ISSUE 03 | VOLUME 20 | WINTER 2013

British Infertility Counselling Association
bica
Reg. Charity No. 803743

Journal of Fertility Counselling

- BICA is the only professional association for infertility counselllors 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

image:Claire Louise/FreeDigitalPhoto.

Editorial

Welcome to the winter edition of The Journal of Fertility Counselling in which contains all our regular news and updates. In this edition, we focus on an area which is often overlooked - what happens when fertility treatment doesn't work, and we have a number of articles which touch on this theme in different ways.

We are delighted that the outgoing Chair of the HFEA, Professor Lisa Jardine, has given us permission to reproduce her reflections on fertility treatment in a talk originally broadcast by the BBC which we are sure members will find gives them food for thought. .

We are featuring two personal accounts of living with childlessness; one from NLP practitioner Lesley Pyne, and another from the founder of Gateway Women, Jody Day. We also have an article from the USA, in which two women who have written about their experiences of unsuccessful treatment explore these issues.

BICA Executive member Gerry McClusky has put together a fascinating refelection and analysis of the evaluation of the seminar run in Northern Ireland on becoming a family using a donor, and another member of the Executive, Claude Rennert has written a moving and thought-provoking account of a sibling's grief.

I am sure you would all join me in thanking Isobel O'Neill for her sterling work as Books Editor and I wanted to let you know that we are now looking for someone to take over this role.

Finally, I would like to take the opportunity to wish you all a merry Christmas, and happy new year!

Kate Brian, November 2013

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

31 Jan 2014 - **Workshop -Complex issues:surrogacy and donation,** London

27 & 28 June 2014 - **Introductory Course for Counsellors** Manchester

BICA Regional Meetings

South West Forum - 7 March 2014. Contact Linda Breeze 01363 776184

South East Group: 24 Jan 2014 10.30 am, Ashford. Talk and discussion on Legal Parenthood and Parental Consent, the differences and challenges. Contact Mary McCann on 07759701173 for any information.

Central England Forum - 21 March 2014, Leeds. Contact Suzanne Dark email suzannedark91@gmail.com mobile 07941 639015

National and International Events

4 December **Double Take: Twins in Genetics and Fertility Treatment, Progress Educational Trust** Institute of Child Health, University College London

8-7 January - **British Fertility Society Annual Meeting** www.britishfertilitysociety.org.uk

BICA Regional Contacts

Wales

Lynda Mizen
linda.mizen@btinternet.com

Scotland

Anne Chien
anne.chien@nhs.net

Northern Ireland

Patricia Gilbert
bsr@ireland.anglican.org

North West

Ruth Lancaster
0161 928 2563
ruthyestelle@gmail.com

North East

Sue Bedigan
Tel: 0191 2638579
sue.bedigan@ghnt.nhs.uk

Janet Owen
Tel: 01642 644961
jowen.avantgroupltd@tiscali.co.uk

Central

Suzanne Dark
Tel: 07941 639015
suzannedark91@gmail.com

South East

Mary McCann
mccannmary@hotmail.co.uk

London

Ophra Gilead
Tel: 020 83614414
ophragilead@gmail.com

South West

Wendy Martin
Tel: 0117 924 9488
wendymartin8@hotmail.com

BICA Roles and Responsibilities

(for contact details go to bica.net)

Chair: Ruth Wilde

Vice-Chair: to be appointed by EC

Hon Treasurer: Sandra Bateman

Hon Secretary: Caroline McLean and Jill Belcher

Membership Sec: Angela Pericleous-Smith

Press Officer: Sophia Parsons

Scotland Rep: Anne Chien

Northern Ireland Rep: Gerry McCluskey

Wales Rep: Lynda Mizen

Information Officer: Gerry McCluskey

Website Co-ordinator: Tracey Sainsbury

Website Sub-Committee: Caroline McLean and Jill Belcher

Journal Editor: Kate Brian

Journal Distribution: Bev Loftus

Journal Sub-Committee: Sheila Pike, Lynda Mizen, Anne Chien

Publications: Angela Pericleous-Smith

Chair of Events Sub-Committee: Suze Fisher

Events Sub-Committee: Tracey Chester, Jill Belcher, Caroline McLean, Gerry McCluskey

Fundraising Coordinators: Sandra Bateman, Sophia Parsons, Claude Rennert

Training Group: Jennie Hunt, Janet Owen (Co-Chairs), Anne Chien

Consultations: Sophia Parsons

HFEA Liaison and Professional Organisations Group Rep: Ruth Wilde

HFEA Licensed Centres Panel: Jim Monach, Janet Owen, Sheila Pike

Accreditation Board Chair: Jim Monach

Accreditation Board EC Rep: Sandra Bateman

PROGAR Rep: Gerry McCluskey

Human Fertility Rep: Kate Brian

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)

Role changes

My two-year term as Chair of BICA ends on 31 December 2013. I have been on the Committee since 2008 and whilst I will remain active in the world of infertility counselling, I will be stepping down from the committee too. It has been a great privilege to be at the helm of BICA and I have been very fortunate to have had so many opportunities to expand both my knowledge and skills, which, although challenging at times, I have much appreciated. I would like to thank all the members of BICA and colleagues in the infertility sector for trusting me to lead our small, but highly influential organisation over the past two years. Particular thanks are due to my colleagues on the Committee and Training Group for supporting me (and my often-pedantic ways) during this time.

I am delighted to let you know that I leave BICA in safe and very competent hands, as Tracey Chester – the infertility counsellor at King's College Hospital in London – will take up the position of Chair from 1 April 2014. Tracey has been a counsellor for over 20 years and also has significant experience in setting up and managing counselling services. She will be a great asset to BICA.

In the transition period between January and March 2014, members of the committee will act as Chair and in addition to keeping on top of the day-to-day management of BICA, will continue to drive the many projects and activities that BICA is currently engaged in. These include

- Transfer to a new improved website expected Spring 2014
- Engagement with the HFEA about improving access to counselling services within clinics
- Engagement with the HFEA regarding their Donation Strategy
- Engagement with the HFEA regarding the revised Code of Practice (due Oct 2014)
- Counselling Survey of patients (in collaboration with INUK)
- Counselling Survey of BICA members
- Updating the BICA Guidelines and Practice Guides
- Collaboration with the International Infertility Counselling Organisation (IICO) for ESHRE 2014
- Seeking fund-raising opportunities
- Seeking opportunities to provide training to other organisations and clinic staff
- Provision of downloadable resources for BICA members
- Reviewing the terms of listings on the "Find a Counsellor' tool to ensure it meets the needs of people seeking specialist infertility counselling

If there are other projects and activities that you would like to see BICA getting involved in, please let us know.

Book Review Editor

There is a vacancy for a BICA member to take on this role. Book Reviews have always been a popular feature in the Journal and we urgently need someone to source relevant books and reviewers.

If you are interested in getting more involved in BICA, but don't want a big commitment, this could be for you. Please contact Kate Brian, Journal Editor, to express an interest.

If you would like to be a book reviewer – please also contact Kate.

Emotional impact of infertility in the news

The last couple of months have seen some high profile stories and events about the impact of infertility. For example:

- Merck Serono in conjunction with INUK published the results of their survey of 500 women, concluding that over 60% of women feel stigmatized for not having had children.
- National Infertility Awareness Week took place at the end of October and many BICA members were involved in running Support Groups and contributing to Cake sales to raise awareness and funds for INUK during the week. BICA is also a supporter of INUK's 10th Anniversary "Talking about Trying' Campaign
- INUK in conjunction with HealthUnlocked is running an online survey currently showing that 91% of infertility sufferers who responded show signs of depression

- JodY Day who runs the Support Group 'Gateway Women' for women who are childless by circumstance was interviewed on Women's Hour talking about the 'grief of childlessness'
- Lisa Jardine – the outgoing Chair of the HFEA - in an article for the Independent on 4 Nov 2013 spoke about one of her biggest regrets being that not enough is written or talked about the downsides of IVF. She said: "IVF is a wonderful story of hope but we still have to deal with the fact there is an increasingly large pool of people who are grieving as a result of this process. They have beautiful counselling at the beginning – the counselling is there; that's not what I'm talking about. I'm talking about the sense of abandonment at the end because at the end there isn't counselling."
- Lisa has also been on Woman's Hour discussing the lack of information about success rates, difficulties managing expectations and the impact on women who don't succeed. Lisa has given permission to the Journal to reprint the article which sparked this debate in this edition of the Journal

This media attention is a great opportunity for BICA members to respond to what is clearly seen by some as a lack of available support for those struggling to deal with the aftermath of unsuccessful treatment and those who for many reasons are involuntarily childless. We need to ensure that our specialist counselling services are reaching the people who really need our support. Some clinics can focus too much on ensuring that counsellors complete tick boxes on what has been discussed in 'implications counselling' without paying enough attention to the other end of the process.

The Executive has ensured with all these 'stories' that we have commented, for example in INUK press releases, and raised awareness of BICA's specialist counsellors by providing a link on the Woman's hour website. Tracey Sainsbury has also been busy tweeting and updating our Facebook page as these stories have emerged. All infertility counsellors can make a difference by raising awareness of your own counselling services and working towards improving access to counselling for those who could really benefit from it.

Training

The BICA Training Group as we go to press will shortly deliver their first 'Couple Counselling' workshop aimed at counsellors and therapists who work in the field of infertility to develop skills when working with couples. They have also announced the date for next year's introductory training, which is aimed at experienced counsellors new to the field of infertility or to those who would like to update their skills. It will be held in Manchester on 27/28 June 2014.

The Training Group has been busy sharing its infertility skills and knowledge by delivering a workshop for Relate Counsellors. This was very well received and they are now in a position to offer this more widely to other counselling organisations that come across infertility in their work. If you know of any organisations that may be interested, please contact Jennie Hunt or Janet Owen training@bica.net

The Training Group has also been successful in securing the contract to deliver infertility counselling training in Malta to a newly established infertility service.

In response to the new guidelines on Surrogacy and the increasingly complex legal parenthood issues that many of us face, particularly in relation to known donation, the Training Group are offering a one day 'Complex Issues' workshop on 31 January in London. They will be joined by a Fertility Law specialist and a Parental Order Reporter. If you come across any complex legal issues in your work, this course will be invaluable. For details of how to register and for further information, please see the website.

The Training Group is also now offering 'Breaking Bad News' sessions to multi-disciplinary teams in licensed Centres

Dates for your diary

Accreditation Workshop: Thursday 8 May (p.m. only)

BICA Annual General Meeting: Friday 9 May 2014

And finally… please remember to:

- **Pay your membership subscription (if you haven't already)**
- **Follow BICA on Twitter**
- **Like BICA on Facebook**
- **Order your Amazon goods via the BICA website to raise funds for BICA**
- **Regularly access the website for updates and information. For help, please contact Tracey: website@bica.net**
- **Update your 'Find a Counsellor' entry on the website if you are accredited**

- **Send resources and information on CPD CPD opportunities for posting on the website and promoting through social media to publications@bica.net**

Thank you and best wishes from

Ruth Wilde (Chair) on behalf of your Executive Committee

Jim Monach

Gerry McCluskey

Claude Rennert

Anne Chien

Suze Fisher

Tracey Sainsbury

Lynda Mizen

Sandra Bateman

Angela Pericleous-Smith

Jill Belcher

Caroline McLean

Tracey Chester

Sophia Parsons

exec@bica.net

BICA needs a Book Review Editor - can you help?

We urgently need someone to source relevant books and reviewers. If you are interested in getting more involved in BICA, and enjoy keeping up to date with the latest fertility-related books, this could be just the role for you. It involves seeking out books with the help of the Journal Editor, finding suitable reviewers and commissioning reviews. Please contact Kate Brian, Journal Editor, to express an interest.

Report on London Forum: October 2013

Forum attendees were pleased to welcome two invited guests to this meeting: Alison Bagshawe, founder of Altrui, the UK's first bespoke egg donation service, and Lisa (not her real name) who generously offered her personal experience of being an egg donor. Alison, whose background is in nursing and fertility counselling, was already known to some of us; but all were eager to hear of her work with Altrui, which she left Guy's to found in 2010.

Alison explained she created the company in response to the huge numbers of patients she saw going abroad for egg donation only reluctantly, because of a shortage at home. Her aim has been to create a personalised service where donors are recruited, valued , informed, prepared and looked after throughout the donation process with Altrui acting as a link -and Alison herself matching - with prospective recipients.

Although there was also close questioning about reported delays in some recipients finding ALTRUI donors, Alison was very well received; and the informed nature and preparedness of Altrui donors was remarked on by those counsellors present whose clinics use its services.

Lisa, who has donated once, and who proved a robust advocate for the informed and supported donation which, Alison says Altrui was set up to promote. Lisa was immensely open in discussing all aspects of being an egg donor: answering multiple questions about her motivation before, her experience during, and her feelings now and for the future.

Lisa also provided a timely reminder to us all about of the sort of questions arising in an Implications session which are felt to be most helpful. For example: "What do you feel about this donation?" would have been welcome and productive, she thought. Instead, the counsellor's frequent repetition of: "Are you sure you want to do this?", left her only offended and defensive.

Counselling aside, Lisa says she will donate again because the first experience was very positive and personal. She felt validated and supported in the process and, because all Altrui donations are one to one, knowing she has helped a specific couple is particularly meaningful to her: "To me it's a cell. To them it's a baby"

Report on SW Forum

by Linda Breeze

The SW Forum met at Wendy's house in Bristol, with nine of us gathering from a wide geographical area, and several apologies sent with real regret about not being able to attend. This group has developed a democratic, person-centred style, with a framework to deal with the business of the day and allow plenty of flexibility within.

After volunteering for the roles of chairperson and scribe, we started with a round of 'where are we now?' The subjects raised from this sharing are many and varied and lead us to choose topics for the morning and ideas and dates for next year. This time, issues included re-accreditation, HFEA inspections, working practises and job situations in NHS/self-funded clinics; information about running support groups, HFEA news, INUK infertility week; grief at the end of treatment. Three practise dilemmas were identified for further discussion:

- Sibling donation
- Mixing treatments using own/donor sperm
- Safeguarding adult patients and assessing risk.

Ideas were explored and compared and continued as we shared a delicious pot-luck lunch – how does it always manage to work so well, spontaneously?!

The afternoon session was led by Jane Hill from DCN who had come down from Sheffield to talk to us about their parenting workshops. She explained the content and cost of these and how they were targeted for different groups i.e. heterosexual/single sex couples and single women. The feedback received from experience of running these workshops is used to develop the teaching and participants report the benefit of sharing feelings in a group setting away from a clinic.

We were inspired by Jane's enthusiasm for her work and discussed making it available in the West Country.

All too soon we were out of time, some hurrying off for trains or lengthy journeys home, others able to socialise before leaving. This forum is such a valuable time together as so many of us work on our own and well worth the effort to attend.

Dates for 2014 - Fri. 7th March at Norma's

Mon.6th October at Wendy's

Update on the Central England Regional Forum

The CERF group has grown in popularity over the last few years; going from a nuclear group of 4-5 counsellors in the early years to a current membership of 19 counsellors. The geographical region covered is large (Hull, Leeds, Sheffield, Manchester, Nottingham, Leicester, Coventry and Birmingham). The group holds two meetings each year and members are prepared to travel some distance to these. Centres with sufficient space to accommodate the group are forthcoming in offering us accommodation...indeed, some even provide a free buffet! It provides a very rich environment for networking, sharing practice approaches and experiences, discussing topical issues and sharing useful reading / updates on books or articles of interest to practitioners and / or clients.

At the last meeting, Sheila Pike gave feedback on our BICA/IICO meeting in July and the group explored the issues that arose, particularly in relation to surrogacy and the ethical challenges facing counsellors working with clients seeking treatment overseas. This was Sheila's last meeting as organiser and Chair and there was a very happy final gathering, involving a few drinks, before everyone headed homewards. As for the future, Suzanne Dark will be taking over as organiser and the chairing of the meetings will be the responsibility of whoever is hosting. .

Diary date for 2014 - Friday 21st March in Leeds

The 18th October 2013 marked the last CERF meeting chaired by Sheila Pike. A sad occasion for many I am sure. Those of you who know Sheila or have had the pleasure of meeting her will know what a loss to the infertility world Sheila's impending retirement will mean.

Over the years I have found Sheila extremely approachable, always able to call upon, to talk issues through whether of a professional or person nature. Her commitment, passion and work ethic are extremely admirable, going well beyond the call of duty especially given the infertility and medical books Sheila calls "bed-time reading"!!

Sheila, I hope you manage to find the time to attend occasional BICA events and CERF meetings and I wish you joy in your new endeavors and a very fun and fertile retirement.

Angela Pericleous-Smith

Report on the Alternative Parenting Show

by Tracey Sainsbury

The Alternative Parenting Show is now a regular event on the both the fertility and LGBT calendars. There has been an annual increase in both exhibitors and people attending; noticeably with gay couples seeking egg donation and surrogacy as a pathway to parenthood.

There were new additions from familiar faces this year with Natalie Gamble Associates bringing along their stand for their new surrogacy non-profit making company, Brilliant Beginnings. The London Women's Clinic, a sponsor for the event, also launched the London Egg Bank.It was also great to see a higher number of exhibitors relating to fostering and adoption, specifically those seeking to build greater links with single and same sex couple adopters and foster carers.

I spoke to a packed room about contemplating single motherhood and was joined by Sophie Zadeh from the Centre for Family Research, University of Cambridge, who is coming to the end of a project looking at solo mums.

Talks were designed to empower those present with factual information and insight, from the organisations present, research and personal experience. It was great that the Donor Conception Network, whose conference sadly took place on the same day, still were able to have a formidable presence, with Caroline Spencer sharing her experience of becoming a single Mum by choice including the importance of sharing information early.

The event has a crèche for children and many used it throughout the day, the positive vibe promoted by the event being very much about fertility and family, rather than assisted conception as a hopeful solution to infertility. But feedback from many of the heterosexual couples present was positive around access to useful information for anyone, especially those needing egg or sperm donation to try to conceive.

I am trying to decide if it is a useful event for counsellors to attend, I conclude maybe! Hearing some of the questions from those attending (often years) before planning any form of treatment was both enlightening and interesting, including around how to adjust information for online enquirers around support organisations that can be accessed and useful before treatment.

I did of course let everyone who asked know that they can find a local counsellor to explore implications prior to trying via the BICA website!

Report on Progess Educational Trust Event - Hype, hope and headlines s

by Dr Gabrielle Samuel (originally published in BioNews)

Last week the charity that publishes BioNews, the Progress Educational Trust (PET), organised an evening debate entitled 'Hype, Hope and Headlines: How Should Breakthroughs in Fertility Treatment Be Reported?' in partnership with City University London. This event explored how and when fertility research should be reported in the media, and where the responsibility lies to ensure that such reporting is not overhyped.

The location of the debate, which seemed to be (by way of many stairs) the deepest basement lecture theatre of the university, did little to deaden the enthusiasm and opinions of the chair and panel. The packed and diverse audience included journalists, press officers, clinicians, representatives of professional bodies, and students.

Typical of PET debates, the first half hour consisted of the panellists putting forward their opinions about the subject title. While these opinions differed substantially (the panel included a newspaper editor and two clinicians) all three panellists aligned closely with the need for responsible reporting.

The first speaker was Professor Simon Fishel, managing director of the CARE Fertility group. Professor Fishel used his ten minutes to talk about responsible reporting against the backdrop of evidence-based practices. Whilst, at times, I felt that his point was lost, his main argument seemed to be that 'all scientific knowledge is provisional' and journalists need to understand this: it is important to decipher how a published piece of research has been conducted to be able to determine how reliable the results are. Randomised controlled trials, said Professor Fishel, are the gold standard for evidence-based practices, but there are other approaches which can also be used to help understand the effectiveness of a new technology. Media reporting of science research must reflect an understanding of these approaches.

There was no chance of missing the opinion of the second speaker, Nick Macklon, professor of obstetrics and gynaecology at the University of Southampton. Professor Macklon opened by highlighting the vulnerabilities of families going through IVF, as well as their desperation to have a baby. He asked us to imagine a couple having undergone unsuccessful IVF, sitting at a breakfast table, opening the newspaper and reading that there had been a ‘breakthrough’ in IVF treatment. He pointed out that such a family would no doubt excitedly ‘fly out the door’ in search of this breakthrough before inspecting the last paragraph, which may have mentioned the limitations and/or lack of evidence for the research, and of course the expense of such a treatment.

This anecdote was used as a springboard to highlight the damaging effects of ‘hyped’ news articles reporting breakthroughs in fertility research. For Professor Macklon, while it is important to get science out to the public, there will always be a risk to victims which we must acknowledge - and not just this generation, but also the next, since the way future generations perceive technologies (whether those technologies work or not) can influence the use of those technologies in healthcare. Journalists, he said, need to be more critical and take more responsibility.

The last speaker, Dr Hannah Devlin, science editor of The Times, defended herself well from the other speakers. Her main point of departure from the clinicians (which to me seems quite an important point) was in terms of where to draw the line about what should be reported. For her, it doesn’t just have to be randomised controlled trials that reach the media - reporting incremental steps in science is also acceptable. Hannah spent a lot of her time just wanting to be understood as a journalist/editor. She pointed out how she too strongly disagrees with the use of the term ‘breakthrough’; that she understands the difference between ‘this is proof’ versus ‘just illustrating the science’; and that we must remember that sometimes standards do drop and that this is not always the fault of the journalist, but rather the constraints they are under - often having to churn out a couple of stories every day.

The brutality of our Chair, Fiona Fox, director of the Science Media Centre, to adhere to the time limits for each of the speakers allowed for a much-needed long and lively audience discussion. In fact, Fiona was so excited following the speakers’ presentations that it was her who kicked off the stream of questions that flooded in. The first few audience comments, revolving around control and access to information, prompted a lively interaction between Professors Fishel and Macklon concerning the question: ‘even if the clinician is genuinely excited about her/his research, is this really the best time to report it?’

Fiona quickly broke up the panellists’ increasingly heated discussion on this topic to allow for further audience contribution. Many of the questions that followed centered around issues of obligations - where does the responsibility of reporting lie. Some audience members felt it was wrong to put the responsibility onto journalists - although journalists need to act with integrity, clinicians and scientists also have a role to play in managing expectations of patients. In fact one audience member asked us to pay homage to the highly accomplished science journalism that we have in this country! The panel agreed with such comments, though pointed out that this is in fact a difficult endeavour, and that what is maybe needed are better resources for patients who are not so reliant on newspapers - much like they have in the USA.

I was incredibly surprised that the issue of clinicians’ vested interests in media publicity - particularly fertility specialists who are mainly employed in private establishments - was not raised until the later in the event. Though this did not stop the enthusiasm with which the issue was debated. After a lively discussion, the consensus on the panel seemed to be that fertility experts had no more or less of a vested interest in getting their research into the media than ordinary academics, who also needed publicity to garner further support for their own research field. In all areas of research, then, some clinicians will benefit from speaking to the media and some will not, but we shouldn’t trust other academics any more or less than fertility specialists.

The chair finally closed the event by pointing out that while science communicators generally want to be responsible, hype in the headlines most likely stems from all contributors, including scientists, press officers, journalists and editors. What it comes down to, said Professor Macklon, is ‘pausing’. All professions involved in science communication should pause before deciding whether to publish.

My own research, which has explored how science press officers view their role as science communicators, suggests, however, that such simple recommendations are unlikely to have much effect. My interviewees’ views of what is ‘responsible’ reporting and what is ‘hyped’ often differ from such views in other professions.

PET would like to thank Connie St Louis at City University London for her invaluable help co-organising the event.

BICA would like to thank BioNews for permission to reproduce this review

Accreditation Scheme

by Jim Monach

The accreditation scheme continues to offer the opportunity for BICA members to have the quality of their specialist counselling skills and knowledge acknowledged by the public and colleagues in related professions.

The Accreditation Board has been monitoring developments in the wider counselling field in relation to the initially proposed regulation of psychotherapists and counsellors and the current system of accredited voluntary registers. In March 2011 the government announced that it was not currently their intention to proceed with statutory regulation of psychotherapists and counsellors. They put forward proposals to create a system of quality assured voluntary registration accredited by the Professional Standards Authority (PSA - previously known as the Council for Healthcare Regulatory Excellence). In February 2013, the PSA launched the Accredited Voluntary Register Scheme, which enables organisations holding their own Voluntary Register to be accredited by the PSA.

When the plans were unveiled for accreditation of voluntary registers, the BICA Executive considered whether BICA should apply to have its Register of Accredited Members accredited under this scheme. However, now that the detail is clear, the Executive has concluded that BICA does not have the resources to do this. Organisations are required to demonstrate that they meet the 11 required standards and must pay a minimum fee of £12,000 on application with a further minimum £9000 annual fee for reaccreditation.

We will however do what we can to ensure that our accreditation processes harmonise with the national register where possible.

We were delighted to award AMBICA to our first colleague outside the UK – Ann Bracken of Dublin. Congratulations to her and we hope that this might be a way forward for others. Congratulations also to Chris Bulmer, Lynda Mizen and Angela Pericleous-Smith all awarded AMBICA since the last journal.

All those who applied were successfully reaccredited under the process first adopted last year, with the exception of one who has left BICA.

The list of accredited members on the website has been used by HFEA Inspectors to determine whether they need to make any enquiries during inspections about counsellor qualifications, insurance, CPD etc. Those counsellors who are BICA accredited have benefitted from not having to undergo the usual inspection of their practice as the HFEA is satisfied in these cases that BICA has itself undertaken the necessary professional examination of their practice.

This year the HFEA has involved Counsellor External Advisers (All BICA Accredited) to assist in inspections of clinics where there is no BICA Accredited Counsellor and intends to wherever possible continue to do this in order to assess whether counsellors and the counselling services within clinics meet the requirements of the Code of Practice.

As you are aware, the HFEA published a document entitled ‘Counselling qualifications and equivalence’, which set out the evidence that counsellors need to produce (if not BICA-accredited or registered as working towards) in order to demonstrate specialist competence in infertility counselling. The Executive has circulated this to all members, but takes the position that BICA accreditation is the best route for infertility counsellors to demonstrate their specialist competence to their clients and other professionals in the field.

As some counsellors work in more than one clinic, it is difficult to ascertain how many clinics now have a BICA accredited/working towards accreditation counsellor, but it is estimated that this is now the case in over two thirds of licensed clinics.

For more information on the BICA accreditation scheme, please see the website, or contact me by email -

Jim Monach, Chair, Accreditation Board at accreditation@bica.net

National Infertility Awareness Week

October 28 - November 3

The UK’s first National Infertility Awareness Week was organised by Infertility Network UK and proved to be a hugely successful event, not only raising awareness but also encouraging fertility clinics and individuals to get involved in fundraising for the charity. The week also provided a focus for new fertility support groups to lauch across the UK, including one facilitated by BICA Chair Ruth Wilde in Southampton and the first group dedicated to those experiencing secondary infertility which meets in Central London.

Cake bakes were held across the UK throughout the week and chef Jamie Oliver donated a cupcake recipe while TV star Wendi Peters gave her recipes for muffins and a sponge. Professor Lord Winston and the first IVF baby Louise Brown both sent messages to the campaign, along with former Olympic swimmer Sharron Davies.

BICA’s Ruth Wilde at Complete Fertility Cake Bake

Some fertility clinics offered free consultations to prospective patients during the week, whilst others held ‘meet the expert’ events which were open to all. More than 70 events were held across the UK, with some fertility-related cakes (see opposite) on display, including one made by BICA Exec Member Tracey Sainsbury!

Becoming a family with the help of a donor - Seminar, June 2013

Reflections and analysis of event evaluation forms

by Gerry McCluskey

Reflections

The idea of having a group event for people who are thinking about forming their family through donation had been running around in my head for a long time. As a fostering and adoption social worker I was conscious of the significant benefit of support groups, information events and training workshops for people who form their family in a different manner. Foster Carers and Adoptive Parents have different challenges to deal with but the overlap with forming a family through donation is that it is a different way to form a family, there are specific needs and issues to consider and there is a lot of research and personal experience available to enhance each individual's/couple's journey.

As I continued to provide 'implications counselling' for scores of couples, I became more and more conscious that there were additional means of facilitating these couples, sources of information and experience beyond mine which could be pivotal in helping couples deal with their reservations, questions, anxieties or simply their information needs. Counselling has a significant role to play in dealing with the personal and relational aspects of a couple's journey, but there appeared to be a 'collective' need beyond this which required to be addressed.

Privacy and confidentiality are paramount considerations in infertility work. Questions arose as to whether the very act of arranging a group threatened these important tenets. There were concerns that the take-up response would be poor because we live in a close knit community and therefore people would be more cautious about privacy. Such questions and concerns were daunting. Seeking couples' views about the idea of a Seminar and discussing confidentiality with the HFEA went a long way to ameliorating these concerns; working for an agency independent of a clinic eased some of the potential complications. The catalyst however, was a comment made by Professor Ken Daniels at a Donation Workshop organised by PROGAR/BASW (June 2012) – 'We need to test out perceptions'. So, with some trepidation, that's what we did.

The 'Becoming a Family with the help of a Donor' half day seminar was in the 'active planning' stage for a ten month period between late 2012- mid 2013 during which a Steering Group (see end of the report for details) met on several occasions to plan and organise the event. Consultations occurred with a range of interested professionals whose experience influenced the format and content of the seminar. Discussions were also held on two occasions with the Clinical Team at the Regional Fertility Centre, Northern Ireland.

Advertising of the event was largely by word of mouth via infertility-related organisations within Northern Ireland, Republic of Ireland and the U.K. It had been decided not to use the media for advertising in order to maintain a degree of confidentiality for this initial event.

Funding for the event was secured through grants from The Big Lottery and Lloyds TSB.

There were four main speakers at the seminar: Marilyn Crawshaw, Researcher and Author, Jane Ellis, mother of donor conceived adults and Trainer with DCN, Sam Gregory, donor conceived adult and contributor to DCN events, and Danny Ruddock, father of donor conceived children and Trainer with DCN. Four FCSni personnel contributed to the facilitation of the event: Ian Slaine (CEO), Gerry McCluskey (Fertility Counsellor) and Patricia Gilbert (Fertility Counsellor) while Marie Walker (Administrator) provided organisation and administration for the day.

A total of 96 people signed-up for the seminar, 8 of whom were professionals allied to the infertility world. 10 people cancelled their attendance in advance of the event, 13 people did not attend on the day. Out of the 73 who did attend, 7 were professionals and 66 were people who were thinking about, planning or who had had successful treatment with donation. A total of 65 evaluation forms were returned representing 89% of the total attendees. (See Appendix 1 for content of evaluation form)

Evaluation Forms Analysis

As can be seen from Table 1, all aspects of the event, invitation process, venue and presentations were ranked as excellent or good by between 95% - 99% of those who returned evaluation forms. The presentations by those who had direct personal experience of forming a family through donation (Parent and Son, and Father) received a rating of 83% excellent which endorses the importance for this group of hearing personal stories. This finding was supported by a range of comments made in answer to other questions on the form (Q9).

Invitation Process: Of the 18 people who added comments to their rating, 8 were positive in that they stated that ‘nothing’ could be done to improve the process or that it would be difficult to improve on the process. One person commented that he/she was made to feel very welcome and three indicated that improving the process was ‘not applicable’.

Of those who suggested that improvements could be made, five people indicated they would have welcomed more notice being given re. for example venue, agenda with timings. Two people commented on the e-mail registration, one wanting it to be made easier and one wanting a quicker response. One person suggested that the event could be advertised more widely within NI.

Venue/Facilities - As Table 1 shows, 97% of attendees considered the venue and facilities to be good or excellent. Of the 14 additional comments, three indicated ‘not applicable’ which is taken to mean that improvements could not be made and 3 stated more overtly nothing could be improved. 4 people made positive comment about the venue e.g. setting is perfect, large airy room, remote and beautiful, great venue, very well prepared. 1 person commented that there was noise from next door while one person suggested that biscuits could have been provided with the coffee on arrival. Another suggested that water could have been provided on each table.

Three people noted that there were children in other parts of the venue and indicated that this was problematic for an event focusing on infertility.

TABLE 1. Satisfaction rates of constituent parts of event

	Excellent	Good	Adequate	Poor
Invitation Process	66% (43)	28% (18)	3% (2)	0% (0)
Venue/Facilities	77% (50)	20% (13)	1.5% (1)	0% (0)
Research/Theory	62% (40)	37% (24)	1.5% (1)	0% (0)
Parent and Son	83% (54)	14% (9)	1.5% (1)	0% (0)
Father’s Experience	83% (54)	12% (8)	0% (0)	0% (0)
Overall Benefit of Day	80% (52)	17% (11)	3% (2)	0% (0)

Overall benefit of the Seminar: 97% of attendees indicated that they found the seminar to have been excellent or good, with the vast majority (80%) rating it as excellent (Table 1). The two people (3%) rating it as adequate indicated on their forms that they would have welcomed a greater emphasis on egg/embryo/family donation because those were the treatments relevant to them.

52 of the 65 respondents provided additional comments on the specifics of what they found useful. Of these 52, 7 were attending in a professional capacity and 45 were ‘patients’ at some point in the journey of having treatment with donation.

From the responses it is clear that support and education are valuable for people who are forming their family through donation and that this type of event has a significant role to play in providing this support and education.

37 people specifically mentioned the educative benefit (i.e. acquisition of knowledge, information, insight, advice) of the event for them. The comments below illustrate the educative impact of the event:

‘We have always known we are going to tell our daughter, but this has highlighted it and advised us more’

‘It has helped me formulate my ideas on egg donation and my approach to my infertility’

‘We have a donor-conceived child and it helps to prepare us for the time when we start to tell her how she was conceived’

‘Broadened knowledge of things from both perspectives’

‘Importance of telling’

‘Really got an insight into telling and talking’

‘Advice on upcoming obstacles. The child’s information, not ours’.

20 people highlighted the informative and support benefits to them of hearing the presenters’ personal experiences as the following quotations demonstrate:

‘It was just so informative to hear ‘real people’ sharing their ‘real experiences’ and I could totally relate to their journeys’

'So touching and food for thought to hear personal stories of those who have been through the process. Being so honest about their fears and experiences'

'Hearing from people who have lived through the donor experience is invaluable'

'Good hearing how the parents' feelings have changed during the process'

'Very useful to hear real stories as opposed to reading brochures, on-line, etc.'

'Great to be able to listen to a donor-conceived person'

'We had not heard anyone talk about their own personal experience before'

'Finding out first- hand how different people approach things'

Using a donor to help form a family is a relatively recent development and the 'novelty' inherent in the approach can lead to a felt sense of 'difference' at best or 'stigma' at worst. The fact that this means of conception is most often predicated on a couple's infertility can add to this sense of difference or stigma with the consequence that individuals and couples can feel isolated throughout the process. The supportive benefit of this type of event in combating such isolation was mentioned specifically by 16 people as the following selection of quotations demonstrates:

'*It turns out that I am not alone with problems…Also that it is possible to build normal relations'*

'….knowing there are others going through this and thinking the same as us because sometimes you do feel alone'

'It is reassuring to know we're not alone and that donor conception can work'

'It helped my wife and I to see that others were going through the same thing for a start'

'Meeting people in similar situation makes it real and not alone'.

TABLE 2 – Impact of event on views and attitude towards further events

	YES	NO	BLANK	OTHER
Event changed views	32% (21)	60% (39)	6% (4)	1.5% (1)
Would like further events	86% (56)	11% (7)	3% (2)	0% (0)
Would like to be contacted	75% (49)	----------	25% (16)	0% (0)

'Has been fantastic to know we are not alone – great to hear some real stories and the speakers were all great'.

Views changed as a result of the event: 21 (32%) of people stated that their views had been changed as a result of the event, 39 (60%) people indicated that their views had not changed, 4 people left the question blank and one person answered 'yes and no' (Table 2).

17 of the 39 who stated that their views had not been changed did not add further comment. Most of the 22 'no's who did add comment indicated that their overall position with regard to donation had not changed, the following quotations being representative:

'I am for donation/was before/this has not changed'.

'If it wasn't for donation we wouldn't be a family'

'I previously supported donation'.

'I'm still undecided'.

'I was always open to the use of a donor'.

'Still feel the same as in I want to do it'.

'I am very pro telling a child about his/her origins'.

However, 6 of the 22 'no's who made additional comment indicated that although their overall position had not changed the event had added value to their thoughts/feelings:

'I was already supportive of it though the session reinforced this'

'We are planning a family by donation – today's discussions have been reassuring that we have made the right decision'.

'It highlighted the importance of being open about the conception process/also importance of UK legislation around anonymity – things I strongly believe in'.

'It has strengthened my positive views'

'Reinforced the positive aspects of donation'

'We would need a donor so I think it is a good idea and believe it gave me a better level of understanding'.

Of the 18 people who added comments to their 'yes', the event had changed their views, the responses were evenly divided over what could be grouped into three categories –(i) more informed, (ii) impacted feelings and (iii) encouraged substantive change.

More informed:

'I feel much better informed both in relation to research and the more personal impact for those directly affected'

'Most positive! Especially regarding sperm donation. This is due to the very honest description of experiences'.

'Has helped me understand the complexities and emotional issues associated with DC'.

'Questions raised with answers that I would not perhaps have thought of or considered'.

'Realise how important it is to tell a child and communicate about the Donor'.

'*…in some ways. Danny's talk was very illuminating about the reality of the range of emotions involved around the parent identity…..very good to hear'.*

Impacted feelings:

'*It is normal – just a different journey'*

'Helped with stigma thoughts'.

'It makes it all feel so much more 'normal''.

'As a mum of DC twins, it was so wonderful to meet and have many fears and anxieties regarding telling and talking sit so much better'.

'Feel more on board with idea'

'concerns re. child and telling'

Encouraged substantive change:

'Not sure if it's for us'.

'To tell a child from a younger age'.

'If fortunate to become pregnant through egg donation I would now tell my child'

'Not in relation to donation itself. But more thought into finding out more about donor at the stage of focusing on getting pregnant – hadn't really thought too much beyond that.

The one person who answered 'yes' and 'no' to the question about the event changing views clarified:

'Interesting to hear stories/experiences, definitely informed and updated opinion'.

Further Events/Meetings - The vast majority (86%) of participants indicated that they would welcome another event being arranged. (Table 2) 35% of these preferred an annual event while 37% suggested a quarterly event. 15% (8 people) made a range of suggestions including twice-yearly, monthly, annually and quarterly together. Only one of the 7 people who indicated they would not want a further event gave a reason for this (not necessary). Two people left this question blank.

Nature of Future Event - Although 56 people indicated they would like a further event, an additional two people chose to answer the question about the nature of future events. The vast majority (48%) wanted an event to address information, support and social needs. Information is important to 51 people, support to 41 people and the social aspect to 35 people.

Topics of Interest for Future Events - 42 (65%) people made comments about the issues they would like to hear discussed at future events. The issues raised are wide-ranging and given the precision of the detail on the forms it is apparent that this is a group of people who are clear about their needs. Some topics were more frequently mentioned than others e.g. experience of egg and embryo donation was mentioned 15 times although this may have been influenced by the fact that the presenters who were talking about their personal experience had all formed their family through sperm donation. The issues which were mentioned three times are highlighted in bold:

- *Personal Experience and Information*: **egg/sperm/ embryo donation experience; family donation experience; couple's experience;** siblings' experience; telling family members; double donation; same sex couples – similarities/differences; donor conception 40yrs+; surrogacy; initial response to diagnosis; **experience of being donor-conceived**; **local couples experience**; emotional context for male when female partner is pregnant; **overseas donation**
- *Research*: **relevant research developments;** social conservatism/religion as it impacts donation; **scientific evidence/research into genetics; outcomes for donor conceived families**; non-biological father/child relationships; relationships between donor/non-donor siblings; **updated statistics on dc children/adults**; local statistics; epigenetics; **egg donation.**
- *'Telling' DC Child*: bibliography; be able to purchase books; **groups/workshops for parents wishing to tell;** workshops for donor conceived children.
- *Donors:* medical info re. donors; **donor's personal experience; motivation**.
- *Future Matters*: info. on tracing anonymous donors;

experience of meeting your donor.

- *Treatment*: EEVA; new treatments for male infertility; financial issues; dealing with treatment failure; **research and developments re. treatment;** financial and emotional management of cost; pros and cons of treatment in UK v. overseas; success rates.
- *Clinic related:* **experience of different clinics**; fertility services available; **treatment overseas.**
- *Counselling*: How to access; provision of small group discussion re 'telling'; support for men

Promoting Donation as a Recognised Route to Family Formation:35 (54%) people responded to the question about promoting donation as a recognised route to family formation in the community. The range of answers are listed belowwith the most frequently cited suggestions being donor related groups/presentations, use of media and advertising.

Suggestions for promoting donation as a recognised means of family formation

- *Group*s: further seminars like this one; talks at local support groups; create donation support groups; presentations at clinic Information Evenings; advertised donation related open evenings.
- *Media*: local TV; documentaries; newspaper articles; celebrity ambassadors.
- *Social Media:* blogs; social media sites; set up online site
- *Advertising*: advertise events; advertise/campaign for donors; leaflets/written material/posters for GPs surgeries/health centres.
- *Networking*: link those who attended today
- *Miscellaneous*: free counselling; working with schools and workplaces.

Open to Future Contact

75% of the attendees left their details for contact about future events. As with the high number of people who attended and the significant number who returned evaluation forms, this response indicates that there is a significant appetite among this group for donation related group events. (Table 2)

Conclusion

It is clear from the high numbers of people who signed up for, attended and returned evaluation forms with substantive and discerning comments, that this was a much needed and well- received event. The sound and wide-ranging suggestions for topics to be included in future events and the range of ideas about the types of groups/events which could be arranged is a ready template to be taken forward.

Acknowledgements

This event could not have come to fruition without the help of the other members of the Steering Group: Dr. Gillian Williamson RFC., Helen Burdett RFC., Sharon Davidson INUK, Ian Slaine CEO FCSni and Patricia Gilbert FCSni. Much gratitude goes to the funders of the event, Lloyds TSB Foundation for NI and the Big Lottery. Special thanks to the speakers for kindly sharing so much of their knowledge,experience and time before, during and after the event.

Appendix 1

Evaluation Questionnaire

How would you rate the invitation process? Excellent,good,adequate,poor.

What could we do to improve this for you?

How suitable were the venue and facilities for this event? Excellent,good,adequate,poor.

What could have been done differently?

How informative for you was the session on Research, Theory and Professional Practice? Excellent,good,adequate,poor.

How informative for you was the conversation with a parent and her son? Excellent,good,adequate,poor.

How informative for you was the session on a Father's Experience? Excellent, good,adequate,poor.

Overall how useful has today's seminar been for you? Excellent,good,adequate,poor.

Please tell us why?

Have today's discussions changed your views of donation? Yes/No.

Please explain your answer.

Would you wish a further meeting to be arranged? Yes/No.

If yes, please tell us how frequently e.g. annual daylong event, quarterly event, other.

What topics would you wish to hear more about?

What would you wish to happen at the event you have chosen? Information, Support,Social.

Please tell us which topics you might wish to hear more about.

What methods could the FCSni use to enable donation treatment to become a more openly recognised form of commencing a family in our community?

If you wish us to contact you about future events, please provide your details.

Patricia Gilbert

FCSni

A Point of View: IVF and the marketing of hope

by Professor Lisa Jardine, CBE

Modern medicine can achieve extraordinary feats in repairing and protecting the human body, from hip replacements to life-extending cancer treatments. But for most of us, I think, there are two areas of medical intervention that have a very special status and deserve the closest ethical attention: birth and death, the creation of life and its termination.

Just such close scrutiny was given to an amazing breakthrough in the treatment of infertility - the birth of the first “test tube baby”, Louise Brown, in Oldham in 1978.

As further successful IVF births followed, it was quickly decided by the British government that some sort of ethical and legal oversight was needed.

Treating infertility by combining egg and sperm outside the womb, and then replacing the resulting embryo in the mother, was an established clinical reality. The question was, is it ethically acceptable to carry out the procedure, and what limitations and controls should be placed upon it to satisfy public concern?

In summer 1984, the report of the Committee of Inquiry into Human Fertilisation and Embryology - the Warnock Report - was published. The task of the committee had been “to examine the social, ethical and legal implications of recent, and potential developments in the field of human assisted reproduction”.

The report highlighted the “special status” of the human embryo, and proposed the establishment of a regulator. The legislation derived from the report continues to govern In Vitro Fertilisation (IVF) in the UK 30 years later under that regulator, the Human Fertilisation and Embryology Authority, or HFEA.

Dame Mary Warnock - now Baroness Warnock - turned out to be the ideal person to steer the public moral debate on IVF. As commentator Andrew Brown wrote in 2003: “Her distrust of grand schemes and theories [made] her much in demand as a kind of philosophical plumber to the establishment - whenever some tricky problem arose, she could be trusted to get things flowing again.”

Born into an old-fashioned, well-to-do family, Warnock studied Classics at Oxford, and became a lecturer in philosophy at St Hugh’s College in 1949. Turning her attention to schooling after the birth of her five children, she became head of Oxford High School in 1966, and spent six years championing girls’ secondary education.

In the 1970s, she moved into public life and began to demonstrate her considerable skills as a committee chair capable of dealing with tricky political and ethical issues. She chaired a Home Office Commission of Inquiry into the use of animals in laboratory experiments, and a government commission on the education of children with special needs.

Her clear-headedness and keen intellect helped dissect the issue and structure the agenda in whatever controversial arena she engaged in. These talents were complemented by her administrative skill, and her shrewd grasp of politics. She knew which recommendations would work administratively while being politically workable too.

Even she probably did not anticipate the furore the Warnock Report would cause. There was opposition from religious figures, politicians and the general public to the very practice of this way of creating new life. It is a real tribute to the care with which the report was written that eventually legislation to regulate IVF went on to the statute book, and the regulatory body to oversee it - the HFEA - was set up. “Perhaps the greatest achievement of the Warnock committee is that it managed to get an ethical consensus that people understood as well as shared,” observed a former HFEA chair.

The results of Warnock’s astuteness are to be seen in the formal structure of the HFEA as established in 1990. It must have expert medical and scientific representation, she advised, but it ought to be led by a lay chair - someone with strong ethical beliefs, but outside the IVF sector. Each of its decision-making committees should also have a lay majority.

I have served as chair of the HFEA for the past six years. Next month will be my last authority meeting. So it seems an appropriate moment to reflect on my experience in that role.

I have seen at first hand how the regulation of IVF uses the most elegant features of UK regulatory legislation to best advantage.

Legislation is passed which lays down a broad-brush picture of a sensitive area’s activities and how they need to be monitored. Then the specialist regulator monitors those activities on a day-to-day basis - in the case of IVF, recording the details of every one of the 60,000 cycles carried out in a calendar year, inspecting and licensing clinics in both the NHS and the private sector and approving research involving embryos.

In a fast-changing field, decisions on difficult or anomalous cases are taken on an individual basis, with the best available expert advice, and policy is developed to cover new techniques and circumstances as they emerge.

The most important consequence of the close scrutiny the HFEA gives is that public confidence is robustly maintained, even as the possibilities given to those unable to have children naturally, but desperate to do so, expand at a giddying speed.

Baroness Warnock will have been barely aware in the 1980s of clinical possibilities which now enable parents who carry a rare genetic defect to have their embryos screened, and an undamaged one selected, so that the baby will not die in infancy. She could not have imagined the technique of mitochondrial replacement - removing the nucleus from an egg with mitochondrial abnormalities, and placing it in a donor egg.

Over the past two years, the HFEA has carried out a consultation process with clinicians, scientists and the public in order to advise the present government on whether this technique - which has up to now only been allowed in the research laboratory - should be introduced into clinical practice.

Perhaps surprisingly, the public supported the new technique, if it could prevent serious illness. They had little objection to its being approved for clinical use, as long as it was scrupulously overseen by an appropriate regulatory body.

Like any outgoing chair, there are, of course things I regret not having achieved.

My personal mission when I took up the post was, inevitably given my interests, public engagement - disseminating as widely as possible both the benefits and disadvantages of all aspects of assisted reproduction.

This proved to be unexpectedly difficult to do. There is an extraordinarily high level of coverage of any story involving IVF in the media - celebrity births, tales of miracle babies after years of trying, and above all, breakthroughs in clinical practice which may bring hope to thousands wishing for their own child.

This is a sector that trades in hope, and the papers and women's magazines are full of encouragement.

Yet the success rates for IVF remain discouragingly low. The last figures we have show that for every cycle of IVF, fewer than a third of patients will emerge with a baby (the figures are somewhat higher for women under 35). That leaves two thirds of would-be mothers and fathers with the heartbreak of "failure".

And the costs are high - 60% of IVF treatment in Britain is carried out in private clinics, but the HFEA has no control over the prices charged. A couple - and nowadays that means same-sex couples as well as traditional partnerships - is likely to have spent something of the order of £15,000 for the three cycles it is likely to have taken should they be fortunate enough to become pregnant.

I would have loved to have been able to have spoken more often and more publicly, with more words of caution for those proposing to undertake IVF, or postponing their family because IVF seems a reliable option should natural conception fail. Columnist Zoe Williams wrote a telling piece about the heartache of unsuccessful treatment last month, headlined 'Where's all that grief going?'

But newspapers today want banner headlines and excitement. Public information is nowhere on their agenda.

Try as I might, I have not been able to talk at length to all those families out there who are about to enter the world of IVF, or who are undergoing treatment and being persuaded to try again and again when it fails, or who are entering their 40s and hoping IVF will allow them to start a late family.

The world of IVF is a market, a market in hope. Those who enter it deserve to be fully informed of its potential to deliver grief and a sense of failure, as well as success.

Reproduced with kind permission of Professor Lisa Jardine and originally broadcast on BBC Radio 4 on Sunday 27th October 2013

Emma’s story - Why a review of birth registration is needed

by Emma Cresswell and Marilyn Crawshaw

Emma Cresswell is, to our knowledge, the first donor conceived person in the UK to bring a court case that has enabled her to have the name of her ‘father’ removed from her birth certificate on the grounds that he is not her biological father. This is an important development and Emma explains why it mattered to her.

‘*My mum and her partner were engaged when he found out that he was infertile. They decided to undergo AID treatment and were successful. When I was born, my mum’s partner was registered on my birth certificate as my father. However he and my mum separated very shortly afterwards and I had no further direct contact with him until I was 13. Throughout all that time, he also refused to pay child maintenance and my mum raised us alone. Although I had contact with the man that I understood to be my biological father from the age of 13, the relationship was not a strong one. When I was 19, he told me in the middle of an argument that I was donor conceived.*

My mum told me that she and her partner decided when they were having AID treatment that they would not tell other family members. After they separated, my mum decided that she would tell me one day but not until I had completed my education at the earliest. She was completely unaware that her ex-partner was going to take this decision away from her by telling me in the way he did.

I applied to court under Section 55a of the Family Law Act 1986 to have the ‘father’s’ name removed from my birth certificate on the grounds that he was not my biological father. I provided the court with three statements supporting the application: from myself, my mother and my mum’s ex-partner. My request was granted and I am pleased to say that I have now been issued with a new birth certificate which leaves blank the name of the father.’

Emma, now in her mid 20s, joined the Birth Registration Campaign several years ago as she feels strongly that the birth registration system in the UK should enable anyone conceived through donor-assisted treatment to find the details of their origins. She also believes the existing system makes it more likely that donor conceived people will not be told information to which they are entitled and that changing the birth registration system would encourage parents to be open from infancy. Her mum also supports the campaign.

What is the Birth Registration Campaign?

The Birth Registration Campaign Group’s members include donor conceived adults and organisations mainly from the field of adoption. The campaign believes that all people have the right to full and accurate information about their genetic as well as their legal parentage, in particular when details of their genetic parentage are stored in ‘third party’ records. The latter applies to those being raised by either adoptive parents or heterosexual or same sex couples and individuals who have used donated gametes and/or surrogacy arrangements to create their family. It believes that such information would afford them dignity but also would enable them to make fully informed life decisions, including in relation to their health and well-being.

Currently in the UK, individuals with information stored on third party records have no statutory right to be informed of their origins (though they have a statutory right to information about their genetic ‘parent’ if they are aware of their origins providing that treatment took place in the UK post 2005). They are therefore reliant primarily on their parents telling them of their origins. Research suggests that growing numbers of parents are being open with their children but heterosexual parents appear to be lagging behind same sex parents and ‘single mothers by choice’ in doing so.

The Birth Registration Campaign argues there is an urgent need for the current birth registration system to be modernised to reflect the diverse family forms in modern day Britain and to make clear that birth certificates have become a statement of legal parentage rather than genetic parentage. Historically, birth registration was intended to record the biological parentage of children but such an aim has long been compromised, not least through changes enabling those without biological connection to be registered as legal parents following fertility treatment (Bainham 2008; Blyth et al 2009).

However, the Campaign also wants to see a birth registration system that does not compromise a person’s privacy or that of her or his family. It does not, on the whole, favour the birth certificate itself being annotated to indicate that the holder is adopted or born following surrogacy arrangements or donor conception treatment. Such annotation is currently made on the long birth certificate issued following the granting of an Adoption Order or [surrogacy] Parental Order, compromising the privacy of those affected if they have to produce their long birth certificate for official purposes.

Proposals from the Birth Registration Campaign

The Campaign is proposing the introduction of a national system that places all people on an equal footing. One suggestion is that the current practice of having two certificates – a short one and a long one – is abolished and replaced by a certificate of birth showing legal parentage together with a second document/certificate that shows a person's genetic parentage (as far as is known). For example the latter could denote whether they are adopted or born as a result of donor conception or surrogacy. The document that shows the person's date of birth and names of legal parents would be used for public purposes and statute would provide that it must be accepted for all official purposes where a birth certificate is required. This could be called form A. The second certificate, form B, would show whether or not the person had a genetic relationship with the legal parent(s). This would only be available to the individual concerned and his or her custodial parents in order to retain privacy. Form A would make it clear through a standard insert that it was not necessarily a statement of the person's biological parentage, and that for this information a person should also have a copy of form B, the certificate of genetic heritage. The certificate of genetic relationship would enable the holder to know if they were, say, adopted or donor conceived and where they would need to contact if they wished to obtain more information about their genetic origins.

Furthermore, the Campaign believes the time is long overdue for the introduction of the option of 'online registration'. Such an option would not only introduce greater choice into the system (parents could choose whether to register the birth in person or online) but would potentially be cost saving and bring this service in line with moves towards digitalisation elsewhere.

In summary, the Campaign is pressing for the Government to review the birth registration system as a matter of urgency thus honouring the commitment made by the previous administration during the passage of the HFE Act 2008.

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Emma Cresswell is a donor conceived adult in her mid 20s. **Marilyn Crawshaw** is a longstanding BICA member, editor of the BICA Practice Guide Series, Honorary Fellow at the University of York and an Independent Researcher & Practitioner.

Selling the Fantasy of Fertility

by Miriam Zoll and Pamela Tsigdinos

(Originally published in The New York Times, Sept 2013)

On Sunday in New York City, a trade show called Fertility Planit will showcase the latest inventions in the world of reproductive medicine under a banner that reads: "Everything You Need to Create Your Family." Two dozen sessions will feature many of the sponsors' products and therapies, with an emphasis on hopeful breakthroughs ranging from genetic testing to embryo thawing techniques to genome sequencing.

But the fair's most powerful strategy is the suggestion that all your answers can be found within the event hall — and that the power to overcome infertility can be found within yourself.

As former fertility patients who endured failed treatments, we understand how seductive that idea is.

Americans love an uphill battle. "Don't give up the fight" is our mantra. But the refusal to accept physical limitations, when applied to infertility, can have disturbing consequences.

Medical science has achieved great feats, improved and saved the lives of many. But when it comes to assisted reproductive technologies, science fails far more often than is generally believed.

The European Society of Human Reproduction and Embryology reports that, on average, of the 1.5 million assisted reproductive cycles performed worldwide, only 350,000 resulted in the birth of a child. That is a 77 percent global failure rate. In the United States, the Centers for Disease Control and Prevention puts the overall failure rate at almost 70 percent.

Behind those failed cycles are millions of women and men who have engaged in a debilitating, Sisyphus-like battle with themselves and their infertility, involving daily injections, drugs, hormones, countless blood tests and other procedures.

Thirty-five years after British scientists brought the world's first "test-tube baby" to life, assisted reproduction is a $4 billion-a-year industry. It's hard to miss the marketing and advertisements associated with fertility clinics and service providers that are understandably eager to do what any business does best: sell to prospective customers.

But what they're selling is packaged in hope and sold to customers who are at their wits' end, desperate and vulnerable. Once inside the surreal world of reproductive medicine, there is no obvious off-ramp; you keep at it as long as your bank account, health insurance or sanity holds out.

It's no wonder that, fueled by magical thinking, the glorification of parenthood and a cultural narrative that relentlessly endorses assisted reproductive technology, those of us going through treatments often turn into "fertility junkies." Even among the patient-led infertility community, the prevailing belief is that those who walk away from treatments without a baby are simply not strong enough to run the gantlet of artificial conception. Those who quit are, in a word, weak.

As a result, both of us pursued increasingly invasive and often experimental interventions, many of whose long-term health risks are still largely unknown.

Now we know better. Ending our treatments was one of the bravest decisions we ever made, and we did it to preserve what little remained of our shattered selves, our strained relationships and our depleted bank accounts. No longer under the spell of the industry's seductive powers, we study its marketing tactics with eagle eyes, and understand how, like McDonald's, the fertility industry works to keep people coming back for more.

Some people do, of course, become parents through this technology. But we rarely hear from the other side, former patients who, in refusing to give up, endured addictive, debilitating and traumatizing cycles. Those contemplating treatments have a right to know about the health risks, ethical concerns, broken marriages and, for many, deep depression often associated with failed treatments. They need objective, independent advice from health care and mental health professionals focused on the person's well-being instead of the profit.

Being unable to bear children is a painful enough burden to carry, without society's shaming and condemning those who recognize that their fertility fantasy is over. It is time to rein in the hype and take a more realistic look at the taboos and myths surrounding infertility and science's ability to "cure" it.

Miriam Zoll is the author of the memoir "Cracked Open: Liberty, Fertility and the Pursuit of High-Tech Babies."

Pamela Tsigdinos is the author of the memoir "Silent Sorority: A Barren Woman Gets Busy, Angry, Lost and Found."

Thank you to Honor Jones at the New York Times for permission to reproduce this article

How I turned my childlessness into a force for good

by Lesley Pyne

The thought of coming to terms with childlessness and living a positive life seems unattainable for many women when they're in the midst of their struggle, so I'd like to explain how I turned my pain and experience into a way of supporting others.

I'll tell you bit about my personal experience and in the process, explain what's it's really like to be childless, explain how I healed and tell you how and why I now help others,

A quick resume

We'll never know, but I was probably too old at 34/35 when we started trying to get pregnant; we had too many goes at IVF and decided to stop once I reached 40. Once we'd told the clinic that we'd failed they never contacted us again, we were never offered support or counselling so we had to find our own way.

It took me over ten years, the support of other women and learning Neuro Linguistic Programming (NLP) techniques to heal and to be able to write this article.

Based on my own experience and that of the many women I've met and worked with, common emotions experienced when you are childless include; sadness, loneliness, isolation, devastation, anger, exhaustion, frustration, fear, loss, depression, failure, shame, loss of self-esteem and confidence. I could go on but to sum it up in one word, it's GRIEF.

Grief for

- the children and life you'll never have, that you'll never watch growing up,
- the years (and money) you wasted trying,
- the friends you've lost because they can't understand you and you can't bear to be with their children,
- the confidence that you used to take for granted and has now disappeared,
- in some cases the relationship with your husband/partner which has broken because of the stress you've both been through,

- not being able to make your husband a father, and your parents grandparents,
- your story which you need to keep secret from your family, friends and work colleagues because you know that if you start to tell it, you'll break and they won't understand,

And everywhere, just everywhere are families, parents, babies and pregnant women constantly reminding you of what you'll never have. It's heart breaking and what's worse is that it's invisible to the outside world. No one knows you're grieving because you kept your story secret. I lost my Mum some years ago and it was far easier for people to show empathy because she was a real, tangible loss.

Obviously not everyone feels all these emotions to the same extent. Most of them are, however, common and our experience of not being offered support is also not unusual. If support is offered, it's only available immediately and this is too soon, the emotions are too raw. Many couples are left completely on their own, not knowing where to turn for help.

My experience is that women struggle more, or maybe they just want to talk more than men, so this often causes problems for couples. Many women say that their husband/partner 'doesn't understand' or that they've shut themselves off, and in some cases this leads to separation or divorce.

I don't need to tell you that, to heal grief we experience four phases (denial, anger, bargaining and depression) before getting to acceptance. As with any grief, some get to acceptance fairly quickly, others can take a long, long time and some may get stuck in one spot, typically I would say depression/sadness.

And acceptance itself can be an enormous barrier because it means really accepting at the core of your being that you will never be a mother and this can start the whole grief cycle all over again.

It's taken me over ten years to get to acceptance and that's not unusual.

An early step in our healing process was joining More To Life (MTL), and finding a community of others who were also trying to get through this in a positive way was invaluable. Over the years we've laughed, cried, grown and healed together. Finding a community and a safe place to tell our story was such a positive step.

They say that time is a great healer, and to some extent I found that to be true, yet even many years from time to time those negative emotions like sadness and grief kept coming back.

Not having children raises other questions such as 'what's my purpose?', 'how can I l make a difference in the world?', 'shall I change my career' and 'what shall I do with the rest of my life?' and I really struggled with these. There were certainly some positives such as increased flexibility but when your only dream has been taken away it's hard to know what to do.

I decided to train in NLP as the mixture of communication skills and techniques looked like it might provide the answer. Two things happened:

The work I did permanently stopped these feelings coming back, and replaced them with self-confidence, self-acceptance, inner peace and happiness.

I learned how to use the techniques to help others to heal and to live a positive life.

How did the healing work?

NLP includes many powerful techniques which help clients to let go of emotions and beliefs which are holding them back. A set of these, called time line techniques enable clients to let go of negative emotions from the past such as anger, sadness, fear and guilt quickly and effortlessly; delete dis-empowering beliefs that hold you back such as 'I'm not good enough…' 'I can never be…'

In a sentence, when a client goes back to the event in the past where the emotion was created with their current learning and knowledge then the learnings that they get will dissipate the emotion so that it no longer holds them back now. The techniques can also be used to create the future the way you want it. And each technique only takes a few minutes.

I healed my sadness so that it no longer comes back to affect me now. I changed those negative beliefs that were holding me back and I learned how to build my confidence. For me this was an amazing transformation,. I wasted too many years of my life feeling sad and I want other childless women to be able to put their grief behind them to live a positive life.

I therefore support women who have partly healed their grief and are ready to move on to a new life, but are stopped by (a) the feelings that keep coming back and (b) not knowing what that life is. I use NLP, time line and other coaching techniques to do that.

My key steps

So in my experience the four key things which help childless women to heal are to:

- name the feelings as grief,
- find help and support to heal and also to create a positive future,
- find a community of like minded people (in person, or on the web), where you can share, in a positive way, where you can grieve, nurture and grow,
- the pain and shame of these issues is exacerbated by keeping them secret, so find a way and a place to safely tell your story.

Thanks for reading. I'd love to hear what you think, so please email me with comments or observations.

Lesley Pyne supports childless women to heal their past and to create a life they love. She went through "too many" unsuccessful cycles of IVF and uses her first-hand experience and professional skills in NLP and time line techniques to help other childless women.

Her website is www.LesleyPyne.co.uk and she can be contacted by email at info@LesleyPyne.co.uk

Lesley Pyne

The clients you don't see

by Jody Day

When I separated from my husband and partner of 16 years I was 38. Much too soon afterwards I started internet dating, confident that I'd 'meet someone and do IVF' and felt unshakeably convinced that motherhood was still ahead of me. I was wrong. I'm 49 now and I've spent the last five years coming to terms with that.

During my years of babymania following an all-clear laparoscopy at 33, I saw just about everyone else including nutritionists, acupuncturists, homeopaths, herbalists, healers, shamans, priests – anyone with a leaflet, frankly or written up favourably in the media. I may as well have randomly walked around London putting £50 notes through people's letterboxes for all the good it did. But each person told me what I wanted to hear - that if I stopped this or started that I would get pregnant soon. I peed on every colour of stick and force-fed my husband vitamins until our fridge looked like an up-market pharmacy. One month I decided that if we had sex every single day surely I had to get pregnant. It was an exhausting month!

At no point, not once, did anyone, not my GP, gynaecologist or surgeon suggest to me that as I was fast approaching the critical age of 35 we might like to consider IVF. Amazing really. But I always knew it was there in the distance, the magic bullet that would make everything OK, if I really, really needed it to. I had a couple of articles about 'miracle baby' IVF stories cut out from newspapers and tucked in the bottom of my jewellery box. I kept them there like talismans, like magic spells to be used in an emergency only. I was scared of the injections, scared of the reported roller coaster of emotions that the hormones unleashed – my marriage was rocky enough due to my husband's emotional fragility (and the alcohol he used as self-medication) that I felt I couldn't afford to lose the plot. I was the 'together' one. And anyway, I didn't need to worry because everyone kept telling me I'd be pregnant soon and that all I needed to do was relax, practice these breathing exercises, take these vitamins, give up coffee, do more yoga, meditate, give up acid-forming foods, go on holiday, visit this shrine, get really fit, have sex on a cushion, let go of my negativity, pray…

As I tipped into my forties I remained in an absolute bubble of denial about my impending childlessness. I had a couple of serious relationships, but neither of them were right to do IVF in. When my last, and most serious, post-divorce relationship ended I was almost 44. Even I, by now, knew I was probably too old for successful IVF and I couldn't afford it anyway. I was single, broke and utterly lost. I'm grateful that I didn't know about donor eggs at that point, because I think any more hope would have driven me nuts. I've written in my blogs for Gateway Women that perhaps hope is 'the most toxic fertility drug' and women from all over the world knew exactly what I meant. Solo motherhood never appealed, either as a biological or adopted mother, and it was out of my reach financially anyway.

I never identified myself as 'infertile', even though I was unable to conceive naturally from the age of 29 to 44. I'd had an abortion at 20, terrified of motherhood after an unstable childhood, and so felt reassured that 'everything worked'. I never joined any infertility online communities or went to a fertility clinic. I was convinced I was potentially fertile and everyone was quite happy to collude in that fantasy with me. I'm young looking for my age, always have been. My mother, from whom I inherit my youthful looks, promised that I'd be grateful for it when I was older. Funny that. Terms such as 'ovarian reserve', 'FSH' etc were not in my vocabulary nor that of anyone I consulted, nor mentioned in the triumphalist articles about the joys of late motherhood and the miracles of IVF. I knew no one who had wanted to become a mother who hadn't achieved it, by natural or assisted means. I knew no involuntarily childless women in my peer group nor in the wider culture. Sure, some women chose not to have children, but for everyone else who wanted to be a mother it happened for them, didn't it? I was in therapy and had been so since just before my divorce, but my childlessness was never explored. It seemed to be invisible to everyone.

The moment that I realised that I was no longer childless on the way to becoming a mother but that I was now a childless women for life is one that will stay with me forever. It will probably be one of those that flash before me when I die. It was a gloomy February afternoon in the grotty studio-flat I'd rented following a stormy and distressing breakup. I was watching the rain on the window and the rather dreary London skyline when the traffic noise from the street seemed to become muffled, like someone had muted the sound. I became acutely aware of myself, standing there, looking out of the window. And then it came to me: It's over. I'm never going to have a baby.

But instead of falling apart, something remarkable happened: I fell together.

It started as a strong physical sensation that all the energy I'd been using to run the two separate 'versions' of my life all these years somehow merged back together. It was a very odd feeling, as if the 'Jody who had been going to be a mother one day', and who'd been my constant shadow for the last 15 years, reintegrated with the rest of me – the life I was actually living – the life of a middle-aged childless woman. I felt these two 'channels' of energy connect, deep in the centre of my torso, like wires touching. Years of endless backchat between these two 'channels' came abruptly to an end. Backchat about career opportunities - What about the maternity leave? Would the role be too stressful to get pregnant?; about partners - Would he be a good father? Could he afford to pay for IVF? Did he even want to have children?; about relocating to India: What about the maternity hospitals? How would it be for my children to grow up in India?; about studying for my Masters - better get it done now, won't have time once you're a mother. A calm descended. The infernal, internal, maternal channel went off air.

Making a cup of tea in the kitchen a few minutes later, another new thought popped up: my mind drifted back to when I was 20 and how I used to feel surveying the vast landscape of time ahead of me until I turned 50. In those days it seemed that I had enough time ahead of me to achieve whatever I set my sights on. I pondered, Well, if the years from 20 to 50 can feel like that, why can't the years from 45 to 75 feel the same? As long as my health holds out, surely I can achieve something pretty significant in that time? I stood still, shocked as the next, and most radical thought emerged: When was the last time I had a thought like that?

I'd love to say that halleluiah I was fixed from that moment forwards, but the truth is that what happened that day is that I came out of denial about my situation, about my childlessness. I am so grateful that I received a hint that day of what lay in my future, as I then entered a period of profound grief for the children I would never have, the life I would never live. But I had no idea it was grief – it would have been a huge help if I'd known. I felt so distressed at points over the next couple of years that I fantasised about ending my life. I very nearly took a job in Kabul and when quizzed by a friend about the potential dangers, discovered that the thought of being blown up didn't bother me in the slightest. I had no idea who I was, or what my life was 'for' anymore if I was never to be a mother. I felt marooned in mid-life with no sign of land in any direction. And when I tried to talk about my situation and the intensity of feelings it was bringing up, nobody would listen. All I ever got were yet more 'miracle baby stories'. I gave up trying to talk about it, and started writing about it instead on a blog. From the very first entry I posted in April 2011 I discovered that it wasn't just me this was happening to but an awful lot of other women across the world who felt similarly lost, similarly silenced.

In my experience with various counsellors and therapists during this period, not one of them identified that what I was dealing with was grief. Profound, debilitating, life-changing, character-altering, existential grief. It wasn't until I participated in a workshop on grief as part of my training to become an integrative psychotherapist that I made the connection for myself. That connection pretty well saved my life. It's the part of my writing and workshops that often resonates most strongly with other childless women. 'So I'm not going crazy!' they write or, 'that grief section in your workshop – that was a complete eye opener – now I understand why I'm struggling…'

Not having a family broke my heart. Some may think that's melodramatic, but I know it's true, and so do other childless women. However, grieving that loss and the life I longed for healed my heart bigger than before. It changed me profoundly and in ways I am still discovering. I have come to believe that grief is the shadow side of love, and like the dark side of the moon has to be rotated through for us to be ready to come back into the light. Without grieving for the life unlived we cannot shine again. But it can be tough going and you need the company of others who can empathise with your pain, and not suggest that you ought to be 'grateful' or 'happy' that you don't have children because 'at least' you get to 'sleep in late' or don't have to 'endure' family holidays.

Most of us would trade our spotless cars and silent homes in a flash for the hurly-burly of family life. Yes, we know it's hard, we can see that. You don't need to tell us that – it's in our faces most of the time as Mummy blogs and other media. Sit down and count how many programmes in the TV schedule this week are about having a baby or families… But we'd still rather have found that out for ourselves.

What is less visible and often pushed aside by others is what is hard about our lives as reluctant pioneers. Being part of the 1 in 5 women born in the 1960s who are childless can be lonely, alienating and scary. We're invisible to mainstream culture and often to the therapeutic professions. Not all of us are childless because of infertility as there are many ways not to be mother, including choice. But even a proportion of those choices, when examined, turn out to be rock-and-a-hard place choices. Our lives are complex, just as everyone's are. We are much more than spinsters, career women, childfree women, maiden aunts, wicked stepmothers, witches and crazy old cat ladies.

I had no idea that my Plan B was to become 'the voice of childless women', to stand up in public and speak about the taboo of childlessness. To become a leader, a role model, an activist, a best selling author about recovering from childlessness. Five years on from that February afternoon I can say that although the sadness of not being a mother will always be a part of who I am, it no longer defines me. Being a childless woman defines me, and in our currently pronatalist culture defines how others see me… but my sadness no longer does. Healing from my childlessness has made me pretty fearless. Grief has transformed me. And it is helping me to help others transform too.

Gateway Women gradually evolved from that first blog to my first public talk, first Gateway Women group, first workshop, first retreat, the global private online community, speaking at the Women of the World festival, being on Woman's Hour and publishing my book: Rocking the Life Unexpected: 12 Weeks to Your Plan B for a Meaningful and Fulfilling Life Without Children. It went to number one on Amazon Kindle in its first day – in the fertility section no less. There's a real hunger for the promise that Gateway Women offers - that there really is the possibility of a meaningful and fulfilling life after childlessness. Even that idea alone seems revolutionarily counter-cultural right now in our often 'baby at all costs' culture.

But I've met and spoken to hundreds of your clients, and only one of them had been with a counsellor who mentioned grief at their final post-treatment session. Only one. Obviously this is a very unscientific survey because those that did receive more helpful guidance may never have found the need to search for the support that Gateway Women offers. I do understand that private clinics are often quite strict about what resources they will let you share with clients post-treatment, but still…

I'm not sure that I'll ever 'get over' my childlessness – but I have proved that it is possible to heal around it. What once was once an open wound is now a scar and I can live with a scar, dance with a scar, dream with a scar. It's a part of me now, though it will always be a tender spot. I loved my unborn children, and they will always be with me, but now my life goes forward with them safely inside my heart forever.

I have never seen a fertility counsellor, but if I had, I hope it would have been one that mentioned grief and suggested how I could do my grief work. And perhaps shared with me not to be scared of grief, but to welcome it into my broken heart so that I could be healed to love life again. That it would enable me to forgive myself and others for the dramas and confusions that contributed to my childlessness. That it would heal my relationship with my body, my spirit, my past and my future. That I was not alone and that I needed to find those other childless women so we could help each other get through this. And that some of those women would become my new friends, helping to ease the angry gap in my life as everyone else became wrapped up in their families.

Today I love my life again and being able to guide and support other women as they learn to love theirs again brings me great joy and satisfaction. If I had my time over, I'd still wish to be a mother but these days I'm genuinely fine with the way things have turned out. I find I'm able to enjoy the advantages of not being a mother, take pleasure in being around other people's children without dying inside and really look forward to my future again. The years ahead are unknown and I'm OK with that. There is no path set out for me as a childless woman in our culture; I have to make it up as I go along. But I'm in good company and having come to terms with the genetic dead-end that is my life and death as a childless woman I have a resilience that I trust will serve me well. There are other, less obvious, ways to leave a legacy and touch the lives of others.

Jody Day is the Founder of Gateway Women – the global friendship and support network for childless-by-circumstance women. She is the author of Rocking the Life Unexpected: 12 Weeks to Your Plan B for a Meaningful and Fulfililing Life Without Children.

Jody holds a Certificate in Integrative Counselling Skills and Theoretical Perspectives in Psychotherapy (2010) and is studying towards a Masters in Integrative Psychotherapy.

www.gateway-women.com

Sibling's Grief by Claude Rennert

Being on the Pre-Adoption Course took me back, by surprise, many years ago and after much thought on what would be the topic of this essay, I decided to stay with what kept flashing back in my mind: the example of a birth certificate used in Scotland for pregnancies that end before the age of viability, given to us as a handout after the video "Empty Arms". I don't know how much I can explore within a short essay and although this account is about my personal history, it is one shared by many families but not often looked at from the angle of the siblings. The little research I have done showed that although there is a great deal of writing on parents, little seems to have been gathered on siblings' feelings.

Back in time, one early morning of 1953: "You have a brother", says my aunt who had intruded into our home and taken control of the kitchen and bedtime rituals the night before. What follows (in italics) was written in 1993 whilst in therapy and on a counselling course. This letter, written to my children is the backdrop to this essay and today I feel I can add to its content the self-reflective loop of therapy.

(December 1993 Letter to my children)"The wicked Aunt and the Lost Mother"

Once upon a time I was a little girl whose mother was expecting a beautiful baby, just like my doll. Suddenly the adult world became alien, whispers, and worried faces. "Auntie when can I see my brother? I want to go and see Alain". "Go to your room and be quiet" answered my Auntie.

I remember in the morning rushing to my teacher and telling her and my friends that I had a brother. I remember the feeling of relief, I was no more to be an only child, and I had waited seven years!

The next image, which has stayed in my mind, is this moment in the kitchen, in the evening, when my aunt whilst preparing dinner, turns towards me and says she has some bad news. "The baby is dead", she says. I burned myself on the cooker and cried. No comfort there, I leave the kitchen holding my tears. Tears of what? What pain? Burned fingers (was it that bad?) or tears of grief? I don't know. I have never been able to answer this question as the two events are totally juxtaposed in time.

In reality, my mother had given birth at 36 weeks to a stillborn child. Why then invent a live baby? As an adult I would say because the grown-ups did not know how to tell a young child. The adults around me were whispering and shutting up in front of me and I do remember how isolating and worrying the sudden silences were. "If there are other children in the family, the problem may arise of how to tell them about the death. Generally, it is important to tell the older children about the experience and to allow them to talk about their thoughts and feelings regarding the loss and to help them to grieve for a lost sibling" (William Worden, Grief counselling and grief therapy). No such thing in my home, when mum came back there was no more mention of the baby. Where did all my feelings go?

Me, little girl, I was told to be quiet, not to cry as her mummy was upset, and not to say a word. I did not say or show anything until the day, 25 years later, when Steven, your brother, died. That night I had a powerful dream, *snapshots of the day. My aunt has just told me that I have a brother and, that morning in school I told everybody that I had a little brother. Dark hair like your father, she said. I have been waiting for him seven years. Tomorrow I'll see him. Dark hair, brown eyes, tanned skin, he is beautiful. I know my brother is beautiful. And now – tonight – I have lost him; he has never lived, he died in my mum's tummy but she would not tell me this morning. I want to see him, I have to, I have to know my brother'. I wake up sweating and shivering, I sob, sob, Alain! Alain is dead.*

"Children remember many details of a death event for years. After children appear to stop talking about the death or asking questions it is easy to assume that they are over their feelings. In fact they reported that they continued to think, worry and dream about what happened for a long time (Excerpt from a paper presented at the SANDS Australia the National Biennial conference, 1996 by Dr Carol Irizarry, Senior Lecturer, School of Administration and Social work).

My memories were still present in my subconscious and the second death brought them back to absolute reality, like yesterday. The grief of one allowed to re-call the "forgotten" dead.

'As children grow they may want to discuss again what has happened and try to put the event into perspective of a new life stage. This revisiting may be triggered by the birth of another baby, someone getting married, a birthday or another death" (Dr Carol Irizarry id.) The images in my dream were extraordinarily clear.

I remember going to my mother's room at the maternity clinic. The bed is on the right, the room is very small and all the space seems to me to be filled up by a huge wardrobe. I sit on the bed and wait. Adults talk and I am bored and sad. Why cannot I see him, him with his brown eyes, his tanned skin and his black hair? My eyes cannot leave the linen basket on top of the wardrobe. I get absolutely fascinated by this basket. There is a bulge under the sheet which covers it. My heart beats (I can still feel that accelerated beating) my throat is dry, I don't hear anybody. He is under it, I am sure he is under it. I am too small, I will never be able to have a peep. I never told my parents what I thought that day, it is like if my mouth has been tightly zipped in the presence of the main protagonists.

1993, in therapy I produce a picture which came whilst writing this letter to my children, the picture: Me as a mother crying, having lost her child and inside, Me the seven year old shut up by the adult's messages. Behind the seven year old, the linen basket on top of a wardrobe - an image which I have never erased from my memory. "Other projects of a personal nature can be making drawings for or about the baby that died (Dr Carol Irizarry Id). My picture came 40 years later. Grief in suspense is what I call it. As a therapist it has been a huge learning, it is never too late to grieve, never too late to feel, never too late to heal. As I look at the picture today, I am struck by the fact that it does not go further than the imprinted image. It is a visualisation of the frozen state I was in. Unlocking the pain and fears could not happen to me as a child as there was never space made for it. As the letter says:

We go back home, my father is silent. Everybody is silent. They don't talk about Alain.

Silence became the shroud. I read in the same research paper: "Share as many facts as possible". No such sharing in my case took place and the result is an internalised, unresolved grief. Therapy and the course helped me. But there was more to come, and anyway does grieving ever finish? I don't think so. The feelings change but a loss is what it means. "Gone" say children. "No more". This is simple childlike language which speaks for itself.

November 2002, the video "Empty Arms"… A family lost in grief and a very caring midwife who wraps up a stillborn little baby, a mother, a father and a young child…. I am startled by the smallness of the seven year old – me 49 years ago! I hear myself say inside my head "my god was I that small?" And I watch transfixed this little girl looking, touching, and talking to/about her little sister. I envy her. I cry, I scream inside "they have stolen my brother". I never saw my brother, I was plainly told "you have a brother", "he is dead", "be good with your mum". Silence. No more words, no idea of what they did with the beautiful little brother. Never ever any other reference. In front of my eyes the video carries on, picture of little Moses, a dressed baby, a father who says he feels he has had a daughter and a very tearful mum. Mine never cried (at least in front of me), my dad never spoke except to say "be good with your mother". I understood much later that he was never allowed to mention Alain and was plainly told by my mother that it was his fault if the child died. "Husbands are often the target of their wife's anger" (William Worden id.)

I guess I found my own little way of grieving. I remember picturing in my mind Alain at three to six months old; after all, I had never seen a new born baby. After the event, I started playing lovingly with my doll whom, of course, I called Alain. I remember nappy changing, feeding, talking, holding. Tragedy struck some months later, the day my doll broke: an arm came off and my mother (who hated the doll) took it and threw it in the bin. I pleaded with her for it to be repaired. "It is an ugly doll and you have got others". I never forgot and never forgave, I guess. "Usually children will play out things that are happening to them in their lives or the feelings they are experiencing…. It is often during play that children's misconceptions about what has happened and their unanswered questions start to emerge". (Dr Irizarry id). As I see it today, my repetitive playing was the acting out of my deep need to make my brother real. Unfortunately fate caused more confusion as to the outcome of the death when the replacement object was thrown in a bin by my own mother.

I will learn at some stage that "they, at the maternity unit, have disposed of his body". Dispose!?. You dispose of your litter in a dustbin, don't you? Big dark metal bins. I never thought passing by the hospital that dead babies were put in bins! Alain is a beautiful baby, tall and thin. I think she said "they burnt him first". I remember pictures in my books: big red ovens, the baker places his loaves in them. Yes, it must be of the same kind, they are big enough for a baby. I feel terribly impressed by what has happened to my little brother. From the linen basket into the big red oven, and thrown away in the dark grey metal bin. I am right, I must be right. We have never been to take flowers to any grave. Alain has no grave, why? Other people go and cry at graves, they take flowers, they even have a special day in France for it: 1st November. They dress in dark clothes, they look sad, women have got scarves on their head, they sometimes hold a child by the hand and they walk slowly, then kneel down by a grave and cry. I have seen it somewhere.

I think I would have liked Alain to be in a nice coffin, with white silk and a little pillow, I would have brought him some daisies. I pick up a lot of them in spring. That little white and brown vase would have been right to hold them. Instead, he is in a bin.

These words bring me back to the video, Moses basket, funeral service, and as the video finishes, the feeling that, at last, I have completed the jigsaw, erased the confusion. Although their ceremony has nothing to do with the reality of Alain's fate, somehow it gave me a feeling of completion which I had never touched.

Life goes on of course and fate plays funny twists. When I lose my own child, this time there is a funeral from which I ban my own mother as I shout to my husband "I don't want my mother to come. Anyway, SHE has never buried her own child…." I am quite shocked and surprised. Where did this come from? Anger which was left out on the first occasion? The desire to punish my mother for what she did to me? As I write this, I realise that I exclude my father from this outburst and I accepted him that day. In fact as it happens this was the only occasion when he mentioned how lovely Alain was. I remember him saying "what a shame, he was such a beautiful child, he had my hair, Ah la la quel domage! (my dad was French). I looked at him as I realised he was lost in his own thoughts, with his own child, my brother, and tears swelling up, I said "thank you papa". For the first time he had broken the wall of silence. No more was spoken until my mother died. To me this now makes sense as she had put a veto on the subject. I called my father years later, after the Ideal Child Exercise to ask the first questions, this was last year.

One feeling I would like to touch on to finish is that of yearning for another little brother. Replacement was important in my mind and I kept asking my mother for another one. This brother came three years later but I was disappointed when I saw him and felt I should love him but he did not respond to my dreams. He did not look like my ideal brother and I felt disappointed for a long time. I can also say that no doll replaced the missing one although I was given many more.

As a professional I want not to forget my own journey when working with families who face the loss of a child in any sort of way. If there are siblings, for me, it is about letting parents know that children are OK with the truth, that although it is often difficult as a parent to speak, if they are able to, it will allow their child(ren) to understand their emotions. If it is too difficult for the parents at that time, then children need a space of their own, someone to talk to, draw with, cry with, be angry….. be, just be, to express their feelings and get in touch with reality.

The death of a sibling has a further dimension: Not only old people die, but children are not protected. This turns upside down the concept that death is far away, that one is protected as a child. I do not remember having nightmares, I remember the need to go to sleep with a little lamp. Was this little lamp keeping the great ripper away? Will I ever know? What matters for me is that the silence is broken. My favourite title "breaking the wall of silence" (Alice Miller).

Finally, there is no blame in what I have written, I see my story as a personal illustration of what happens in a child's mind when she is silenced and this is why I have attempted to make sense of it.

Letters to the Editor

Dear Editor.

I am an experienced and fully qualified infertility counsellor and I have been working for a chiefly private IVF clinic as their main counsellor for about 5 years. I work on a sessional basis.

I am suddenly told by one of the nursing staff that the unit/PR has employed another counsellor with no previous infertility counselling experience. Apparently the counsellor contacted the clinic directly. There was no advertisement or obvious interview process.

Although I have tried, the counsellor does not respond to my efforts to communicate with her. I am told by the PR that I have to 'train' the counsellor re infertility counselling and especially, implications counselling. I soon discover that although she wants my expertise, she is not interested in meeting with me or engaging in dialogue regard general counselling issues. I am informed that she is being given the lion's share of the work, I presume because she is charging very little for the counselling.

I feel completely let down by the unit and the PR, and also by the counsellor, who with very little knowledge is completely happy to undermine all the previous work I have done, not only in counselling but also in educating the multi-disciplinary team. She seems to be uninterested in how I feel, except when she comes across a difficult situation she can't handle and needs some advice.

Name and address supplied

Dear Editor,

Thinking about the issues Lynda Mizen raised in her letter [Summer 2013] I felt a comment might be useful. In a book I wrote some years ago [Childless No Choice], I spent some space discussing the phenomenon of 'pronatalism' that is the strong presumptions that favour having children in daily discourse and by implication devalue the childless or childfree. Some of the people I talked to in my research quoted even more extreme reactions to them personally from ignorant 'friends' and others they talked with; e.g. "I hear you can't have children, so I'd better not have you as a friend now that I am trying for children too." True! Lynda's letter highlights that perhaps nothing has changed. In some ways it might be that the high profile given to the assisted conception treatments by sensationalist newspapers, as well as healthcare cuts, perhaps has made the climate even harsher. Meanwhile the NHS makes very little Ac treatment available, and some less scrupulous infertility specialist doctors make a fortune on private treatments. Lisa Jardine's view on BBC Radio 4 Thought for the Day 27/11/13 that the infertile are too easily exploited is very well put. Infertility counsellors are in the difficult position alongside all they have to do with too little time at their disposal, to attempt to support the already flagging self esteem of so many of their clients.

Dr Jim Monach

Dear Editor,

I too attended the accreditation workshop in May and found the afternoon very helpful and as I result I have successfully gained my BICA accreditation.

Reflecting afterwards, I did experience irritation but not with BICA because once my application was submitted the process was very efficient.

The irritation was with myself because my dyslexic tendancies created difficulties with writing in a coherent format.

I am reminded of a quote that I wish to share; 'I know that you believe you understand what you think I said but I'm not sure you realised that what you heard is not what I meant' (Blank Minds and Sticky moments in Counselling Janice Russell & Graham Dexter)

Keep it simple, be transparent and listen to your mentor.

Lynda Mizen

We'd be delighted to receive letters on any topics you'd like to raise, which can be published anonymously, and would be most interested in your responses to any of the issues raised above, which can be emailed to journal@bica.net.

List of current accredited counsellors

BICA offers an accreditation scheme open to all specialist infertility counsellors. AMBICA means Accredited Member of BICA and SAMBICA indicates Senior Accredited Member. AMBICA [IP] are accredited counsellors who work independently from a clinic. All the counsellors listed below have been rigorously assessed by the National Accreditation Board of BICA before being awarded their accreditation. Accredited Counsellors have submitted detailed evidence of their current practice, qualifications and experience. In addition SAMBICAs have submitted a comprehensive portfolio of evidence that demonstrates that they are working at a senior level. Those names given as being registered are members of BICA who are working towards accreditation. Accreditation must be maintained and reassessed on a regular basis. For more information on the BICA Accreditation Scheme, please see http://bica.net/membership/accreditation-scheme

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A note from the Editor

The editor welcomes articles, news, letters, reviews, photos, images and any material relevant to Infertility Counselling. Please send a word processed copy of any written submission by e-mail in Word format. Articles should be between 1,000 - 2,000 words. The editor reserves the right to edit and revise all contributions. The views expressed in the articles and reviews are those of the individual writers and not necessarily of BICA or the Editor. Similarly, workshops, courses and events announced or advertised are the responsibility of the sponsor. Their inclusion does not

A note from the Book Editor

The book editor welcomes book reviews on books relevant to Infertility Counselling. Please send a word processed copy of any written submission by e-mail in Word format. Book reviews should be no more than 1,000 words. The editor reserves the right to edit and revise all contributions. The views expressed in the articles and reviews are those of the individual writers and not necessarily of BICA or the book editor. Similarly, workshops, courses and events announced or advertised are the responsibility of the sponsor.

Their inclusion does not necessarily imply endorsement by BICA. Book Reviews to journal@bica.net

Book review guidelines:

The review needs to relay in distilled form the main argument(s)/ point(s) the author(s) is making including:

- How does it relate to existing literature in the field (please bear in mind this means relevance for fertility counsellors)?
- In what way does it (if it does) tell us something new or that could be adapted to the fertility field?
- 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?
- What is your personal take -did you like the book and why? How has it affected you?
- How relevant is it to the work of fertility counsellors?
- Are there any points, arguments, examples you would like to make based on your own experience/ practice?

Copy Deadlines:

Volume 21 (1) Spring 2014 - 28 February 2014

Volume 21 (2) Summer 2014 – 30 June 2014

Volume 21 (3) Winter 2014 – 31st September 2014

Subscriptions: BICA members receive three copies a year as part of membership.

Annual subscription: ordinary members £55; corporate members £120; overseas members £60. Clinic members £130.

Single issues of the journal (if available) £10 (BICA members) £20.00 (non-members) Copies of articles £7 (£15) – prices include UK p & p (overseas postage details on request).

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Journal Information: Kate Brian - email journal@bica.net

BICA is the only professional organisation for infertility counselling in the UK and attracts both national and international interest. Membership is drawn from counselling and other related professions.

Journal of Fertility Counselling is published by

British Infertility Counselling Association, 33 Goldington Street, London NW1 1UE.

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