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# Journal of Fertility Counselling

- BICA is the only professional association for infertility counsellors and counselling in the UK
- BICA seeks to promote the highest standards of counselling for those considering or undergoing fertility investigations and treatment
- BICA is committed to the total well-being of people with fertility problems before, during and after treatment and of those who choose not to undergo any kind of medical intervention

## Editorial

Welcome to the spring edition of The Journal of Fertility Counselling. In this editon, we feature the latest news from your Executive Committee, as well as a range of features and news about events which we hope you will find interesting and inspiring.

You will find an update on counselling qualifications, and an interesting article on the use of Skype in fertility counselling. There is information about new fertility support services in Wales, and a report on National Fertility Awareness Week.

Gateway Women's Jody Day has written an article about her workshops for women who are childless and author Kate Bettison explains why she and her husband decided to stop fertility treatment. This edition also features an article about integrating complementary and alternative medicine, and Anya Sizer reports on an initiative working with couples who are dealing with the impact of fertility problems on their faith.

We have an update on Infertility Network UK's survey of young people about their knowledge and views on their fertility, and details of an event in April which will consider the need for better fertility education.



British Infertility Counselling Association

There is our regular update from the HFEA along with a couple of new features which we very much hope that you will want to be involved with - looking at why BICA members became fertility counsellors and a topical Let's Talk About... slot.

Kate Brian, March 2015

## **Diary Dates**

More details of all events, and many others, as well as contacts and links can be found at www.bica.net

## **BICA** events

May 6 - Annual BICA Conference and AGM - Lifting the Lid on Legal Issues

June 24- BICA Foundation Course for Counsellors working in Licensed Treatment Centres or Related Settings

## BICA Regional Meetings

**London Forum** -20 May 2.30 to 4.30 pm at the Assisted Conception Unit, Guy's Hospital, 11th Floor, Tower Wing, Great Maze Pond, London SE1 9RT. Contact Anthony Rybb - arybcounseling@gmail.com

**Scotland Forum** -7 July at Gloagburn. Contact Isobel O'Neill or Anne Chien for further details.

## National and International Events

15 April - FertilityHealth Summit: Choice not Chance organised by British Fertility Society, Royal College of Obstetricians and Gynaecologists and the Faculty of Sexual and Reproductive Health

23 April - Society for Analytical Psychology. Symposium: Assisted Reproduction: Emotional and Identify Implications for Parents and Children 9.30-5pm at the Wellcome Collection, London. Details at www.thesap.org.uk

11 June- Fertility Fest, London (see Journal article about this for further details)

## BICA Regional Contacts

#### Wales

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# BICA Roles and Responsibilities

(for contact details go to bica.net)

#### Co-Chairs:Tracey Chester and Anne Chien

Hon Treasurer: Sandra Bateman

Hon Secretary: Caroline McLean

Membership Sec: Angela Pericleous-Smith

Press Officer: VACANT

Scotland Rep: Anne Chien

Northern Ireland Rep: Gerry McCluskey

Wales Rep: Lynda Mizen

Information Officer: Gerry McCluskey

Website Co-ordinator: Tracey Sainsbury

Journal Editor: Kate Brian

Journal Books Editor: VACANT

Journal Distribution: Bev Loftus

Journal Sub-Committee: Lynda Mizen, Anne Chien

Publications: Angela Pericleous-Smith

Fundraising Coordinators: Sandra Bateman, Claude Rennert

**Training Group**: Jennie Hunt, Janet Owen (Co-Chairs), Angela Pericleous-Smith, Susanne Dark, Anne Chien, Gerry McCluskey

Consultations: VACANT

HFEA Liaison: Claude Rennert

**HFEA Licensed Centres Panel:** Lynda Mizen, Janet Owen and Carmel Dennehy

Accreditation Board Chair: Jim Monach

Accreditation Board Deputy: Angela Pericleous-Smith

Accreditation Board EC Rep: Sandra Bateman

PROGAR Rep: Gerry McCluskey

Human Fertility Rep: Marilyn Crawshaw

NIAC Rep: Sandra Bateman

**IICO delegate and Overseas liaison:** Sheila Pike

NGDT Advisory Group Rep: Sheila Pike

BFS BICA Rep: Sandra Bateman

British Fertility Society(BFS) Counselling Rep: Ruth Wilde

Professional Standards Authority: Jennie Hunt

## Update from the BICA Executive Committee(EC)

## Anne Chien, Co-Chair of BICA

The BICA Executive Committee are very pleased to announce that Anne Chien, our Scottish Representative will now be joining Tracey Chester as Co-Chair of BICA.

Anne originally trained as a nurse in 1982 and worked in a variety of specialities within the NHS. She left nursing in 2003, changing her career after completing an Msc in Counselling and Health at University of Abertay, Dundee.

She was employed as a Staff Counsellor in Occupational Health for NHS Tayside and Fife for over 10 years, but also has experience as a Counsellor in GP practice and as a Student Counsellor within the University. She was a lecturer on the Post-Graduate Certificate and Diploma in Counselling at University of Abertay, Dundee for five years and has also worked in private practice as a Counsellor and Counselling Supervisor.

Since 2010 she has been employed as the Infertility Counsellor in the Assisted Conception Unit in Ninewells Hospital, Dundee. She is also the Specialist Counsellor for the Scottish Molar Pregnancy Follow-up Service.

Anne has been an active member of BICA since 2010 and has been on the Executive Committee as the Scottish Representative since 2013. Her other roles within BICA include being on the journal sub-committee, events sub-committee and the training group. She is the BICA representative on the HFEA Multiple Birth Stakeholder group.

She is a Senior Accredited member of BACP and an Accredited Member of BICA.

The BICA Executive Committee feel privileged that such an experienced counsellor and member of the fertility field will be leading us into our next phase as an organisation.

# Annual BICA Conference and AGM - 6 May

A date the Executive Committee hope you all have in your diary. Yes, it is time for our Annual BICA Conference and AGM 6th May 2016. This year BICA are 'Lifting the lid on legal issues', and the day will be spent exploring the legal complexities within the field of fertility treatment. It is now available to book on the BICA website, so don't delay. We hope to see as many members attending as possible.

# BICA Journal to go digital from 2016

The digitalisation of the BICA Journal is finally getting closer.

Later this year the Journal of Fertility Counselling will become primarily a digital journal. The production, printing and distribution of the journal three times per year continues to be a considerable cost for BICA. All overseas members have received their journal digitally for the past 18 months and this has proved extremely popular. Editions of the Journal will be emailed in a PDF format to members and will also be made available in the secure 'Members area' of the BICA website. Any member who wishes to continue to receive a printed version of the Journal should contact publications@bica.net quoting your name and membership number.

Could BICA remind all members to check their email addresses are valid and can receive BICA emails. Those members who use NHS addresses please ensure they inform their IT departments and identify BICA as a valid address. Some members have experienced difficulties due to the strict firewalls in place. Alternatively please change your address on the BICA Website to a non NHS email.

## HFEA Clinic Focus

In December, Clinic Focus was reissued following errors in a previous edition about counselling equivalence. Claude Rennert and Sheila Pike have written an article in this edition of the Journal to clarify what equivalence means. We ask all members to ensure they read this important piece to check that you have the relevant qualifications and accreditation.

# Royal College of Nursing collaboration on fertility preservation

At present the RCN are formulating a working group of professional organisations to look at the issue of fertility preservation and it is hoped there will be good practice guidelines developed. As more news becomes available we will update BICA members.

## **BICA Training Group**

The training group have been busy over the last few

months, their new workshop, 'Insights in Infertility' was developed for general counsellors in recognition of how often they have clients with fertility problems but do not necessarily have much knowledge or expertise in this work. A London workshop was well attended and the feedback was that the course was useful and thought provoking.

## Workshops and study days

**Managing Bad News** - We were delighted to hear that 23 counsellors attended this workshop in Belfast. It was offered under the joint umbrella of BICA and the Fertility Counselling Service, Northern Ireland. This day was successful and again feedback was positive with participants finding it relevant to practice and helpful in knowing what to say in difficult situations.

**Facing the Void and Finding the Way** - 19 counsellors booked this stimulating experiential day looking at the issues facing involuntary childlessness. There were two exceptional speakers who spoke about their personal journeys and feedback from the day was positive.

**BICA Foundation course** - This annual training course is scheduled for 24 – 25th June 2016.

For all BICA Events and forthcoming training, please go to the BICA Website where there is an up to date list and booking available.

## Continued collaboration with HFEA Media & Stakeholder Manager

Yuba Bessaoud continues to be the HFEA link for BICA members if there are any professional queries relating to

practice and HFEA Regulations. Please contact: Yuba. Bessaoud@HFEA.GOV.UK

Please remember to

- Register to work towards your BICA Accreditation
- Pay your membership subscription
- Follow BICA on TWITTER
- Like BICA on Facebook
- Fill out your gift aid forms with your subscriptions.

Thank you and best wishes from;

Tracey Chester and Anne Chien (Co-Chairs) on behalf of your Executive Committee

Sandra Batemn Gerry McCluskey Caroline McLean Lynda Mizen Angela Pericleous Smith Claude Rennert

Email -exec@bica.net

## **BICA Journal to go digital**

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## Update on Counsellor Qualifications taken from the HFEA's Clinic Focus, January 2016

Last month we published an article on counselling accreditation and equivalence which we have updated to provide clarity on patient access to counsellors that are accredited by the British Infertility Counselling Association (BICA), or working towards BICA accreditation or equivalent.

Counsellors who work in HFEA-licenced clinics should be accredited by BICA or be working towards this accreditation or equivalent.

*Guidance note 2: Staff of the Code of Practice sets this out as follows.* 

2.12 Treatment centres should ensure that at least one individual is appointed to fulfil the role of counsellor. All counsellors should have specialist competence in infertility counselling and:

a. hold a recognised counselling, clinical psychology, counselling psychology or psychotherapy qualification to the level of diploma of higher education or above, and

b. be accredited under the scheme of the British Infertility Counselling Association (or an equivalent body), or show evidence of working towards such accreditation.

2.13 A member of staff appointed to the role of counsellor should be able to provide evidence of being an accredited member of, or working towards accredited membership of, a recognised professional counselling body. The body should have a complaints/disciplinary procedure, and the individual should have agreed to abide by an appropriate code of conduct or ethics.

Accreditation through one of the below schemes, together with sufficient evidence will be considered as equivalent to BICA accreditation and therefore compliant with section 2.12(b) of the Code of Practice referenced above:

Bodies providing relevant professional accreditation schemes:

• British Association for Counselling and Psychotherapy

- British Psychological Society
- British Association for Sexual and Relationship Therapy
- British Association for Behavioural and Cognitive Psychotherapies
- Counselling & Psychotherapy in Scotland
- Counsellors & Psychotherapists in Primary Care
- Irish Association for Counselling & Psychotherapy
- United Kingdom Council for Psychotherapy
- UK Register of Counsellors/Psychotherapists
- UK Association for Humanistic Psychology Practitioners

#### Evidence

The following evidence must be available for review during HFEA inspections. For questions around counselling requirements, please contact your inspector.

- Relevant case material submitted during the last five years, normally as part of an accreditation process or for a peer reviewed academic paper or publication.
- Ongoing effective communication with team colleagues in relation to clinic policy, welfare of the child decisions, protocols etc. whilst maintaining appropriate professional boundaries.
- Regular practice monitoring by auditing practice, seeking patient evaluation and measuring performance against key Quality Indicators.
- Having attended BICA's Introductory Training Course and/or other similar infertility counselling training.
- Maintaining annual CPD of at least 30 hours of which 10 hours minimum must be specialist infertility counselling related CPD.



# Counselling qualifications and equivalence

by Claude Rennert and Sheila Pike (Counselling External Advisers to the HFEA) and Jim Monach (Accreditation Board)

Aware that the 28 February 2013 edition of Clinic Focus was difficult to locate, the HFEA has issued a full reprint in the January 2016 Clinic Focus.

However, it appears that the HFEA wording is unclear for some and I hope these few lines will clarify the situation.

Here are the points that any inspector will look for :

• It is expected that all Infertility counsellors working in clinics will hold a recognised counselling qualification at Diploma level or above from one of the organisations listed in the article.

#### AND

• that they should have specialist competence in infertility.

This latter can be evidenced in two ways,

• By being an accredited member of BICA, (or by showing evidence of working towards BICA accreditation).

#### OR

 By being able to demonstrate equivalence in line with the requirements listed in the article. This route includes being accredited by bodies providing relevant professional accreditation schemes (as per list) TOGETHER with sufficient evidence of specialism as listed under 'Evidence' in the January 2016 Clinic Focus article. All of this evidence must be available on the day of inspection. Inspectors will decide whether the evidence submitted meets the equivalence criteria.

It should be noted that holding accreditation from another counselling body alone, such as BACP, does not count as equivalence, as it does not demonstrate the **specialist** competence, which the BICA scheme is **specifically** designed to show.

## The use of Skype in counselling

### by Jacqui Feld

At a recent London BICA meeting a discussion took place about the use of Skype in counselling sessions, with concern that in using Skype it might be possible for unauthorised access to compromise confidentiality.

Some members of the London BICA Group said they already feel comfortable using Skype based on their own understanding or research; namely that the encryption system, personal log-in and passwords Skype have in place to protect users, together with counsellors' own passwords, firewalls, etc makes for safety using this tool.

The meeting agreed it would be helpful to look into this. Information gathered was fed back to members, with subsequent responses from individuals unable to attend the original discussion.

Below is a short summary of the information gleaned, including feedback from one London BICA member, not able to attend the meeting but who gave useful comment on this important topic.

The article should in no way be considered a definitive statement on Skype, rather a useful springboard for discussion.

BACP and the Information Commissioners Office (ICO) both offer guidance for professional working in areas where date protection is paramount.

#### BACP "Good Practice in Action 047 Ethical Framework for the Counselling Professions-Supplementary Guidance. Working Online" by Prof Tim Bond (published Jan 2016).

#### In summary

Individual practitioners must ensure their own electronic devices are encrypted so they can offer clients confidentiality and security around the technology they are using. Equally clients must take responsibility for their technological equipment.

Prof Bond notes that legislation about confidentiality may be different in different countries.

#### **Information Commissioners Office ICO**

#### Website references

Principles 7 on security and Principle 8, that data is not transferred to other countries without adequate protection.

Both BACP and ICO identify how in some cases the UK Government can override confidentiality.

#### **Private Practitioner Indemnity Insurance**

Counsellors working solely in private practice should seek clarification from the legal department of their own professional indemnity insurance company.

The legal guidance offered to me gave reassurance that given that Skype is considered a highly robust encrypted system, as long as individuals take every precaution protecting their own resources (laptops, passwords, firewalls), plus all reasonable steps to update these systems, and keep a record of the systems to demonstrate the protection they have in place.

If all this is in place, Skype is considered to be safe and confidentiality unlikely to be compromised. I was told in the extremely unlikely event of such a happening occurring, it would be the hacker who is creating a criminal offence.

I understand that for those working within organisations, such as the NHS, as one member mentioned, protocols exist for the use of this tool because of concerns about security. I am not privy to any information in this regard.

There are now several online counselling courses available for further training..

#### Skype

Is owned by Microsoft and all information has to pass through its server. The encryption to protect Skype conversation is not between the counsellor and client but via Microsoft. The Skype website gives clear statements of safety. Only Microsoft could decrypt messages, although in theory Govt can demand Microsoft decrypt, this could only be done via a court order in the USA were Microsoft is based.

## Some members asked for a few words about encryption.

Encryption means data or information is converted into a code to prevent unauthorised access or concealed by converting it into a code.

Skype communication is encrypted between your computer and Microsoft servers, so any hacker would have to hack Microsoft servers in order to decrypt communications.

If interested, you can read more about how Microsoft can decrypt your conversation at the request of legal authorities from their end:

- https://support.skype.com/en/faq/FA31/does-skypeuse-encryption
- https://en.wikipedia.org/wiki/Skype\_ security#Eavesdropping\_by\_design

Encrypting the entire hard drive makes sense if you are worried that someone may steal your laptop and try to access information on it.

A simple Windows password does not protect against accessing data; anyone who has physical access to your laptop can easily take out the hard drive and copy all your files.

If one were to decide to encrypt their hard drive, any data recovery (in case of computer failure), will be extremely difficult (very expensive) or maybe even impossible.

Keeping secure backup of your files will be crucial - but that means you will have to implement encryption on your backups as well.

If running Windows 7 (Enterprise or Ultimate) Windows 8 (Professional or Enterprise) or Windows 10 it is possible to use Bitlocker to encrypt your hard drive.

 http://windows.microsoft.com/en-gb/windows-8/ bitlocker-drive-encryption

Again, this feature will not stop authorities from being able to access files on your hard drive, since Microsoft keeps backup of security key on their own servers.

Finally, my enquiries from a number of sources is that Microsoft (Skype) encryption can be considered good enough against thieves and even corporate-sponsored hackers.

Many in our profession and in the wider world of therapeutic practice find Skype is an extremely useful resource in expanding the possibilities of offering counselling to clients for whom otherwise it might not be possible or practicable to provide sessions.

Whatever individual personal views, Skype does have a validated established place in the counsellors' toolkit, see BACP Counselling and Psychotherapy Research Journal; 'A Naturalistic Study of the effects of synchronous online chat counselling on young people's psychological distress, life satisfaction and hope'. Dec 2015 Mitchell Dowling & Debra Rickwood.

In conclusion, exploration of this topic has demonstrated the importance of clarity and understanding of the Skype tool in order to underpin and portray a consistent framework for practice. Indeed it is clear that, as a profession body, we might wish to draw up guidelines for good practice in the use of Skype.

The upcoming annual meeting in May could be an opportunity for BICA members to share knowledge, experience and thoughts on Skype and, through wider discussion, take this matter forward

## Congratulations to Ruth Wilde

\*\*\*\*\*

Congratulations to Ruth Wilde, former BICA Chair, who has been selected to join the HFEA as one of its twelve Authority members. The Authority members determine HFEA policies and review treatment and research licence applications. Ruth has been invited to serve on the Licence Committee and the Statutory Approvals Committee of the HFEA. Her role is a public body ministerial appointment for three years.

Ruth says: "It's a huge honour to be appointed as a member of the Authority and to be part of the future of fertility regulation and policy. It is particularly exciting and welcome that ministers have appointed a counsellor to this role, demonstrating the commitment of the HFEA to supporting patients through their fertility difficulties and showing how much counselling is valued as part of the multi-disciplinary service provided to patients. I'm really looking forward to sharing my experience of many years of patient interactions to inform future fertility policies and standards."

Ruth has worked at Complete Fertility Centre in Southampton as their Senior Fertility Counsellor since 2011, and has previously worked in fertility clinics in Birmingham and London. Ruth also runs a monthly patient support group at Complete Fertility which is open to anyone from the region who is experiencing fertility problems. She has been a Counsellor for nearly 20 years, specialising in infertility since 2002.

Ruth served on BICA's Executive Committee for many years as well as being a former Chair. Ruth was elected to the British Fertility Society's (BFS) Executive as Counselling Representative in 2010 and has represented both BFS and BICA's interests, and fertility counselling generally, at national events and meetings.

## Launch of new support service for fertility patients in Wales

Infertility Network UK launched its first dedicated patient information, advice and support service in Wales in a ceremony at the Welsh Assembly led by Darren Millar, Shadow Minister for Health and Older People in Wales in December. The launch was attended by BICA Executive Member Lynda Mizen and Journal Editor Kate Brian.

The new service, which was made possible by an award from the Big Lottery Fund, will enable the charity to set up face-to-face and online support groups, a Walesspecific information service, employ a Welsh coordinator to manage the service and hold annual patient information events.

The launch was hosted by Darren Millar and attended, among others, by fellow Welsh Assembly members Julie Morgan and Kirsty Williams along with Rob Pickford representing the Big Lottery Fund; Peter Bowen-Simpkins and Dr Thackare from London Women's Clinic Wales and Dr Sofia Gameiro from Cardiff University

Receiving the cheque from Rob Pickford, of the Big Lottery Fund, Susan Seenan - I N UK Chief Executive, Alice Matthews - newly appointed I N UK Wales Co-ordinator and Andrew Coutts - I N UK Business Development Manager



Susan Seenan, chief executive of Infertility Network UK said: 'We are delighted to be launching a patient support service in Wales. For the first time in many years, all those who struggle to become parents will have a local patient support service that understands their particular problems, addresses regional issues and challenges and is locally managed.'

## National Fertility Awareness Week

### by Catherine Hill

*Are you #1in6? Do you support #1in6?* From mid-October through till National Fertility Awareness Week 2-8 November 2015 social media was buzzing with pictures and posts of the #1in6 couples and others struggling to become parents.



*We are #lin6; I am #lin6; I support #lin6* image after image declared. The pictures revealed how fertility struggles affect everyone: couples posted photos of their wedding day, their husband in military uniform, kissing and holding hands, holidays in the sun, walks in the countryside and simply sipping coffee (you can see a selection at http://www.infertilitynetworkuk.com/nfaw/ some-of-our-lin6-supporters/).

National Fertility Awareness Week is vital in raising awareness of the huge emotional, physical and social impact that fertility problems wreak. The fertility



journey often feels incredibly lonely: many people hide their distress from those around them. Encouraging the public and fertility professionals to support the week hopefully helps those affected to feel less isolated and know they are not alone.

It is a fantastic opportunity for infertility to shed some of its taboo status and to get the message across that together we are stronger. Each year sees more and more people take part: individuals directly affected by fertility problems, their families, friends and work colleagues; clinicians, counsellors, alternative practitioners, therapists and health professionals too.

While the social media campaign was thriving, other supporters were busy in the kitchen. Across the country, egg and sperm were coming together in alternative confectionery creations in our Great Cake Bake. We were delighted to see so many within the fertility community showing their support in this way. Individuals, fertility clinics, hypnotherapists all held cake bakes and organised coffee mornings and cake sales and auctions to help raise awareness and funds too. Thank you for: 'all luvved up' fertility muffins; sperm cupcakes, courgette chocolate



brownies; #1in6 cakes and many more.

News of the fertility week and Great Cake Bake spread overseas and we loved seeing the chocolate sperm and eggs cakes from the Finnish Infertility Association Simpukka. They held a 'Bake a cake' day in their offices and challenged other European fertility associations, as well as organisations within Finland to join them with a bake a cake day and a donation to the awareness week.

Celebrating a Fertility Friday with colleagues or friends in the month leading up to National Fertility Awareness Week and during the week itself is a great way to bring members of the fertility community together and put fertility issues in the spotlight. Why not join us this year with a cake bake, coffee morning, tea party, sponsored walk, swim or cycle, or a dress down at work day. What would work best for you and your team?

One of the key aims of the awareness week is to put fertility issues firmly in the media headlights. With the support of the fertility community and our amazing group of INUK media volunteers who bravely shared their stories we managed to do just that: grabbing the front page and headlines in national newspapers, generating multiple column inches in the regional press (thanks to all the local clinics, individuals and organisations who helped with this), appearing on national radio shows and featuring in women's magazines.

For a change, one focus was the male half of the fertility equation. Together with Nuffield Health, we raised awareness of male fertility issues: highlighting that fertility issues are as likely to be a result of male problems and making sure that male voices and men's feelings about fertility struggles were heard. We're grateful to the INUK media volunteers who opened up about what it's like to be a man on the emotional rollercoaster of fertility treatment.





Each year our sibling organization Fertility Fairness releases the latest freedom of information data on provision of fertility services by clinical commissioning groups (CCGs) in England. The worsening of the postcode lottery for access to NHS-funded IVF in England made headlines in many of the nationals and across the local press.

We revealed that the north of the country is the best place to live if you hope to access NHS-funded fertility services; the worst places to live are Essex and London. In Essex, both North East Essex CCG and mid-Essex CCG have cut NHS fertility services completely (except in isolated, complex medical circumstances), and Basildon and Brentwood CCG are consulting on doing the same. In London, every CCG (bar one) offers just one NHS-funded cycle of IVF.

Did you read any of our #1in6 fertility blogs? We were overwhelmed by the response we had from organisations, therapists, acupuncturists and others offering support, as well as individuals at all the stages of the fertility journey, including when treatment has failed. We received blogs from as far afield as the Gold Coast, Australia, blogs from men as well as women; from couples; about the experience of living with epilepsy as well as fertility problems; and one entitled 'Why I'm glad my IVF failed' – their happy ending was adoption.

There are so many ways to be involved with National Fertility Awareness Week; don't be left out. Make a note in your diary now: 30 October - 6 November 2016. Please do make a date with us and help support the #1in6 in 2016

Healing the lives of childless women, one workshop at a time...

by Jody Day, Founder of Gateway Women



Photo:Simon Fairclough

Gateway Women will be five years old this year. It'll be five years since I wrote my first blog in the hope that someone, anyone, even just one person would read it and understand the hell I was living through: the hell of being childless when that absolutely hadn't been the plan; the hell of being the only childless-not-by-choice woman amongst my entire circle of friends, family, acquaintances and colleagues; the hell of watching my friendships evaporate, my sense of purpose and meaning wither and an entry into a deep dark night of the soul that I had no idea how I was going to get out of.

However, not only did someone read that first blog, but Gateway Women got its first online mention the day after and, childless women from all over the world starting commenting, saying things such as, 'How did you know the exact words in my head?' and, perhaps the most healing words any of us feeling isolated in our distress can hear, 'Me too'.

By the summer of 2012, after a lot of encouragement and with great trepidation, I created and ran the very first Reignite Weekend in London, a two day weekend workshop for women reluctantly coming to terms with childlessness and looking to move forward into their 'Plan B'. The weekend was a mixture of powerful story-sharing, grief work and creativity and, with some fine tuning and tweaking, it remains the model of the weekend that I still lead quarterly in London and, for the first time this year, in the US. I've now led it more than twenty times and the impact of this weekend both on participants, and on me, continues to humble and astonish me.

As Kate (43) wrote in a public testimonial: 'I can't describe the massively positive effect finding GW and attending a Reignite Weekend has had on my outlook, my life, my relationships, my ability to smile at babies and their mums again!'

On the Saturday morning of my workshops, I see women arrive tightly buttoned up, nervous and shaky, sitting as near to the door as possible, ready to bolt at any minute. Gradually I see them soften and open as the session unfolds. I see a look somewhere between disbelief and relief on their faces as they hear parts of their own story coming out of other women's mouths. I watch them gradually let go of their fear about being open as they realise, perhaps for the first time, that no one's going to say, 'It's OK, you've still got loads of time,' or, 'You could still adopt,' or, 'Women of fifty are having babies now,' or any of the other wellmeaning phrases that they've all heard, so many times. I watch them as they look around and begin to admire and identify with other women, feeling relieved to know that they are not alone in having been brought to their knees by childlessness. I hear their thinking start to shift as they begin to realise that maybe, just maybe, it's not all their own fault. Then come the laughter and tears (often much more laughter than anyone was expecting!) as they work together to tease out hidden prejudices, to share their shame and watch it evaporate, to tentatively start forgiving themselves, their bodies, their choices, their fortunes and watch as new friendships form based on trust, respect and shared experience.

One of the things that gave me the courage to create the Reignite Weekend was my own experience of the power of personal testimony gained through attendance at a 12-Step group called Al-Anon, which is for friends and families of alcoholics and addicts. My marriage had broken under the combined weight of my infertility and his addictions and, in Al-Anon, I found a group of people who weren't 'experts' and who didn't offer advice: we simply shared our stories. I came to learn that there were aspects of my own pain that were mirrored in other people's stories, and hearing how they'd dealt with them (or not dealt with them) gave me hope that I too could find a way out of the mess my divorce had left me in, and the awful powerlessness I'd experienced watching the man I loved trying to destroy himself. Fast forward almost 15 years and he has been 'in recovery' for several years, something he needed to find his own route to, and I am, in effect, 'in recovery' from my childlessness. There are parallels because my

childlessness is something I will always live with; the effects are lifelong. As my friends and family's children become young adults, I know that in time I will also have to cope with not becoming a grandmother, and once again being unintentionally different from so many of my peers and once again an outsider in mainstream culture. Staying in a good place mentally and emotionally when the media and culture still sees childless (and childfree) women as deviants of some kind is a daily practice, much like sobriety.

One of the many difficult aspects to childlessness is that of losing some or all of your peer group 'to motherhood'. Those Gateway Women who've been through fertility treatments also report a surprising 'blindness' to their situation by their former fertility chums, who blast them with ultrasound pictures by phone, or fail to understand why coming to yet another baby shower is just beyond their grieving childless friend. Relationships within families of origin can also take a major hit, particularly when parents and others unconsciously prioritise the needs and options of the childled siblings over the childless one.

Friendships between mothers and nomos (not-mothers) aren't impossible, not by a long way, and I have several, but they can be very difficult during the early stages of both childlessness and infancy. The difference in experience between one woman who is acutely grieving and may not be able to even bear to meet her friend's baby and a new mother hopefully so utterly in love with her baby that she's a bit 'tone deaf' emotionally to others can become a stumbling block to continued friendship. It requires very sophisiticated emotional footwork to get through this stage (from both women) and sometimes it's too painful or difficult to make that much effort. Not everyone's got the emotional stamina for it.

One of the hugely important outcome of attending a Gateway Women workshop is that, in addition to providing the tools and space to process your grief and identify the beginnings of your Plan B, it will hopefully provide a much-needed infusion of new friends to fill some of the gaps. What I encourage them to do is to meet regularly (both online and offline) with the women they've met in the workshop, and to get their need to be understood from within this group, rather than expecting to get that in places and with people where it's proven tricky in the past. Even encounters with besotted new mothers can become more bearable if you have a group of childless friends you can send a text to about it, or share a whinge with Gateway Women's private online community. Such thoughts might seem 'unsisterly' to others, but for childless women, having a safe place to share how it feels is a sanity (and friendship) saver.

The need to belong is a core human need. Not becoming a mother, not becoming part of the community of mothers, not being considered by our culture as a 'real woman' because you've never been a mother, being sidelined by your family and friends, considered immature at work, left out of gatherings of friends... the ways that not becoming a mother can impact a woman's sense of belonging are so much greater than most people might think. One of the many things that Gateway Women workshops do is to connect childless women to their tribe, and encourage them to meet up at reunions a few times each year, to start Gateway Women Meetups in their own towns and areas, to become part of the community of childless women around the world. Gateway Women now hosts free social Meetups in UK, Ireland, Europe, USA, Canada, Australia, New



Zealand and South Africa and has a global reach of two million women and is growing all the time. The need for connection is powerful.

In the UK alone there are about 1.5 million women in their forties and fifties childless not by choice (with an additional 10% childfree by choice). Some of those will be childless after unsuccessful fertility treatments, many because of other reasons, such as not having a suitable partner during their fertile years. As the roomful of women sits down for a Reignite Weekend with me, I often wonder how long it will take until we can end the devastating isolation that can come with childlessness? I've seen a lot of change in the public discourse in my five years of advocating for, writing about and supporting childless women, but I suspect it will take a generation to really shift things, as it did with attitudes towards the LGBT community. Childless women (whether by choice or not) currently make up 20% of our mature female population, possibly rising to 25% in the next ten years. It's time for us together to find our voice in a world that sometimes only seems to give respect to sentences that begin, As a mother....



Photo: Yvonne John

Jody's new book, '*Living the Life Unexpected: 12 Weeks to Your Plan B for a Meaningful and Fulfilling Future Without Children'*, was published on 25 February, and we will be reviewing it in a future edition of the Journal.

It is an updated version of her first book,'*Rocking the Life Unexpected'*, which was taken up and published in a new, extended edition by Bluebird, Pan Macmillan. Jody held a launch for her book in Central London which was attended by many members of her Gateway Women network along with leading figures in the field/

You can find Jody's Gateway Women website at **www.gateaway-women.com** 

## A New Life

#### by Kate Bettison

When my husband, Kirby, and I met in 2004 we soon realised we had so much in common – liking the same types of movies and music, fans of the same footy team, and being very close to our own families. One of the most important things we shared was wanting children in the future.

Our courtship was fast – we met in October, bought a house and moved in together in January, we were engaged on Valentine's Day 2005, and were married on the 8th of April 2006. Once we were married we were ready to start our family, and we even started picking out names. Jacob Arthur, Samuel Kirby, Ruby Grace, and Audrey Margaret. I had starting thinking about what the nursery would look like and we couldn't wait to meet our children.

When the next two years passed and our babies hadn't arrived we turned to IVF, but after three unsuccessful rounds in 2008 with very poor results in terms of embryo number (three embryos overall) and quality the reality started to sink in that perhaps we would never have our children.

Before what was to be our last round of IVF at the end of 2008, we had decided that if that cycle didn't work we were going to take a break and go to New York for a holiday and then contact the IVF clinic again to see if they could do more testing to try and find a reason for our lack of success.

Needless to say we went to New York in July 2009. The holiday was amazing, especially for me as I had never been overseas before. I loved New York and could easily have spent much longer there than just a few weeks.

We returned home, and somehow the subject of trying IVF again didn't really come up until the end of that year when we contacted the clinic for the test on my eggs. The test did not go ahead as the clinic did not listen to me when I said that I thought I was ovulating and that my period was going to come soon – they said I was wrong, but it turned out I was right.

From that time on we started thinking about whether we would try IVF again or not. There were issues to for us to consider that I think are fairly common. Our success rates had not been good and the chance that we would end up with a baby in our arms was minimal, each IVF cycle was at least a couple of thousand dollars, I was getting older and with my age there were increased risks for both me and the baby during pregnancy and afterward, the clinic couldn't give us any reasons as to why it was so difficult for us to have a baby, and, while Kirby and I are very close, each failed cycle was taking a toll on our marriage.

Additionally, I have had major clinical depression since I was 23 years old, which is well-controlled, but between 2009 and 2010 I was diagnosed with focal partial epilepsy and unexplained hypertension. We had to consider the potential negative impacts these conditions and the associated medications could have on our child.

We were also left feeling hurt after the cancelled test at the end of 2009. The clinic didn't contact us regarding rescheduling the test, and we never actually heard from them again. We felt that we had been put in the 'too hard basket'. This was difficult to take – we thought that we were important to the clinic as an individual couple, but we ended up feeling like numbers.

WHEN KATE BE

Most of the above are rational, weigh up the pros and cons, reasons. None of them were enough for us to decide not to continue with IVF, because each of them still left us with a life bereft of children. We couldn't sit down and make a decision on whether to continue IVF or not because sensibly we knew we shouldn't, but by not continuing our lives looked scarily empty.

What we needed was to be able to picture a life without children that could be fulfilling.

This picture didn't come into place by force or all at once, but rather over a period of time which started, on reflection, when we went to New York. We thoroughly enjoyed our travels and we started to think about other places we wanted to go – Tasmania (Australia), South America, South-East Asia, the British Isles (where many of my ancestors were from), and a cruise around Alaska

> to see the glaciers. Thinking about travelling to all these different places whenever we wanted to (and could afford to!) was exciting, and to date we have travelled to various parts of Australia (including to Bathurst for a 12 hour car race for Kirby's 40th) and I travelled on my own to Thailand for my 40th to stay at an elephant sanctuary and then visit Sukhothai and Chiang Mai.

> In 2010 I received my Masters of Creative Writing from a local university. In 2008 I had left my full time job due to the strain of IVF and instead began doing casual work as a project officer a few days a week. I had more time to write and I loved it. Once the casual work ended in 2011 I started editing on a freelance basis and writing my book "When You Can't Have Kids" (which is the same title of my blog, and covers many of the issues we faced after we realised we wouldn't be having children), and I also started writing fiction. I relished the time I could devote to writing and it has become a part of who I am.

Many of our friends have had children in recent years and I'll admit it has been hard sometimes but we have developed strong bonds with each and every one of them. One little girl loves to come and stay at our house and make a big mess with me in the kitchen making pancakes. Another little girl asks us to come and read to her and give her butterfly kisses if she is going to bed while we are visiting. And one of the little boys likes nothing better than to get us into a game of footy and show us how he can count. They belong to us and we belong to them.

In May 2010 Kirby and I went with my sister-in-law when she was having 4D scans taken of her baby. I was wistful, but excited, to see the baby moving about. Then in July, he was born. We fell head over heels in love. He was our precious little nephew and we were his Aunty and Uncle.

It was only when we could see a life for us without children that we truly accepted that we would not be trying IVF again.

Now our lives are filled with travel, plans for travel, writing for me, our fur-kids (two cats and two dogs), being Aunty and Uncle to our nephew and nieces, spending time with our friends' children, getting into BMX for Kirby, spending time with our friends (some of whom also do not have children), and many, many other things. We even plan to take up mountain-biking soon!

Our lives are not better or worse than if we had become parents, they are just different and they are fulfilling. Sometimes we do wonder if we should have tried IVF just one more time and we yearn for our children. We talk about how old the child from each cycle would be and what kinds of mischief they might be getting up to. We picture them playing with our nephew and leading him astray and we feel an emptiness. I actually don't mind those times as much as I used to because it's kind of nice to think about our children – it makes them seem more real. I've even merged photos of Kirby and me using an online program to see what they might have looked like! From the moment Kirby and I met we pictured being parents to children, and we have had to work at redefining our relationship to one where we will always be a couple. This hasn't been easy, but it was essential to our marriage surviving as at one point both of us seriously wondered if we wanted to stay married to each other if we couldn't have children. It has helped to discover and develop all of the things that fill our lives now and to find out what works for the two of us.

All of the things that need to be considered in trying IVF again – success rates, health, money – didn't count for anything until we could envisage a life without children that had purpose, fulfilment, and a respectable share of happy times. And that is what we have now and we feel truly blessed.

#### 'When You Can't Have Kids' is published by CreateSpace and is available from Amazon.

# Integrating Complementary and Alternative Medicine

## by Nick Dalton-Brewer and Nitish Narvekar

Complementary and alternative medicine (CAM), terms so often heard, so often used synonymously in spite of the distinctly opposing meanings. For example, the Cochrane Collaboration define CAM as any system of medicine, therapy or belief other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period, whereas the National Centre for Complementary and Alternative Medicine (NCCAM) define complementary as any therapy which is adjunctive, and alternative medicine as any therapy used instead of conventional medicine. [1] [2] In addition, therapies considered CAM in the West may already be integrated with conventional medicine (CM) in other countries, one such example being traditional Chinese medicine (TCM). So CAM rests in an ambiguous space that has yet to be truly delineated. Nevertheless, CAM services are growing in popularity and represent a significant growth industry.

The impetus therefore is to heal the split between CAM and CM and currently this is being driven by a range of factors including patient and institutional demands. In the US, for every three healthcare dollars spent by individuals, two are spent on purchasing CAM services. Whilst intuitively one may feel that integrating the two service industries is likely to increase costs, the opposite is true. A trial of 150,000 men and women registered with a Dutch health insurer reported that patients using integrated CAM / CM clinic services are more likely to live longer, and the associated healthcare costs were lower compared to non-integrated clinics, primarily by prevention of long term health problems. [3] A selection bias however, cannot be ruled out, i.e. those who use integrated services may have a different healthcare and behavioural profile compared to those who use nonintegrated services.

With women delaying childbearing, infertility is set to rise, although there is no population data yet to support this. What is very true is that more women and couples are seeking fertility treatments and in the UK there is between 5 -10% year on year increase in the demand for in vitro fertilisation (IVF) treatments. Since the turn of the century, IVF success rates appear to have stagnated with the current UK live birth rates being 25%. Given this, the long duration of treatment, and, multiple therapeutic end points along the way, it is no wonder that infertility and its treatments can be stressful for women, and, couples. Moreover, stress negatively affects IVF and pregnancy outcomes. [4] To add to this, the process of seeking treatment also creates stress. For example, women visiting an obstetric and gynaecology clinic can experience an elevation of stress to the point of clinical anxiety and depression. [5]

The process of homeostasis is the method of maintaining balance in both psyche and soma. Where balance is threatened we are equipped with psychological and physiological responses to restore balance. Threats to homeostasis such as infections, wounds or cancer, or relationships, work and social pressures induce the fight / flight response, an elevation of activity in the hypothalamic – pituitary – adrenal axis (HPA) increasing secretion of cortisol, adrenalin and noradrenalin. Both short and long term stress are implicated in a range of conditions including anxiety, depression and infertility. [4] [6]

Acupuncture treatments are effective in the treatment of anxiety and depression. [7] This may be a result of acupuncture modulation of the HPA. There is also an abundance of research based evidence showing that acupuncture modulates a range of cell signalling molecules involved in the immune, endocrine and nervous systems and it is probably through these mechanisms that acupuncture's effects are exerted, notwithstanding other mechanises that are also thought to exist. As a result, acupuncture treatments affect female fertility by increasing arterial blood flow, improving endometrial receptivity, and inducing ovulation in anovulatory patients suffering from polycystic ovarian syndrome. [8-10] acupuncture treatments at embryo transfer. While some studies have shown significant improvements in pregnancy and live birth rates, results of meta-analyses are inconclusive, due in part to the study populations and methodologies used. [11][12][13][14] Moreover, many trials involving acupuncture follow the gold standard for clinical trials and design randomised placebo controlled trials. Yet some data demonstrates that placebo acupuncture may not be inert. [15] Placebo acupuncture varies and examples include superficial needle insertion, insertion of needles into acupoints that are considered not involved in the treatment, or a blunt retractable needle that taps on the skin. The problem with this approach is a) it is impossible to pretend to do acupuncture and b) since acupuncture influences so many cell types it is impossible to know the exact physiological effect of placebo treatment. So, until an inert acupuncture placebo is developed, using a placebo will continue to confound the results of future acupuncture trials.

A mindfulness approach to medical treatment embraces a holistic approach in patient care, so we have established a specialist CAM clinical service integrating acupuncture and other CAM therapies into standard clinical practice in the treatment of fertility. We are currently conducting a mechanistic randomized controlled trial investigating the effects of acupuncture on modulators of human implantation.

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## Waiting for children

#### by Anya Sizer

Ask the average person currently waiting to find out if they will ever be parents if anyone has ever said something unhelpful to them and the answer would almost certainly be a yes .But try adding to the common list of platitudes ('*Just relax*'. '*Why don't you just adopt?* 'etc) layers such as '*Maybe it's not God's will*' or '*Maybe you aren't praying hard enough*' and you might begin to understand some of the added complexities of being a person of faith going through fertility issues .

It was my own personal experience as a Christian going through IVF for six years that led me to conclude that church was by far the best and yet also the worst place I could find myself in .

Certainly church can provide a community to care and hold you as you go through any of life's dark moments, and there were many moments of such care for us when we were going through IVF.

One example and perhaps the most amazing for us was the 40 days of support given to us via a rota of dear friends praying for us every single day we were having treatment.

However church can also at times be the last place you would want to be .So often Christians seem to hold up the 'ideal' of marriage and therefore of parenthood as the end goal to which we should all be aspiring .

Church and Christian conferences can feel full of shining families, parenting courses and all manner of help for anyone with a family . An easy and instant community to merge into .

For the infertile, who some have even insensitively described the 'barren', couple grief can be compounded by feeling like an outsider in the one place that should ultimately feel like home . There are very specific additional complexities to being a Christian facing such a life challenge . Not least is the almost inevitable questioning of where is God in such pain and what happens to my faith after I have had to go through this experience ?

Such a realisation for myself and a group of others has led to the creation of one of the UK first courses specifically to support Christians through this time

Now in its fifth year the *Waiting for Children* course consists of five sessions focusing on various aspects of trying to have a family :

- Session one: Survival Tips looks at the enormity of going through treatment especially from a Christian perspective
- Session two: Impact on Couples explores some of the common ways men and women experience treatment and some coping techniques to help yourself and each other .
- Session three: Adoption the reality of adoption and the different but no less valid route to parenthood it can provide
- Session four: Fertility treatment and ethics explores how to cope with the demands of treatment and some of the ethical issues that may arise for Christians
- Session five: Living fruitfully this final session discusses how to not lose sight of who you are , your self-worth and ultimately the concept of a God who knows and loves you where you are now . This session specifically explores the idea that such values are based on God's love and acceptance for us as we are and thus not dependent on achieving the 'goal'of parenthood .

We do not need children to be complete though that may well be a work in progress to accept such value .

In terms of structure, the couples all are welcomed in at the start of the evening and listen to a brief talk led by the leaders on the night's theme, interspersed with video interviews with other people also discussing how they found the journey.

There is then a break for tea followed by open questions from the participants to discuss with the leaders once back in the group .

The atmosphere is relaxed supportive and encouraging and perhaps most importantly hopeful

Crucially, it is this last objective that is key to the course and specifically as a Christian course . For much as there are most certainly drawbacks to being a Christian going through such issues, there is also ultimately the concept of a bigger picture even in the sadness that underpins the course . The hope in something more .

This is not to say that participants leave with a head full of heaven rising above earthly emotions, far from it. In fact people are encouraged to be as honest and real as they need to be, and if that means expressing hurt about other church goers or even anger towards God that is totally acceptable. Indeed the Bible is full of vulnerable people trying to work out their paths in life and very often questioning where God is in this for them . It is this spirit of realism rather than false piety that is encouraged .

Going through fertility struggles for many people leads to a dark night of the soul and for Christians this is often especially true, challenging their perception of not only who they are but who God is in all this sadness.

It is so important then that couples are fully heard and listened to. No question is foolish and wonderfully all too often there is more laughter and solidarity than people may have anticipated .

To go back to the earlier concept there is a sense of community and arriving 'home' amongst people who just get it .

At the end of the evening a prayer of blessing is said and couples can stay for individual prayer and support from course leaders if they wish to

The Waiting for Children course is obviously not meant to fix the problems overnight, but rather to give couples support and space to explore some of the issues . To realise they are not alone and hopefully gain resources as they go forward .

The Waiting for Children course takes place at The Brompton Cafe, Holy Trinity Brompton Road in Central London

The Church website can be found at https:// www.htb.org and the email for the course is waitingforchildren@htb.org



## Time to teach the facts of fertility

The vast majority of young adults in the UK (87%) do not know female fertility is declining by a woman's late twenties, reveals a new survey from Infertility Network UK.

The survey of 16-25-year-old women and men shows the pressing need for fertility education, with three out of four young adults responding that they do not enough about how fertility declines with age or wanted more information about fertility. Less than one in five (18%) young adults were aware that fertility treatments, such as IVF and ICSI, have an average success rate of just 25%.

Susan Seenan, chief executive of Infertility Network UK said: 'Fertility is our future. This survey, and results from our successful fertility education project in Scotland (funded by the Scottish Government), highlight very clearly that there is a need and a demand for fertility education among young adults. That is why it is so disappointing that, in England, the Government has yet again turned down Infertility Network UK's request for funding to facilitate fertility education in England. '

She added: 'Being aware of the facts of fertility is so important. Our survey shows that 98% of young adults say they do want children, yet the harsh reality is that not all of them will be able to: 1 in 6 couples in the UK struggle to become parents. What is needed now is clear, concise fertility education for young people: on how age and lifestyle choices affect both female and male fertility, and on how to protect and maintain fertility. All young adults should be aware that female fertility is already declining by the time women are in their late twenties; everyone should know the five ages of female fertility.'

In Scotland, Infertility Network UK is in the third year of an education project funded by the Scottish Government to tackle the problem of a lack of awareness of issues surrounding fertility in the region and to prevent, where possible, the heartache of infertility for a future generation. The project ensures that people are informed on fertility issues: how precious their fertility is; the impact of lifestyle choices on their fertility; how to take care of their fertility and how and when it declines. Not all fertility problems are due to lifestyle issues, but creating a better understanding of how these issues may affect future fertility and giving young people the right information allows them to make an informed choice about decisions which affect their future fertility.

Results from Infertility Network Scotland's 2015 survey of university and college students revealed that only 1 in 5 students are aware that lifestyle factors may affect their future fertility, while just 1% of females and 0.5% of males are aware that age affects fertility. Similarly, only 3% of females and 0.5% of males are aware that sexually transmitted infections cause fertility problems. Following discussion with Infertility Network Scotland, 99.5% of students surveyed said they would now give more consideration to present and ongoing lifestyle choices that could affect their future fertility.



## The National Fertility Summit

The British Fertility Society (BFS), Royal College of Obstetricians and Gynaecologists (RCOG) and Faculty of Sexual and Reproductive Health (FSRH) are holding a national Fertility Summit on Friday 15 April at the RCOG in London, to inspire debate and action on how to improve young people's knowledge of fertility and reproductive health.

This event, led by BFS Chair Adam Balen, has been convened in response to the recent debate about the lack of knowledge about age-related decline in fertility, and the goal is to help ensure that young people have a greater understanding and awareness of fertility and reproductive health so they are equipped with the right information to make an informed choice about their own fertility journey.

The event will include speakers and debate on the quality and extent of sexual and reproductive education in primary and secondary education in England, and will bring together stakeholders from across the education and health sectors, including charities, government and frontline professionals, as well as young people. The event's scope and focus has been drawn from the expertise and experience of a wide group of stakeholders within a Fertility Health Task Force.

You can book your free place at: https://www.rcog. org.uk/en/courses-exams-events/

## Update from the HFEA

# Legal parenthood and the professional support service

by Yuba Bessaoud

In this edition, HFEA media and stakeholder relations manager Yuba Bessaoud gives updates on the professional support service and issues around parenthood

#### **Professional support service**

As many of you will know from past editions of this Journal, and presentations that we've given at BICA conferences around the country, last year we set up a professional support service for people affected by donor conception. Aimed at donors and donor-conceived people from treatment carried out at a licensed UK clinic, the service offers a number of free and paid-for support sessions provided by professionally-trained counsellors PAC-UK on our behalf. PAC-UK provides a range of phone, online and face-to-face support sessions from their bases in London and Leeds.

People who donated between August 1991 and March 2005 and are considering re-registering to become



identifiable; and donors who are aware that a donorconceived person has applied for identifying information about them, are entitled to two free support sessions. This is also available to donor-conceived people over 16 years of age if they are considering finding out information about their donor or their donor-conceived siblings. And donors, donor-conceived and siblings wanting to meet each other can get three free support sessions with PAC-UK intermediaries. For those people who aren't donors or donor-conceived but have been affected by their experiences of it, such as family and friends, the service is available for a fee.

The service is initially being run as a three-year pilot, and while we've had a few people use the scheme so far, we obviously want even more to benefit from it. So we'd really appreciate your help in getting the message out there even more. If you come across anyone you think might benefit from accessing the service, please tell them about it. Of course, it may be that you already talk to donors who are thinking of re-registering and who have come back to their clinic to talk about their options. That's great, and we don't expect you to turn them away! But if you feel they would also benefit from the support service then let them know. And if you come across donor-conceived people thinking about contacting us to find out about their donor, or donors who have already been contacted by their donor-conceived child, please tell them our support service is here for them.

#### Legal parenthood

25 years ago we were established by an Act of Parliament to supervise the use of what was then a relatively novel medical process - IVF. Then, in 2008, the Act was updated, in part to better reflect modern relationships. Parliament considered a range of complex scenarios, including: if an unmarried couple use donor sperm, who should the law consider as the legal parents?

The birth mother is always a legal parent - that is a given. As long as the right forms have been signed, the donor won't be the father. But what about the mother's partner? If she's married or in a civil partnership, her spouse is the legal parent. But in couples who aren't married or in a civil partnership, they must both sign consent forms to make sure that the partner gets official recognition.

These are obviously serious matters, with far-reaching consequences. Legal parenthood creates a lifelong connection between parent and child, and affects issues such as nationality, inheritance, contact rights, and medical, educational and financial responsibility. So it's pretty far reaching, and yet it can all be solved quite simply by signing the right consent forms with a clinic's help. But as many of you will know, issues around legal parenthood have been prominent in the last



year or so because of a number of clinic errors around ensuring patients were given the right information to make informed consent, leaving them with uncertain parenthood status. The culture in this area must change to ensure that all clinic staff fully appreciate the importance and value of proper, informed consent giving and taking.

While the majority of clinics got it right most of the time, and the vast majority of patients treated will have no doubts about who is the legal parent of their child, there have been, and still are, some outstanding cases before the courts that will require a formal judgment about parenthood on the individual facts involved, which means it's difficult to predict how the court will rule in each case. While it's possible more cases will come to light in this area - and we've made it a priority through our audit and inspection processes to make sure we know of every instance - it looks as though the majority of cases are now known about and are being dealt with. But that doesn't help the patients who have been affected by these errors, who we expect to be offered full support in resolving matters by their clinic.

What this sorry episode has shown is that it is fundamental that there is a clear consent-taking policy in every clinic, and a shared understanding among all clinic staff of how and why getting things right, first time, is so important.

While it would be unrealistic to expect no errors to be made ever again, we do expect that the new requirements placed on clinics, including the establishment of robust training schemes wherever appropriate, will lead to such cases occurring only very rarely from now on.

In the next couple of months we'll be publishing a brand new leaflet on legal parenthood, giving clear guidance on the law and what to expect from clinics, so drop by our website soon to download it, and when you speak to anyone you think might benefit from reading it - patient or staff - do please let them know.

In the meantime, if you have any questions about our work, you can email me: yuba.bessaoud@hfea.gov.uk



# How I became a fertiltiy counsellor: Lynda Mizen

A new regular feature

Lynda Mizen is a member of the BICA Executive, and works as a fertility counsellor at the Wales Fertility Institute.



Whilst on holiday in Turkey 2010 I was asked by a member of our party who was a fertility nurse about my work as a counsellor. I briefly explained to her where and how I worked, as I had I always been cautious about answering such questions for fear that the enquirer may go on to engage in a more personal disclosure and wish to have therapy by default. Relieved this was not the case, as after all I was on holiday, we continued to share aspects of our work.

I told her that I had always had an interest in how people coped emotionally with physical illness and this dated back to my first ward as a student nurse when a patient was referred to as a 'typical rheumatoid'. I did not understand the comment so studied the disease process of rheumatoid arthritis. I learned it was a chronic debilitating condition and I was then able to place the remark in context. The patient had requested a high level of nurse input and sadly some staff viewed her as demanding rather understand she was very uncomfortable, lonely and anxious due to her constant pain which limited her mobility. She had lost her identity to the disease and sadly to some of the staff.

Later that afternoon whilst reclining on a sun lounger I reflected about my counselling training. When I was at home as a full-time mum I considered attending an evening class. So I began researching the local Welsh Cookery classes but they were time tabled for the daytime. In the prospectus listed alphabetically under Cookery was Counselling: An Introduction to Counselling Skills and it was in the evening. I enrolled with some disappointment that I may never learn how to make a bara brith but consoled myself a counselling course would always look good on the CV should I ever intend to return to nursing. So it began many years of study in counselling and supervision.

Almost a year later in the spring of 2011 the fertility nurse I had talked to on holiday contacted me to ask if I was interested in some work at the local hospital in the assisted reproduction unit. I negotiated four hours per week on a Friday as this fitted in with my other contracted work. I was niaive at this point with little Knowledge about treatments, licenced clinics or the workings of the HFEA. I joined BICA and attended a two day foundation course. This helped considerably not only from the content of the course but from the sharing of practice by other established counsellors working in the fertility world.

Unbeknown to me at the time there were major changes happening with regard to the provision of assisted reproduction in South Wales. The Welsh Government wished for all fertility services to be provided by the NHS with talk of a new unit opening. This would mean the end of a contract with a private supplier. This created considerable angst for people waiting to be treated due to the uncertainty of when and where they would be treated. Counselling referrals increased and I was asked if I would like more hours. I took this opportunity ashamedly because the economic climate had affected some of my existing work and I needed to provide financial security for my family.

However working within a multidisciplinary team supporting people during their fertility journey and drawing on all my previous counselling experience soon made me realise there was so much that can be done to alleviate the pain and distress some people experience during treatment. This was an area I now wished to focus on and learn more about.

I was fortunate enough to gain full time employment at the new unit in 2013 when it opened and although many of the people are attending for the same treatment and their reactions may be similar, none of them are 'typical fertility patients'. They are unique individuals that I have the privilege to help in the course of my work.

We want to hear about about how you became a fertility counsellor. If you'd be interested in telling us what led you into fertility counselling, you can email us at publications@bica.net If you're featured in this section, you also get to answer our special Counsellor Quiz Questions, so over to Lynda...

**Night in or night out?** *Depends on the weather - Night in during the winter, night out during the summer.* 

Presently reading? One Shot by Lee Child

**Twitter or Facebook?** Twitter

**Email or Telephone?** *Email* 

Coffee or Tea? Americano

**Take away or cook from fresh?** *Cook from fresh* 

Pub or Restaurant? Restaurant

What's in your lunchbox for work? If it's a Monday then leftovers from the weekend, otherwise soup in the winter, salad in the summer

#### What's in your fridge when you come

**home?** Cheese, salmon, chicken, ham, salad stuff, relish, milk, bottled water, fruit juice, natural yoghurt, fresh fruit, Australian lager and British cider.

**Chic Flick or Science Fiction?** *Chic flick* 

Smart or casual? Casual

### I couldn't get through my weekend without: A lie in on a Sunday morning

# A Fertility Fest in a Quiet House

Anyone reading the BICA Journal knows the emotional impact of infertility. But does wider society? Does the medical profession? Could we even say that people going through it fully understand the effect it has on their mental health? This summer the world premiere of a new play and arts festival in Birmingham and London aims to broaden the discussion around the subject amongst patients, practitioners and the public.

The play, by the award-winning writer Gareth Farr, is called The Quiet House and opens at the Birmingham Rep on 26th May before transferring to London's Park Theatre for a five week run until 9th July. It tells the story of Jess and Dylan, a thirty-something couple who are in love and want to start a family. It shouldn't be an unrealistic dream. It's what many young couples want and get. But for Jess and Dylan it isn't going to be easy. Enter infertility, followed by IVF, with all the desperation, disappointment, heartache and hope they bring.

Gareth Farr, the writer and his wife Gabby, a theatre producer, have been through IVF themselves and were successful on their fourth attempt. They now have twin girls. But they both say that the experience was devastating and has shaped the people they are today. Farr says: '*I felt alone, I felt that nobody really understood, and I felt a sense of shame that I wasn't expecting.*'He hopes the play will help shine a light on the experience of infertility and tackle the taboo that surrounds it despite the fact it's estimated that one in six couples struggle to conceive.

Alongside the play, Jessica Hepburn, author of The Pursuit of Motherhood and Infertility Network UK Trustee is producing a conference style arts festival over two days exploring assisted and alternative routes to parenthood and involuntary childlessness after IVF.

Fertility Fest will take place in Birmingham and then again in London and will bring together over twenty artists from a range of different disciplines including writers, visual artists, composers, theatre-makers and film directors in a day of discussion and debate. Those appearing at the festival include the visual artist Tabitha Moses who won the Liverpool Art Prize in 2013 for her series of lightbox installations which depict embryos floating in the cosmos of a Petri dish and were made with the needles she used to administer her fertility drugs. And the photographer Aaron Deemer who undertook a project on fertility clinic producing rooms. The award-winning poet Julia Copus will be reading her beautiful series of poems about the experience of going through IVF from her collection, published by Faber & Faber, entitled The World's Two Smallest Humans. And the musician and composer Fergus Davidson will be sampling a new piece about his and his wife eight-year journey to have a child.

Fertility Fest is the first time so many leading artists have been brought together to discuss their shared experience of the world of fertility and infertility and they will be joined on stage by some of the country's foremost medical experts. At each of the venues there will also be a 'Quiet Room' which is being overseen by BICA accredited fertility counsellor, Tracey Sainsbury, and a team of volunteers to offer people attending a space for reflection and support.

The Quiet House and Fertility Fest are being sponsored by the London Women's Clinic and have received major support from Arts Council England and the Wellcome Trust. The arts often hold up a mirror to society that make people look at it in a new way and events like this could be hugely influential in helping the world better understand the emotional impact of infertility and IVF.

The Quiet House by Gareth Farr will be at Birmingham Rep from Thursday 26th May to Saturday 4th June and at London's Park Theatre from Tuesday 7th June to Saturday 9th July. Tickets £11.50-£25

Fertility Fest will be on in Birmingham on Saturday 28th May and in London on Saturday 11th June. Day tickets £35 including a performance of The Quiet House. For full details see and http://www.birmingham-rep.co.uk/event/ the-quiet-house/ https://www.parktheatre.co.uk/whats-on/ the-quiet-house



## Let's talk about:

## Succession planning

### by Lynda Mizen

Now I am not wishing to spend time on debating whether Prince Charles or his first born son Prince William should succeed to the throne if the Queen abdicates in her ninetieth year.

I prefer to wax lyrical as to whether Eddie Jones, the first Australian to coach the English rugby team has been a good choice to succeed Stuart Lancaster [but that will have already been decided by the rugby pundits by the time you receive this journal.] The debate will now be on who should coach the British Lions on the forthcoming tour to New Zealand in 2017.

I make no apology for writing about rugby in my introduction because I am passionate about the game. Passion induces an intense emotion particularly during the 6 Nations rugby tournament and at Easter the Passion also reminds us of suffering. I am also passionate about counselling and about supporting BICA members in their work with our clients who are often suffering.

What I do want to discuss is where the next generation of fertility counsellors will come from? And how active are we in considering who may continue the legacy we have created in our clinics? Hopefully with no one suffering as a consequence of our succession planning. I am hoping that the new feature 'How I became a Fertility Counsellor' will inform us all and we can pick out themes that will be helpful with our future planning.

Returning to rugby again, at a local club level we nurture young players to learn the skills of the game in the hope that they will be interested to continue to learn how to perform at a higher more competitive level. This often requires a dedicated team of volunteers who see the potential in the young players.

For me the joy of rugby has always been the banter between opposing teams but the admiration of skill whatever side you are on. This is epitomised when you can have players who join together at national level and their supporters stand side to side applauding good play.

I know as counsellors we can be sometimes 'working for the opposition' and it does not always sit easy when there is competition amongst clinics. This can overshadow our good work and our focus for the future. So how do we entice counsellors to 'come and play for our team'?

I am suggesting we all reflect on how we can raise our profile outside the fertility world. Connect with each other and share good practice regarding recruitment. Link with training establishments that we consider may produce counsellors who could make the transition into fertility work.

### Most of all let's talk about it!



## The HFEA Conference 2016

A number of BICA members attended this year's HFEA annual conference held at the Inmarsat Conference Centre in London on March 24.

The conference was opened with a welcome talk from HFEA Chair Sally Cheshire, and the theme of the day was 25 years of regulation as this is the HFEA's 25th anniversary!

The other main theme of the day was the new HFEA website and Clinic Portal which many working in clinics have been waiting for. There was an opportunity to take a first peek at what is planned.

Juliet Tizzard, the HFEA's Director of Strategy and Corporate Affairs, gave the first presentation and showcased the new website, which is focused on patients and will be much easier to navigate and to search than the existing site. It is filled with information, and will be a great resource for counsellors as well as for patients. Juliet also showed the Choose a Fertility Clinic section of the site which for the first time will include patient ratings of their clinics using a star system and will also have an inspector's rating too based on the length of the clinic's licence.

After the coffee break, Director of Compliance Nick Jones introduced the new Clinic Portal which again aims to be much more user-friendly and straightforward.

After lunch, former ITN Science Editor Lawrence McGinty, a familiar face to many in the audience, chaired a panel session looking back over 25 years of regulation. Panellists for this session were Professor Adam Balen, Chair of the British Fertility Society, Emily Jackson who is Professor of Law at the London School of Economics and a former HFEA member, Peter Braude who is Emeritus Professor of Obstetrics and Gynaecology and King's College and Editor of the Journal of Fertility Counselling, Kate Brian.

Lawrence opened the session by showing a clip from ITN news which showed how attitudes to IVF and research had changed in the last 25 years. He went on to ably chair a wide-ranging debate on regulation over the last 25 years and the impact it has had. He closed with a straw poll of the audience on whether regulation had been a good thing which showed overwhelming support for the HFEA.

The panel session was followed by a choice of two workshops. The first workshop looked at '*Avoiding breaches of patient confidentiality*'. While the HFEA's latest report on adverse incidents in clinics shows a reduction in the overall numbers, every incident that takes place is one too many. There is a particular concern about the numbers of incidents involving breaches of patient confidentiality and data protection. During this workshop, there was practical advice from the Information Commissioner's office on best practice and how to avoid such incidents happening. The other workshop during this afternoon session focused on '*Movement of gametes and embryos across borders*'. The HFEA has been keeping clinics informed through Clinic Focus about two new EU Directives on import and coding that are coming into practice in April 2017 and what they might mean for clinics. This workshop was an opportunity for clinic staff to have their say on how these Directives could be implemented, and those attending were asked for their views on the general import and export processes.

The final session of the afternoon was a summary and closing talk from Peter Thompson, the HFEA's Chief Executive.

The Conference was a very busy day, full of information, and it was extremely well attended. There were 250 delegates and the counsellors there were joined by consultants, nurses and other clinic staff.

There were also a number of exhibition stands and Infertility Network UK, the Donor Conception Network and Progress Educational Trust were represented along with Lifecycle and One at a Time.

#### \*\*\*\*\*\*\*

### **Book Review**

Our Journey: One Couple's Guide to US Surrogacy by Richard Westoby

#### Published by CreateSpace

This is a useful practical guide which shares valuable information about a couple's experience of their journey through the surrogacy process in the U.S. The author wishes to share their personal experiences with others, so that they can be more informed about the complex process. The book is very easy to read and provides a step-by-step guide to surrogacy in the U.S.

The author begins by briefly encouraging the reader to consider which route to parenthood is the best option for then. The couple decided that having a genetic link to them was important; therefore they then explored types of surrogacy arrangements and decided that traditional surrogacy most suited them. Different laws apply to different countries, therefore careful consideration was given and the U.S. was decided as being the best option for them. This was further narrowed down to which state, as these have different laws and finally whether East or West coast was most convenient to them for travelling to and from the UK for meetings, appointments and eventually the delivery of their twins.

Helpful advice is given about how the process works and the importance of obtaining information about US surrogacy agencies and their reputations. Professionals whom they recommend and other sources of information are also shared throughout the book, which is useful for others considering surrogacy in the U.S. Costs are often referred to and these are not surprisingly much higher than expected at the outset. Towards the ending of the book, the actual costs are shared and are almost double what was expected at the outset. The readers are reminded that surrogacy is a lucrative business in the U.S. for all the professionals involved in the process.

It was interesting reading about the screening process for egg donors and surrogates as there seems to be no psychological assessments done within the agencies which were used. The screening seems to be extensive despite this and the selection process for both intense. The couple decided on a known donor and it was interesting hearing how they developed a process to narrow down their choices and finally select their donor.

The surrogate was initially introduced via Skype, which sounded risky, but thankfully for the couple their 'gut' reaction was right and they seem to be very fortunate with all those involved in their journey. The importance of trust in those involved is reinforced through out the book. This most importantly included both the donor and the surrogate being responsible and trustworthy for example in relation to taking the prescribed medications during treatment cycles, the surrogate being healthy during the pregnancy and both the donor and the surrogate fulfilling all the terms of the agreement.

They seemed to develop a close relationship with their surrogate and cared for her before, during and after the process. They encourage others to be open and honest within their relationships with surrogates about their previous experiences of surrogacy, what kind of relationship would be expected during the process and in the longer term, and how much contact would be acceptable. More details of their journey which they shared included legal parenthood, thoughts on additional tests like amniocentesis and discussion around selective reduction or termination (if applicable) all of these were identified as important issues which need to be openly discussed and agreed upon.

When considering the pregnancy they encourage the reader to carefully choose an obstetrician, agree who will attend appointments like scans and who will be present at the birth. They go on to share their excitement about their pregnancy being confirmed and the practical arrangements before their babies arrival. They also acknowledge that they were privileged to have employed a maternity nurse for the first few weeks and then a full time nanny to help them with childcare.

Legal issues such as the complex immigration laws for citizenship prior to returning to the UK and the application process for parental orders in both countries are explained. Again useful advice is given in relation to ensuring that all paperwork is in order, how long the process takes, what's entailed and how much it costs.

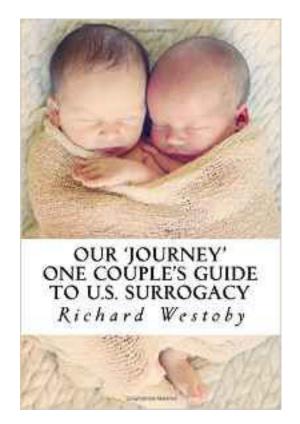
More in-depth information about the complex health

insurance system in the U.S. and again useful advice in relation to this is shared. The importance of other insurance policies like life insurance for the surrogate, which covers her in the event of death, are also mentioned and insurance companies are recommended.

Choosing the right clinic seems complex in the U.S. The couple took time to carefully research clinics, as they did with many aspects of the process. Again they share helpful advice on recommended clinics, costs, number of cycles, packages of care and whether to consider genetic screening.

Each short chapter ends with helpful questions which the author encourages the reader to consider. These also provide a summary of the main points covered in each chapter which is helpful as it becomes a reference book for others embarking on surrogacy. It is carefully laid out and reads like a journey with helpful details of each stage.

It's acknowledged that surrogacy is more expensive in the U.S. in comparison to elsewhere in the world. However by being open and transparent, the couple hope that in the future, surrogacy will become more efficient and less costly. The book is a very useful and is an up-to-date resource for anyone contemplating surrogacy in the U.S. It's also a very useful reference book for professionals working in assisted conception units. It's a very open and honest account of one couple's experiences of surrogacy, which others can gain insights into and learn from.



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- •How well are the author's ideas communicated?
- •What are the merits of the book or what is it lacking in depth, detail, originality, interest etc.? The aim is to be even handed.
- •How readable is it?
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- •Are there any points, arguments, examples you would like to make based on your own experience/ practice?

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