, and I just want to know I am not the only one.

I am lucky because I have an army of professionals around me who know my story and have enabled me to even get to a place that I can try, but the gap falls heavy in my actual world. Among friends, family and the women who line the streets, I feel alone, because to know infertility, you must have lived infertility.

To the women who have a mental illness, who feel that because you have something wrong with your mind, you must suffer in silence because it may jeopardise your fertility journey, you do not have to choose.

#### You do not need to ignore one need for another

Living with a mental illness does not mean you can't grieve infertility. You can be in recovery, fall into old patterns that have served you in the past, you can relapse, but you are not a bad, undeserving person. It doesn't mean you want this any less than anybody else.

If infertility and anorexia has taught me anything, it is that sometimes it doesn't matter how much you want something, it doesn't make it easy to stop. In theory I'd do

anything to improve my chances of treatment working, but in practice, it's hard.

You can have the best intentions and all the will in the world, but a mental illness doesn't just go because you long it to be gone.

To the women who abuse your bodies, feel inadequate, constantly tear yourself apart, and month after month, wonder what it is you have done wrong, I want to tell you that it doesn't have to be like this. You don't have to think like this nor live a life fuelled by selfloathing.

#### **Ending the stigma**

Infertility has been described as traumatic as a cancer diagnosis, yet we quietly inject at home, cry behind closed doors, act like we've got something to hide.

The only way to end the stigma, to no longer feel so intensely alone, is to act like we don't. To talk when you want to hide, to try to find your people, because they must be out there. To hope that children are better educated about infertility so if they have to be part of the club, they are better equipped to deal with it. The only way for things to be different, is for us to do different.

Ultimately, anorexia continues to make my life incredibly difficult, and while I could easily blame myself for the situation I find myself in, I know that I did what I could, with what I had at the time.

I found a way to survive, and I am proud of the fact I am still here. Still fighting for the day when I'll be able to tell a little person, however they get here, how hard I worked to get them; that the pain, sorrow and grief, was all worth it, because mental illness and infertility, has made me realise that the strongest person I've ever met lives within

I hope you feel that too, that you are the strongest person in your story, even when you feel like the weakest.

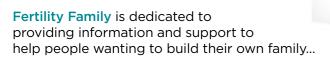
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Dr Gill Lockwood, Medical Director and Fertility Specialist



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1. Montanino et al. 2018

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### TO FIND OUT MORE fertilityshow.co.uk

# Congratulations, Kate!

Fertility Network's Operations Manager, Kate Brian, was awarded an honorary fellowship by the Royal College of Obstetricians and Gynaecologists (RCOG) in September. It was the first ceremony held at the RCOG's new headquarters in London Bridge since the start of the COVID pandemic.

Kate was introduced by Dr Jo Mountfield, Vice President for Workforce and Professionalism, and the fellowship was presented by Eddie Morris, President of the RCOG.

The Fellowship honoris causa is awarded by the RCOG in recognition of the work of individuals who are not members of the College but who have demonstrated the highest levels of dedication, achievement and support for women's healthcare services and/or the work of the RCOG. Only RCOG fellows or members can nominate someone for a Fellowship honoris causa and a panel of assessors reviews all nominations and determines who will be granted a fellowship.

Kate's award recognised her work for the College during her time as Women's Voices Lead from 2016 to 2020. Kate was the RCOG's first Women's Voices Lead, a role aimed at ensuring women's voices are heard at every level throughout the College. Kate made significant contributions to the work of the RCOG, sitting on a wide range of college committees, including the RCOG council, the clinical quality board, and the scientific advisory committee.

Kate was Chair of the RCOG Women's Network, a strategic committee of 14 core lay members and four clinicians from across the UK. Members represent the Network on a wide range of RCOG activities, ensuring the service user perspective is at the heart of RCOG discussions and decisions.

Selected for their expertise and passion for women's health, Network members help the College with the development of guidelines, patient information, training and education, continuing professional development, audit and quality improvement, and policy. They

inform the College about issues affecting women around fertility, gynaecological conditions, pregnancy and birth, right through to the menopause and women's health in later life.

Kate also headed the broader Women's Voices Involvement Panel, an online group of over 600 service users which provides a breadth of experiences from the wider women's health community. The fellowship further recognises Kate's wider work in advocating for women's health at a national level, including sitting on the government's Women's Health Task Force and the National Guidelines Alliance Consortium Board.

Kate was also a member of the National Institute for Health and Care Excellence fertility guideline development group, a former board member of the fertility regulator, the Human Fertilisation and Embryology Authority, and a trustee of the British Menopause Society.

It was a great honour to be awarded the Fellowship honoris causa by the RCOG, and wonderful to be able to attend the ceremony in person at the College. The fellowship recognises the role of women's voices within the College and the work of the Women's Network, and I was delighted to accept it.



## Clinic Ambassadors: a bridge between charity and clinic



# Meet our new Treasurer



A warm welcome to Lucy Thorn

We are delighted to introduce our very first Fertility Network Clinic Ambassador, Maria Satchi. Maria works as a consultant urological surgeon and andrologist at Dartford and Gravesham NHS trust and is passionate about good patient care and support.

The Fertility Network Clinic Ambassador is a new role, open to doctors, nurses, embryologists, andrologists or counsellors, who will work with us to try to improve the patient experience. The Ambassadors will help to raise awareness of Fertility Network with patients and fellow clinicians, acting as a liaison between the charity and colleagues in the clinic.

Clinic Ambassadors will share details of the charity's support services with patients and colleagues, including our regional and specialist fertility groups, our support line, our webinars, and our fundraising and awareness-raising campaigns. They will also be encouraged to share ideas they have to improve or extend Fertility Network's services.

Maria Satchi is delighted to be our first Clinic Ambassador. It was working with a couple who'd been through years of tests and treatment, focused on the female factor, with no support, that led Maria to look for patient resources. That search brought her to Fertility Network and the HIMfertility campaign. She now regularly refers patients to the support the charity can offer.

Maria works across a broad field, covering urology and andrology and also runs a dedicated fertility clinic. 'I find men often come to see me when they're some way

along the pathway, often after they've been having investigations focused on their female partner for a year or more,' she says. 'When people think about fertility, they think it must be to do with the woman and there's a need for more education.'

Maria's aim is to improve the care every patient receives when they start on the route of fertility tests and treatments.

'Infertility is about a couple,' she explains. 'It's not just about looking at one side. Both need to be investigated, but often it's only the female who is referred and sometimes it is only the male. Care is often fragmented and the gynaecologist can be in one hospital and the andrologist in another, with no communication between the two. My goal is for patients to access a streamlined, efficient pathway, and to have access to to patient support as they embark on what can be a challenging journey.'

We're keen to expand our clinic ambassador scheme across the UK so we can work more closely with professionals in the field to ensure all fertility patients are made aware of the support services available through the charity. Ambassadors will be able to use their own experiences to help us to shape the future of our services and to work together to offer the best possible support to every patient, so no one needs to go through fertility tests and treatment alone.

If you are interested in becoming a Fertility Network Clinic Ambassador, please email kate@fertilitynetworkuk.org. We look forward to hearing from you! I joined the Board of Trustees of Fertility Network UK in July 2021 as Treasurer.

While I am new to the board, what I have seen so far is inspiring and exciting and I look forward to using my skills and expertise to contribute towards the continued success of the charity.

#### **Working for royalty**

I qualified as an ACCA accountant in 2012 and I am currently working as head of finance to their Royal Highnesses The Duke and Duchess of Cambridge. I studied my accountancy qualification with my current employer and have worked for them for nearly thirteen years. I lead a finance team that supports the different priorities of the family, making it a diverse and interesting role, with a particular focus in the 'not-for-profit' sector.

I discovered Fertility Network when I was listening to a podcast about fertility. Two volunteers were speaking so eloquently and passionately about wanting to break the often-taboo topic of fertility and helping others to understand what a huge life challenge this can be, something I could relate to on so many levels.

#### My fertility journey

Applying to the position of treasurer seemed like a great way to use my professional experience in a subject area that has been such a huge part of my personal life.

As a fertility patient myself, I really do understand the importance of support, knowledge and feeling connected, all of which Fertility Network provides in abundance.

Ilive with my husband, just outside of London. We are lucky to have supportive family and friends and enjoy spending time with them all. I like to go walking, sometimes running, to keep myself physically and mentally fit. I also love to travel and see new places, although this has been harder to do in the last couple of years!

#### Infertility doesn't discriminate

As a couple, we have suffered from infertility for over seven years, and it has been very difficult juggling our treatment against our careers, studies, relationships, and general life

Even now I feel a sense of shock at times that this has happened to us. It really is non-discriminative, and it could happen to anyone, which is why I feel so strongly about supporting Fertility Network in helping people through this, no matter who you are and what your circumstances may be.

No one journey is the same, and Fertility Network aims to cover a variety of issues including raising awareness and tackling difficult subject areas such as the postcode lottery, male infertility, being 'childless not by choice' with important initiatives such as HIMfertility, more-to-life, support lines, and much more.

It is lovely to introduce myself in this issue of Affinity and I hope that my contribution to Fertility Network can help to make the experience of all those going through similar struggles a little easier.



If you have completed your family, or cannot have more treatment, you may need to make a decision about any remaining embryos.

When the embryos were frozen, you filled in a form giving your consent for them to be stored. At this point, you will have said how they could be used in the future, but you may not have expected that you would have any remaining embryos.

All we were focused on was getting pregnant and having a baby. We were really pleased to have some embryos to freeze. We did not ever think there might be any left over. It was the last thing on our minds.

If you do have embryos remaining, there are a number of options clinic staff can discuss with you, and you will want to make sure you have time to think through your choices.

### Saving embryos for future treatment

If you think you may want to use your frozen embryos in the future, you can choose to

keep them in storage. You will need to pay for this, and there are time limits on how long you can store embryos, so you will want to think about when you will be ready to have a frozen embryo transfer.

#### **Delaying your decision**

Sometimes when people cannot decide what to do with remaining embryos, they opt to leave them in storage. This can give you time to think, but you will need to make a decision eventually.

Our frozen embryos felt like our future children. It was hard to know what to do. We knew we couldn't have more treatment, but we were ignoring it because it was too hard to talk about. We were keeping a window of having another child open although we knew in our hearts that wasn't possible. We saw a counsellor and there were a lot of tears, but it helpedus to bring it out in the open and talk about the choices.

If you are certain you do not want to use your embryos for treatment but are struggling

to decide what to do with them, let your clinic know. You may find it helpful to have a session with the clinic counsellor to help you talk through your options.

#### **Donating your embryos**

You can choose to donate your embryos, either to another patient or to research or training. Not every clinic has the facility for every option, so not every option for donation will necessarily be available.

If the clinic has a link with a research project, you may choose to donate the embryos to scientific research. Work like this uses embryos in their first days of development to help scientists understand more about fertility, miscarriage, and medical conditions. The embryosare not allowed to grow beyond 14 days, and by donating them to research you may help improve treatment for other patients.

We'd had such a difficult fertility journey before we finally had our children. We were given information about the research and donating felt like a positive step. Our embryos could be used to make things better for other people in the future.

Another alternative on offer may be to donate your embryos to your clinic for training. This helps clinic staff ensure they are up to date with the latest techniques in treatment so this will benefit other patients.

Finally, you may choose to donate your embryos to others who are trying unsuccessfully to conceive and need both donor eggs and sperm. If you think this is something you may want to consider, you would have counselling first. It is similar to being an egg or sperm donor, so it is important you have had an opportunity to discuss all the implications of donation.

### Removing the embryos from storage

The other option for your remaining embryos is to have them removed from storage. Once they are removed from the storage tank, they would thaw and would be left to perish.

Sometimes people ask if they can take the embryos home to bury them, but this is not usually possible. You can still choose to have a ceremony to mark the occasion if you would like to.

We had a choice of donating the embryos for training or to another couple, and neither of those felt right. In the end, we decided we'd let them perish. It wasn't easy. I still always think about them on that day, but it was the right decision for us.

#### What happens if we don't agree

Sometimes couples find it had to come to a joint decision about what to do with remaining embryos. It is difficult if you feel differently about your choices. If you are struggling to agree, talking to a counsellor may help you to discuss this through with one another.

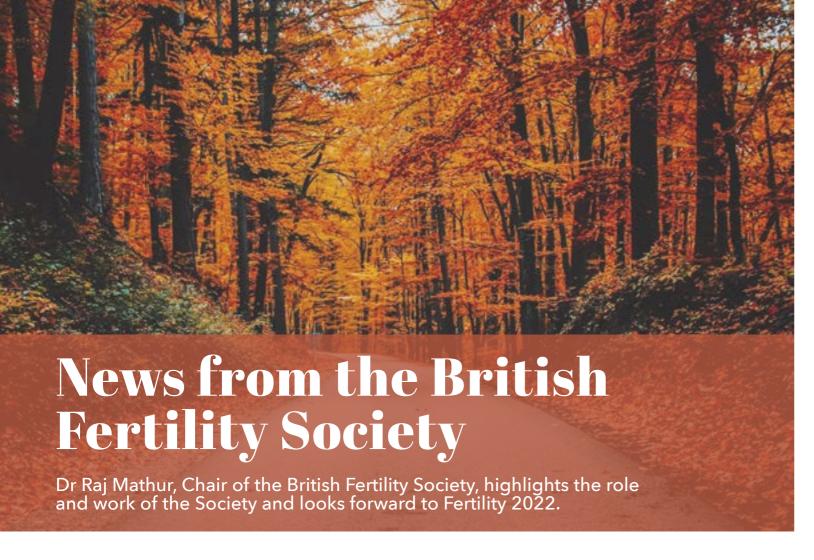
Remember: There are no right or wrong decisions about what to do with remaining embryos as this is a very personal decision. What is important is to make sure you have time to think about the options and to discuss them with staff at your clinic or a counsellor.

It can be hard to have to make a decision, but the key to this is finding what feels right for you.

#### **Further resources**

HFEA information on donating embryos: www.hfea.gov.uk/donation/donors/donating-your-embryos

HFEA information on donating to research: www.hfea.gov.uk/donation/donors/donating-to-research/



The British Fertility Society (BFS) is an organisation that represents professionals involved in delivering fertility care. We have around 1,100 members, ranging from doctors, nurses, embryologists, counsellors and managers to lawyers who are interested in how fertility treatment is carried out in the UK. If you have had fertility tests or treatment, chances are that you will have come into contact with one or more of our members!

The BFS provides training and professional development opportunities for its members, helping to keep them up-to-date and evidence-based in their work. Of course, good patient care requires that we should be appropriately trained and aware, and the Society carries out a number of activities including courses and meetings to achieve just this.

#### **Working with Fertility Network**

We also develop professional guidelines, based on the research evidence, to support our members in delivering care. We have an executive committee where we decide which areas require guidelines to be developed, and it is very important to us that meetings of this committee are attended by a representative of Fertility Network. This ensures that patients have a voice in our discussions.

#### The impact of COVID

Like most parts of healthcare, the fertility sector was affected hugely by the pandemic. We are aware of the impact that suspension of services, delay and social distancing within clinics have had on our patients. At every stage, we have had to balance the need to keep patients and staff safe, with the need to continue with time-sensitive treatment. We developed guidance for clinics to help them resume services safely, including the need for patient support.

It is good to see that the number of treatment cycles in most parts of the country is nearly at the levels seen before the pandemic. However, there are still backlogs and long waits, even before patients are seen by a fertility specialist. Whenever we can, we have emphasised the need for fertility patients to

be prioritised, because of the potential effect of a long delay on their chance of success.

#### **Future work**

Going forward, we are keen to deepen our relationship with Fertility Network, including developing joint patient information resources and ensuring patient input is taken for each and every guideline. We are also looking forward to participating in joint events where we can discuss topics that patients want more information about, as well as answering questions sent in by patients. I recently attended a Fertility Network webinar about COVID vaccines and fertility, and it was fantastic to see the patient engagement and interest.

At the same time, we see a role for the BFS to provide a professional voice in support of our patients, so that we can highlight areas where the regulations or NHS provision needs to be improved. For these issues as well, we work closely with Fertility Network and like-minded organisations.

### **#ExtendTheLimit for eggs, sperm** and embryos

One important area of our activity recently is our support of the #ExtendTheLimit campaign. This was launched by a number of organisations to allow people storing their eggs, sperm or embryos greater choice and autonomy when it comes to their reproductive future. The law as it exists only allows gametes and embryos to be stored for a maximum of 10 years, unless there is a diagnosis of 'premature infertility'.

There are several problems with this, including the problem that there is no agreed definition of 'premature infertility', meaning that the same patient could be treated differently in different settings. A short time limit may have made sense in the past, when we did not know about the safety and efficiency of storage, but the evidence now shows that the length of storage is not a major factor affecting the results of treatment.

Finally, an arbitrary time limit particularly disadvantages women who freeze eggs for their future fertility, say in their mid-20s. They

would only be in their mid-30s when the 10-year limit expires, forcing them to either dispose of their stored eggs or fertilise them with donor sperm, both of which seem to be an unjustified limitation of their autonomy.

We are delighted that the government has accepted the argument of the #ExtendTheLimit campaign and are looking at bringing in regulations that will allow all people who freeze eggs, sperm or embryos to keep them for the same length of time. Now our priority is to ensure that all patients benefit from this change, including NHS and private patients and those using donor gametes or embryos. I am hopeful that the new law will be a great improvement, and one that would have been brought about by a collaborative approach across the UK fertility sector.

#### #FertilityFairness

A constant priority for the BFS when it comes to our patients is that they should be able to get the treatment they need and which is clinically justified for them, irrespective of their ability to pay. Unfortunately, with the honourable exception of Scotland, NHS provision of fertility treatment remains poor and variable, largely determined by your postcode rather than your clinical needs.

This is an unacceptable situation and we will use every opportunity, along with Fertility Network and other allies, to highlight this and press for fair funding. We have to make sure patient voices are heard when decisions about funding of fertility treatment are made, and I believe that professionals also have a role in amplifying that voice and helping it reach the right forums. At Fertility 2022 - our next annual meeting in January 2022 in Liverpool, we will once again give time and support to Fertility Network to make the case for fertility fairness.

Looking beyond that, the National Institute for Health and Care Excellence (NICE) is looking at revising its guidance on fertility investigations and treatment. This will be a major event for patients and professionals alike, and we will be engaging with it fully.



The Fertility Book is the latest addition to the fertility bookshelf, written by leading fertility consultant Professor Adam Balen, and reproductive biologist and nutrition scientist Grace Dugdale. It's a thorough and comprehensive guide to fertility and treatments, which guides the reader through each step of the fertility journey, from preconception care to treatment outcomes.

The first part of *The Fertility Book* focuses on ensuring the reader understands how ovulation and conception works, and gives diet and lifestyle tips for fertility. There are helpful tips for making sure you're getting the nutrients you need, advice about common myths about food, and guidance on why some popular restrictive diets may be best avoided. It deals with the supplements which may be recommended and explains where dietary changes can make a difference.

There's also a useful chapter on stress and fertility issues, covering how to deal with negative emotions and to care for yourself properly.

The Fertility Book addresses all the factors which may affect male and female fertility with thorough, clear and detailed explanations. It explains when to seek medical help and has a comprehensive guide to the tests you may expect. Common causes of fertility problems such as endometriosis and polycystic ovary syndrome are explored, along with some of the rarer issues which can lead to fertility problems for both men and women. There are clear diagrams to help with visualisation and brief case histories to give real life scenarios.

The section on IVF and associated treatments detail exactly what happens at each stage, including the different protocols, and the chances of a positive outcome, the latter showing that cumulative success rates for three cycles of IVF for women under 38 are much higher than we are sometimes led to believe.

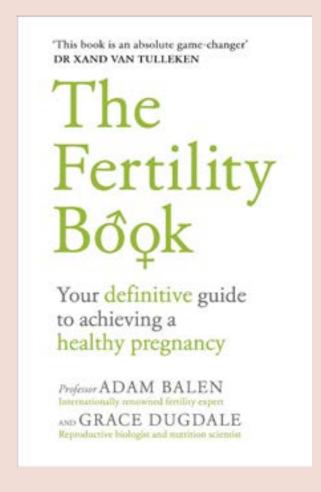
There's a very interesting section on the ethics of fertility treatments which covers the current postcode lottery for NHS-funded treatment, questions about who has a 'right' to treatment, whether there should be age

limits for IVF and the ethical issues raised by treatments such as egg sharing.

What's so special about *The Fertility Book* is that it is written with genuine expert insight, gathered from years of experience working in the sector, with a true insider's understanding of fertility problems, tests and treatment, as well as access to knowledge about the latest developments and updates.

It's all too easy now to find information about every aspect of fertility and a quick Google search can leave you feeling overwhelmed by the sheer volume of advice. Here, it's clear that all the research has been done for you and the list of scientific papers referenced within *The Fertility Book* shows the detailed evidence base for the information given.

The Fertility Book will help empower anyone who has concerns about their fertility, allowing you to feel informed and prepared for what can otherwise seem a complex and confusing pathway through tests and treatment.



# Introducing the Black Women's Group

Our volunteer Ogechi Ekwegh highlights the work of our Black women's support group and encourages others to join and experience its benefits.

The Black women's fertility group is one of the many support groups run by Fertility Network. The aim of this group is to support Black women going through fertility problems.

I came across a post promoting Fertility Network's support group for Black women, and decided to join the Facebook group to get support from women like me. Once I joined, I suggested to the group that we should meet on Zoom. I was happy to be asked by Fertility Network if I would be interested in becoming the volunteer for the group, and took up the opportunity. My role involves chairing the group meetings monthly on Zoom.

#### A peer-led safe space

I volunteered because I think it's a great opportunity to help other Black women going through fertility struggles. It gives them a chance to feel their voices are heard in a safe space. The group is a peer-led group, however, from time-to-time guest speakers come to give a talk to the group. The guest speakers may include medical professionals, or other professionals who specialise in infertility.

#### **Guest speakers**

Recently we had Dr Christine Ekechi join us, who is a spokesperson for race equality for the Royal College of Obstetricians and Gynaecologists. She gave a talk on infertility for Black women, followed by a Q&A session.

Dr Ekechi talked about different fertility treatments, fertility experiences in different races, IVF success rates supported with data, and Human Fertilisation and Embryology Authority guidelines. Many other topics were also discussed.

In September's meeting, counsellor Kezia Okafor gave a talk on managing mental health when going through fertility problems and treatments. Infertility can have an impact on mental health and it's important to create awareness. It can be a lonely journey, and having the right support can help women feel they are not alone.

We hope to have more guest speakers giving talks followed by Q&A sessions in the future. The group really values regular advice from medical professionals, and stories from people in the public eye who have been through fertility struggles. Fibroids is also a key topic as Black women have a higher rate of fibroids compared to other races.

The Black Women's Group is a great support system for Black women going through infertility struggles. Do come and join us.

For Zoom login details, email: blackwomensgroup@fertilitynetworkuk.org

Or join the closed Facebook group for further

www.facebook.com/groups/ blackwomensfertilitygroup



#### Thinking about starting a family?

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Fertility Network's Anya Sizer shares her experience and advice for investigating adoption after fertility treatment.

The decision to investigate adoption for us as a family had always been a viewed as a positive one. We had endured six years of treatment and were hugely fortunate to have had two children from IVF, before deciding to also explore adoption.

In hindsight, I would now challenge some of our initial assumptions that this decision would be just another route to parenthood. Adoptive parenting is so much more complex than that, and as Krish Kandiah, CEO of the adoption charity Home for Good, so rightly puts it:

# "Ultimately adoption is not about family completion but the flourishing of vulnerable children"

Our son came to us at 15 months, a tiny bundle of energy. He was wonderful, but scared and angry about the change in his environment. We faced months of barely any sleep, and days when we were exhausted and overwhelmed. It was a lonely time when we felt we really should be coping well but in reality, each day felt like just scraping by.

I now know that what I was facing, along with many new parents after adoption, is labelled post adoption depression. A challenging mix of lack of sleep and unrealistic expectations from both myself, and others, that led to a deep sense of sadness and isolation. This situation is perhaps even more acutely felt by those whose route to parenthood comes after years of treatment. It is easy and more than understandable to see adoption as the answer to infertility but that is just too simplistic a summary.

Adoption can be an amazing route to parenthood, but it isn't for everyone, and it doesn't magically "solve" the hurt of fertility struggles.

Our son was diagnosed early on with foetal alcohol spectrum disorder, a lifelong



condition which means he will always require extra support and care. It was a gradual process of coming to terms with this and has involved many battles on many fronts.

Adoption has completed our family and we have a lively, funny, affectionate bundle of craziness to call our son and brother, who we genuinely love equally to our birth children. We would not change it for the world, although the process of arriving at this statement has not been easy.

#### What have we learned?

The first thing, I would argue, is that adoption is an incredible option but not for everyone, and certainly not one that should continue to be a default domain for the infertility community. To make it so demeans both the child, and the prospective parent. It is vital to explore the realities of adoption, to get as much information and background as you can, and then decide if this is right for you.

For example, the average age of a child waiting for adoption in the UK is just under four years old and they almost certainly will have a history of neglect, abuse, and probable special needs associated with this. The realities of parenting such a child mean that "normal" parenting is often not the most helpful route, and a new therapeutic model of parenting will almost certainly be needed.

Again, we really do need to be realistic about who investigates adoptive parenting, and we certainly need to challenge the concept of "just" adopting.

#### There is no "just" in adoption

There is some fantastic training and some useful books, but the reality is that you can only prepare so far without meeting your individual child. Looking into the realities of adoption, and working out how you will best support yourself going forward, by putting structure in place, is essential.

I would also encourage a little time out of the fertility rollercoaster, such as a holiday or a break, and then doing anything that helps you reconnect with who you are holistically. As a charity, our helpline is there to support and listen. Our support groups provide peer support from people who understand, and we provide information and help for any stage of the journey.

#### **Preparing for adoption**

So much of the fertility process can be defined as a form of grief, so it can be helpful to realise that you will deal with the ending of treatment in many ways, with a variety of emotions, and that this is normal and healthy.

It may be useful also at this stage to allow some time for talking therapies and peer support to process some of this grief, before rushing on.

When looking specifically at adoption most agencies will ask for at least six months to a year after treatment before starting the process. This can seem a long time at first, but you can still use it to be moving forwards and exploring the realities of adoption.

I would look at organisations such as Adoption UK, and read one or two books, to help give a realistic view of what to expect. Adoption is an amazing route to parenting, but it is, in many ways, different from raising a biological child, and this needs time to explore and process.

If possible, speak to other adoptive parents and try to start thinking of what type of a child you could imagine in your life. Think about what support structures you have around you, and what you might need practically to proceed.

There are also some fantastic webinars for prospective adopters that can help with the realities of this new venture and help as you make the decision to progress down this new path.

#### Finding your support network

The second key learning would be the fundamental need for support when adopting a child. Another phrase I used to happily throw out before we met our son, was that it "takes a village to raise a child".

Since becoming an adoptive parent, I know now this is not just true, but vital in making such a family work and remain hopeful, during the inevitable turbulence. As with infertility, we have found that some people will just not understand or be able to empathise with your experience. However, there will be others who do, and who fill the gap for you when life just seems too difficult to navigate.

Adoption after treatment is a wonderful option for some people, but should not be an "assumed next step" to be taken lightly. It requires the key tools of tenacity, support, and resourcefulness. Though in truth, anyone who has faced the demands of treatment has already demonstrated how to cope and how to use these tools effectively anyway!

Whatever you decide, support is here for you at Fertility Network. Do get in touch to let us know how we can help.

# Volunteering with Fertility Network's Volunteer Co-ordinator Linda Edgar shares more about our volunteering opportunities.

Our volunteers are a vital part of our foundations, helping those who may otherwise feel like they are alone in the brutal battle of infertility.

Volunteers within the Fertility Network UK family come from all walks of life. A deliberate decision from within the charity is that many of these are peer-to-peer. People on a fertility journey will encounter many professionals in the fertility field, but when looking for support, sometimes they just need the emotional kind from someone who 'gets it'.

Peer-to-peer support brings a different kind of empathy, support and understanding. The patients who use our support network really appreciate that there is such an outlet for them. Patients can unload and share if they want to, or they can simply listen in to group discussions. Many find that the more they attend, they braver they feel about sharing their own experience.

#### Why do people volunteer?

Volunteers really hold the baton for Fertility Network UK, spreading the word about what we do and why we do it, encouraging others to become volunteers and do the same.

Our volunteers say that through this, they make lifelong friends, gain confidence, have an enriched sense of wellbeing and purpose, and grow their own networking skills.

Not only this, but many report the psychological phenomenon 'helper's high', meaning they get a great sense of satisfaction and that 'feel-good' vibe from what they do.

#### Our volunteers are amazing

Fertility Network UK rely heavily on our volunteers. Without them, our support groups, zoom calls, WhatsApp groups and Facebook pages would not exist to the extent in which they do.

Our media volunteers are an equally important part of our volunteer team, sharing their experiences with the media, helping us to get the press coverage that we do, and highlighting important issues at a national scale.

Let's not forget those who fundraise on our behalf. As a charity, we rely heavily on donations to ensure that no one of a fertility journey feels like they are alone.

Volunteer interactions, such as sharing personal journeys, keeping confidences, and experiencing the ups and downs of the patients and their peers, make our volunteer community unique, they really do keep us running!

Volunteering and helping others is a wonderful way to gain perspective on your own situation, and that can make you more appreciative of what you have.

Interested in volunteering? Have a look at our Volunteer Information Guide on our website.

fertilitynetworkuk.org/get-involved/volunteering



providing free support services to anyone affected by fertility issues.

If you can donate to Fertility Network UK, please scan the QR

If you can donate to Fertility Network UK, please scan the QR code on your phone to explore ways to #HelpUsHelpOthers. Thank you.





# Fertility in the Workplace

Anya Sizer shares an update on our work with employers to help educate and shape policies that support employees experiencing fertility challenges.

We have now reached over 400 employees through fertility awareness events and it's because of Anya that our relationship with Fertility Network UK is so well established. She's the natural 'goto' for expertise, support and counsel on approach helping to shape future activity and bring insight that will help countless employees and line managers break the taboo and support our overall focus on improving employee wellbeing. Thanks for everything you have done and will continue to do!

It is, as always, a huge privilege to head up the Fertility in the Workplace Initiative for the charity. We are currently working with numerous employers, ranging from banks to international tech companies, government departments and major supermarkets, with everything in between. We are always keen to stress that no one session is the same as another and the process starts with hearing about the specific needs of an organisation, where they are now, and where they want to be.

Very often, the process starts from a conversation with someone who has experienced infertility, and who is brave enough to acknowledge the gap within their organisation and start that internal conversation around this issue.

What is wonderful is that almost every time that process begins, the instigator meets with others within the workplace who have all had a common shared experience. Conversation begins, and support then flows with greater ease than if the issue was being approached in the abstract. It is nearly always the personal

story that acts as the catalyst for change in the workplace, and we are always grateful to those brave people who start the ball rolling. Sessions recently have focused on overviews of fertility struggles within the UK, looking at the emotional impact and the subsequent effects on the workplace.

We have also led specific sessions on male infertility, fertility preservation and awareness, childlessness, and LGBTQ issues. Every week we are contacted by new and different organisations and it is fantastic to see the increasing awareness, not just of the reality of infertility, but of the need for practical and emotional support.

Looking forward, we have a number of workplace sessions coming up during the rest of the year, and early into 2022. I believe this will be an area that sees huge growth and provides some fantastic opportunities for us as a charity. The real benefit will be, as with so much of our work, in amplifying the voices of those affected by fertility issues, and in helping them to get the support they so need.

As one team recently summarised:

This work with The Fertility Network has encouraged colleagues across the business to share their own stories and Anya has supported us every step of the way in removing any stigma around infertility in a sensitive and informative way. We are really looking forward to our continued work together in the future.



# England

We have 36 fertility groups in England, covering 38 counties, and after focusing on areas where we've previously not had a support group, we now have support groups in most of England. With amazing volunteers signing up all the time, we don't think it'll be long before we can boast 'all of England'!

Our volunteers run our peer support groups via Facebook and since the pandemic, we've held our group meetings online via Zoom, meaning many more have attended due to the ease of logging in, over travelling to face-to-face groups, which may have been a fair trek for them. Although we are excited about starting our face-to-face groups again, having seen how popular our online groups are, we will continue to offer these too.

Our fertility groups are all closed Facebook groups. Anyone can search and find them, but they will then be asked membership questions to ensure they can be accepted into the group. Only members can view who is in the group, and see any posts within it. We know Facebook is not for everyone in the TTC community, so each region has a dedicated email address, with many providing one to one support for patients in their area.

We now have 10 specialist groups across England. These groups focus on guest speakers such as specialist counsellors. For example, in the last couple of months we have had BICA Counsellor, Suzanne Dark, talk to our Secondary Infertility Group, and BICA counsellor, Caroline Spencer, talked to our Over 40's group.

A recent addition to our specialist groups is our Black Women's Group, which launched in the spring of 2021. Guest speakers have included, Kezia Okafor, who talked about coping with mental health and infertility. Another, more recent, guest speaker for the Black Women's Group, was Dr Christine Ekechi who is part of the RCOG's Race Equality Task Force. This group has grown to more than 50 members.

Continuing on the specialist group theme, we were recently joined by Carole Gilling-Smith, Consultant Gynaecologist from The Agora clinic, in Brighton, speak to our Single Women's and LGBT fertility group about using donor sperm. Our Moving on from Treatment group recently invited Anya Sizer to talk to the group about adoption, and are soon to be joined by Yael from DC Network to talk through donor treatment. Both Jessica Hepburn and Lesley Pyne have also spoken to the group about living without children.

Our More to Life group supporting those living without children, is volunteer-led and has an online meeting which takes place monthly; the closed Facebook group is also very active. Members of the group were recently invited to join our Living Without Children webinar that took place during World Childless Week. The webinar was hosted by BICA Counsellor, Debbie Howe, and author, Lesley Pyne and is available to download on the Fertility Network UK website.

To get in touch with the England team, please email:

Hannah@fertilitynetworkuk.org

## Scotland

Sadly, here in Scotland, we are still seeing record numbers of people testing positive for COVID-19, only causing further angst for those on their fertility journey. We hope that our ongoing online groups can offer some support to these people.

We've also been experiencing high call volumes from people struggling at work, particularly those working in frontline, people facing roles. We have been supporting these patients in their discussions with their employer, to help them to understand the nature of fertility treatments and how employers can support their employees in remaining safe, with minimal disruption to their businesses.

We've continued our online yoga classes and mindfulness courses, and have set up further support groups via Zoom, WhatsApp and Facebook. Our team facilitates and monitors these groups, so that patients have access to support and information when they need it. We now have geographical groups, so that patients can talk to others who attend the same clinics, and are hosting specialised groups including TTC Endometriosis, TTC Pregnancy Loss, TTC Solo and TTC 35+. Feedback from our patients in these support groups continues to be positive.

After our successful webinar series offered to the LGBTQ+ community earlier this year, we are planning on delivering another six-week series in November. The feedback from the first event was extremely positive and we will build on that success for the second series. A key part of the work in Scotland is educating young people on how to protect their future fertility. This autumn saw our team at Fresher's weeks across Scotland, most of which were hosted outside to ensure safety of the students and stall holders. As September weather can be changeable in Scotland, these events were a challenge on some days, particularly trying to keep our leaflets from taking flight in the strong winds! However, it was fabulous to engage with students face-to-face again, after such a long break, and the students were really interested in the work we do in the charity.

To support the work with students, we encourage students to join our volunteer student ambassador role. This is an excellent opportunity for students to gain confidence in communicating with their peers by promoting the benefits of the Future Fertility programme, and at the same time help them stand out in the jobs market. We particularly welcome students studying medical and science degrees.

We would like to thank the Scottish Government and the clinics across Scotland for their continued support of our services. If you need to get in touch with the Scottish team, you can reach us at:

SharonM@fertilitynetworkscotland.org Sarah@fertilitynetworkscotland.org Anna@fertilitynetworkscotland.org

"Thank you for your fantastic presentation yesterday. It was brilliant that you could still help via Teams." Kathryn Hardie, Midwifery Lecturer, Edinburgh Napier University "Thank you so much for your presentation, it was really interesting and informative."
Tatiana Zorina,
Period Poverty Project Officer,
Dundee and Angus College

### Wales

It has been a busy summer for us in Wales; we have worked with some fantastic organisations, supported some amazingly resilient individuals and, in September, we welcomed a new Project Worker into our team. Nicola has over 20 years' experience working across the fields of advocacy and mental health and she will be providing impartial information and tailored support to anyone who needs it across Mid and North Wales.

We recognise how difficult it is to lose weightandhowstressfulit can be when it is a barrier to getting the fertility treatment you need; so, in June, we launched a 'Mindful Eating' course for those who must reduce their BMI to be able to progress along the fertility pathway. Over a six-week period, 12 participants worked with Veronica Ellis from Mindfulness Connected Learning, to explore their relationship with food, how to think more mindfully about their eating habits and how to recognise when and why they turn to food to manage difficult emotions.

Fertility Network UK is part of the Women and Girls' Health Coalition, working on a third sector coalition policy and a public affairs campaign proposal to develop a Women's Health Plan for Wales. We are thrilled to be working alongside organisations such as Fair Treatment for the Women of Wales (FTWW), British Heart Foundation Cymru, Endometriosis UK, Tommy's and Mind Cymru to secure the Welsh Government's commitment for its implementation.

This September saw us attending our very first freshers' events at Glyndwr University in Wrexham and at Aberystwyth University. It was fantastic to finally get out (quite literally into tents!) to talk to students about how they can safeguard their future

fertility. As a charity, we hear far too often "I wish I had known that sooner" or "why did no one tell me that before?" so, we spent time discussing the factors that might impact on an individual's ability to conceive, and, when and how to seek help.

We had conversations around untreated STIs, the importance of using condoms and getting tested; anabolic steroid misuse and how certain substances can disrupt hormones, inhibit sperm production and speed up the rate at which eggs are lost. We stressed the importance of seeking medical help for any lumps or swellings in the testicles and why it's important to see a GP about abnormally painful, heavy, or irregular periods.

We have collaborated with some brilliant organisations over the last few months, such as the Daisy Network, Diabetes UK Cymru, Brilliant Beginnings, and Cardiff University, to deliver information sessions on a wide variety of issues, including Premature Ovarian Insufficiently, diabetes and fertility, IVF surrogacy, epigenetics, and endocrine-disrupting chemicals. We continue to develop our All-Wales Information Group programme and look forward to many more informative sessions going forward.

For details of all our peer support and information sessions, see our 'Wales Groups' page on the website, and for further information on any of the above, follow @fertilitynetworkukwales, or get in touch with:

Alice@fertilitynetworkuk.org Nicola@fertilitynetworkuk.org Emma.Rees@fertilitynetworkuk.org

# Northern Ireland

After a very difficult 18 months for fertility patients in Northern Ireland, it is heartening to see that waiting times for patients are beginning to improve and treatments going ahead.

We welcome the commitment in the New Deal, New Approach, by the Stormont Executive. This will change IVF funding from the current, single partial IVF cycle, here in NI, to a new implementation of up to three cycles of funded NHS IVF treatment. We are delighted to be invited to work alongside the Department of Health and the Regional Fertility Clinic, to represent patient voices in the proposed move. Whilst COVID has undoubtedly slowed progress, there is a real ministerial commitment to move towards implementation of full NICE guidelines, something we have campaigned for, for many years.

The number of patients contacting us has increased again this year as more have struggled with delays and waiting. We continue to provide support through our virtual channels, online support groups, closed Facebook groups, specialist groups and webinars, along with compassionate one-to-one patient support. Using online channels has opened up even more opportunities to provide the support that our patients tell us they value.

Recognising the need for more wellbeing programmes and focusing on emotional support has been a priority this year. With grant funding from the PHA supported by the Clear Project, we are delighted to be able to offer new Mindfulness programmes via Zoom, based over five months from October to February. The free, eight-week Mindfulness for Life

programmes, for both our 'Trying to Conceive' group and for our 'AceBabes' community, (which is for those who have been successful following fertility treatment), takes place this autumn, and more follow-on courses will be available in early spring next year.

The very talented tutor, Veronica Ellis, from Mindfulness Connected Learning, is helping everyone to find new balance in life and reducing stress and overwhelm, both for those on a fertility journey, and for those who find themselves under a different pressure of being a new parent.

We continue in our efforts to educate on the issues surrounding fertility, with patients, health professionals, including GPs, with employers in the workplace, and also with young people. We hope to facilitate a cultural shift in raising awareness to encourage a greater understanding of the isolation, misunderstanding, grief and constant exposure to thoughtless comments that the 1 in 6 couples affected by infertility may feel every day.

Though it is the second most common question to ask a stranger or acquaintance, when we have run out of conversation about the weather, perhaps it is time to stand up and explain clearly why it is no longer appropriate to ask relative strangers, the heart-stopping question: 'Do you have children?'

To get in touch with the Northern Ireland team, please email:

Hilary@fertilitynetworkuk.org Rachel@fertilitynetworkuk.org

# The Patient Pledge



The Patient Pledge is a partnership between Fertility Network UK and clinics, demonstrating the focus and importance that clinics place on patients' emotional wellbeing throughout their fertility journey.

When someone starts fertility treatment, they may feel apprehensive, worried, scared, and most of all, alone. It is crucial that clinics ensure the correct emotional support network is in place for their patients. If your clinic is one of our Patient Pledge clinics, this demonstrates their commitment to patients and shows how they collaborate with the Fertility Network team to support patients. Clinics that are part of The Patient Pledge are offered training for all staff on the emotional and psychological impact that patients can experience throughout their fertility journey.

We also offer training and help in setting up support groups, which has proved extremely valuable to people during these last 18 months of uncertainty. Our charity still recommends that all support groups remain online to ensure patient safety.

The impact the pandemic has had on patients' wellbeing has been enormous. So many patients lost months of time when clinics closed, and for our older patients, these delays have increased their urgency and anxiety. Fertility Network UK supports clinics by offering our nurse-lead support line, now available five days per week, as well as peer support groups, webinars and wellbeing classes, delivered by professionals in the field, for anyone facing fertility issues. The support of our clinics makes this all possible.

Our charity's aim for 2021 is to connect with every clinic in the UK. We recognise that building a good relationship with clinics is especially vital when striving to achieve the same goal: supporting patients through their fertility journey.

Fertility Network are now seeking Clinic Ambassadors. This volunteer role can be taken on by doctors, nurses, embryologists, andrologists, counsellors, or any other interested members of staff based in UK fertility clinics. The aim of the role is to try to improve the patient experience - you can find out more on page 16 of this magazine.

If your clinic would like to be part of The Patient Pledge initiative or are interested in fielding a Clinic Ambassador, please contact Sharon Martin at:

SharonM@fertilitynetworkscotland.org, or 07411 752688.

Aberdeen Fertility Centre www.aberdeenfertility.org.uk

AGORA Brighton & Hove www.agoraclinic.co.uk

APRICITY London www.apricity.life

Belfast Fertility www.belfastfertility.co.uk

Belfast Health & Social Care Trust Regional Fertilty Centre www.belfasttrust.hscni.net/services/rfc

Bourn Hall Fertility Clinic www.bournhall.co.uk

Care Fertility Group www.carefertility.com

Chelsfield & Sussex Downs Fertility Centre www.thesussexdownsfertility.co.uk

CREATE Fertility www.createfertility.co.uk

Centre for Reproductive & Genetic Health www.crgh.co.uk

The Evewell London www.evewell.com

Gennet City London www.city-fertility.com

GCRM Fertility Glasgow www.gcrm.co.uk

Hull IVF www.hullivf.org.uk

In-Ovo Clinics Belfast www.in-ovo.co.uk

IVF Matters London www.ivfmatters.co.uk

Leicester Fertility Centre www.leicesterfertilitycentre.org.uk

London Women's Clinic www.londonwomensclinic.com

Newcastle Centre for Life www.newcastle-hospitals.org.uk/services/ fertility-centre

NHS Assisted Conception Unit Dundee www.acudundee.org

NHS Edinburgh Fertility Centre www.services.nhslothian.scot/edinburghassistedconceptionprogramme

NHS Greater Glasgow www.nhsggc.org.uk/your-health/healthservices/assisted-conception-service/

NHS Orchard Clinic Craigavon www.southerntrust.hscni.net/our-hospitals/ craigavon-area-hospital

Reproductive Health Group Cheshire www.reproductivehealthgroup.co.uk

Sheffield Teaching Hospital Jessop Wing www.sth.nhs.uk/our-hospitals/jessop-wing

The Shropshire & Mid Wales Fertility Centre www.shropshireivf.nhs.uk

EmbryoClinic Greece www.embryoclinic.eu

IVF Spain www.ivf-spain.com

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