BYE-BYE, BETH ...

I have thoroughly enjoyed my three years as Daisy chair but with increasing work and family commitments have been trying to step down for a while and I am delighted to let you all know that Kate and Marie have just taken over the role. Even better news is that they have a great team to work with including new volunteers Patricia as vice-chair; Vicki as Update editor and Jocelyn as secretary, joining long-standing committee members Erica and John. I wish the whole team all the best in helping Daisy develop and grow.

Beth
... HELLO, MARIE AND KATE!

The past few months have been a transitional period at Daisy, and as we say goodbye to our previous chair Beth Cartwright and thank her for all her hard work over the past three years, Kate and I wanted to take a moment (and some editorial space) to introduce ourselves to the Daisy community.

We are both medical doctors training in obstetrics and gynaecology in London, myself at Queen Charlotte’s Hospital and Kate at West Middlesex Hospital. We are research fellows in endocrine gynaecology and are working in the area of premature ovarian insufficiency under the guidance of Mr Nick Panay, who is an active supporter of the Daisy Network. Kate was Nick’s previous research fellow and I am his current one.

We are both passionate about this under-researched area of women’s health and recognise the need to understand more about the patterns of this condition and provide the support that women diagnosed with premature ovarian insufficiency (POI) need. We officially became co-chairs on 16 October and we also welcome on board our new secretary Jocelyn and new Update editor Victoria. There are also several new members on our executive committee whom you will meet in the next editorial.

As a committee, we will be having our first meeting on 14 December, after which we hope to update you with information and details about our plans for next year and a date for the Daisy annual conference. If you have anything you would like us to discuss at our first committee meeting, please email daisy@daisynetwork.org.uk.

With our new team now in place, we are keen to explore what our current members want and also hear what could make a difference from those that follow our work or attend events. If there are aspects of Update that you as readers and members particularly like or dislike, and would prefer to see kept or changed, please let us know. We would welcome your ideas and suggestions.

We want to gather all your input to make changes that you as members of Daisy find useful.

We are so pleased and excited to be the co-chairs of the Daisy Network and look forward to continuing its great work and making our impact as a charity stronger.

Wishing you a very happy Christmas and all the best for 2015,

Marie and Kate
ALL CHANGE AT DAISY

In addition to the new co-chairs, several other roles within the Daisy Network changed hands in October. The new vice-chair is Patricia, a registered pharmacist who has worked in both the private and public sector and has extensive experience of sales and marketing. She is familiar with changes within the NHS and funding challenges, and is keen to help secure additional funding and develop innovative ways to increase membership and awareness in the medium term. Patricia says: “I would like to be able to contribute in a meaningful and lasting way, so that the Daisy Network can continue to be a key information and emotional support network for women experiencing premature ovarian insufficiency and early menopause, and the complex health and life challenges that accompany it, so that their lives may be lived with confidence, empowerment, quality of life and longevity.”

Jocelyn is our new secretary and Vicki is the new editor of Update. Both of them have personal experience of premature ovarian insufficiency. Brianna, an obstetrics and gynaecology academic specialist registrar, also joined the committee without taking on a specific position. Long-standing Daisy supporter Erica remains the PO Box and membership manager and her husband John is still our treasurer. This gives us a well-balanced committee with roughly half of the members being medics with a professional interest in POI and the other half having experienced the condition themselves or through a close family member.

A NEW ERA FOR UPDATE

Change is afoot for the quarterly newsletter too. As of next year, Update will be available online in the members’ section of the website rather than in print. You will receive an email when the latest issue becomes available. We expect this to save us around £3,000 a year in printing and postage.

As a small charity with limited resources, it is important for the Daisy Network to save money without compromising on the support it provides for members. A limited number of copies will still be printed for anyone unable to access Update online. To continue receiving the printed newsletter, please email editor@daisynetwork.org.uk or write to PO Box 183, Rossendale, BB4 6WZ.
Question:
I have just been diagnosed with premature ovarian insufficiency. I have been through so many things since last year and feel very tired and sad. My GP gave me your website address and prescribed me Elleste Duet 1 mg but I am very scared about HRT. Could you tell me why HRT is mandatory for premature ovarian insufficiency (POI)? Women going through normal menopause use natural therapies to alleviate their symptoms because the plants contain phytoestrogens or help regulate hormones without any side effects. Why is this not suitable for POI as well? Why are doctors so sure that HRT is mandatory when there are not enough studies to confirm this? I’ve had very bad experiences with hormones such as the contraceptive pill, so I’d like to know whether I can just use natural alternatives instead of artificial hormones.

Dr Kate Maclaran answers:
HRT aims to correct the deficiency of oestrogen and progesterone that occurs in premature ovarian insufficiency. This is important both to help with the symptoms of oestrogen deficiency (including hot flushes, nights sweats, poor sleep, skin and hair changes, mood swings, anxiety, fatigue, joint pain, low libido and vaginal dryness) and to prevent the long-term effects such as osteoporosis and heart disease. There are several different types of HRT available and so you may have to try different preparations to find the one which suits you best. Your GP should be able to discuss different types of HRT with you or you can ask to be referred to a specialist if your GP has not already referred you.

Some women prefer to use alternative therapies. However, there is a lack of clinical trial evidence concerning their effect on menopausal symptoms and the effect of taking them for prolonged periods of time. Alternative therapies will not necessarily protect against heart disease and osteoporosis. Young women with POI often need higher doses of hormones than those going through menopause around the average age of 51 and so alternative therapies may not be as effective.

Question:
I’ve heard a lot about egg donation and egg sharing but I’m not sure what egg sharing actually entails. Can you clarify this?

Dr Brianna Cloke answers:
Both of these schemes are a means for a woman to donate her eggs to a recipient who is unable to produce or use her own eggs. There are many reasons why women are recipients including premature ovarian insufficiency, an older woman who is not able to produce an adequate number or good-quality eggs as well as women who may carry a genetic problem that could be passed on to the unborn child. Therefore, women who do not have premature ovarian insufficiency may also require egg donation in order to achieve a pregnancy.
The first reported case of a successful pregnancy through egg donation was in 1983. Since then, the numbers have gradually increased worldwide. Currently, in the UK, approximately 1,300 women are treated with egg donation resulting in approximately 500 births a year. Egg donation is a time-consuming and invasive procedure that carries some risks and it relies on altruistic women. In view of this, in 2012, the Human Fertilisation and Embryology Authority (HFEA) introduced a compensation fee of up to £750 for women who donate their eggs. This has had a knock-on effect of reducing the waiting time for couples seeking donor eggs.

A woman can donate her eggs if she is less than 36 years old, although this does not need to be adhered to if there are exceptional circumstances, and she will be registered as a donor with the HFEA. A donor is either known to the recipient or can approach a clinic or agency independently. Alternatively, if a woman is going through in-vitro fertilisation (IVF) treatment herself, she can donate some of her eggs at the same time through a scheme called egg sharing. However, egg sharing is not offered at all clinics in the UK and a couple seeking egg sharing will need to discuss it with their individual clinic. The usual practice in egg sharing is to halve the eggs between the donor and a recipient at the time of egg collection. This donor is compensated in kind for sharing her eggs, which usually takes the form of a financial discount in the treatment fees. The donor couple and recipient couple will have separate agreements with their clinic. The overall benefit of egg sharing is to reduce the waiting time for recipient couples.

If a couple receive egg donation treatment in the UK, they are the legal and social parents of the child. In 2005, all children born through egg donation were given the right to find out the donor’s identity when they reach 18 years of age. However, the child does not have social, moral, legal or financial rights over the donor. In addition, since 2009, donors (including egg sharing donors) have also had the right to learn about certain aspects of the eggs they donated. This includes whether the donation resulted in a successful pregnancy and, if so, information on the number of children, the sex of the children and the year they were born can be obtained.

For a couple who require an egg donor, potentially the quickest option is a known donor, such as a relative or a good friend. However, most couples are not lucky enough and will need to wait for an anonymous donor. This waiting time varies between clinics and it is worthwhile contacting several clinics for this information. Although this waiting time has fallen recently, many UK couples travel abroad to seek egg donation treatment as this can prove to be a faster option and may be cheaper. However, if a couple are planning to travel abroad, then it is important to do plenty of research into the safety, standards and success rates of the clinic they intend to travel to. Specifically with regard to egg donation, there may be different legal responsibilities of donors and recipients and issues around anonymity.

**Question:**
Are there any natural alternatives to HRT?

**Marilyn Glenville answers:**
I usually write about natural alternatives to HRT using diet, herbs, vitamins and minerals to help with menopausal symptoms and prevention of osteoporosis. But your situation is different; you have a medical condition that has caused you to produce less oestrogen than you would have otherwise until the average age of menopause. The major concern is your bone health and the risk of osteoporosis. So this is where HRT is really Hormone Replacement Therapy because it would be replacing those hormones that your body should be producing, but for whatever reason is not. The risks associated with HRT such as breast cancer, etc. are only relevant to women going through a menopause around the age of 50 and not young.
women with premature ovarian insufficiency. This is logical because “older” women are adding back hormones that are not naturally being produced at that age, but in young women with POI, these hormones need to be replaced until the age of about 50.

So I think in your situation you need to take HRT to protect your bones and also still think about your diet, vitamins and minerals and exercise so that you are aiming to keep yourself in good health.

**Question:**
What sort of foods should I be eating? What is the best exercise for me to do now I’ve been through premature menopause?

**Marilyn Glenville answers:**
One of the most helpful foods are phytoestrogens. They include beans such as lentils, chickpeas, soya and flaxseeds (linseeds). Phytoestrogens (isoflavones) work literally like a key. The cells in your body have oestrogen receptors on them that act like a lock; they need a key that fits into that lock to “stimulate” them into activity. This activity can be beneficial in certain places in the body like your bones and brain where you want the cells to stay active, but it can be negative in other places like the breasts and womb where you do not want cells to be too stimulated, causing them to multiply and then mutate. There are two different kinds of oestrogen receptors, alpha and beta.

You have alpha receptors in your breasts, ovaries and womb and beta receptors in your brain, bones, blood vessels and bladder as well as in your breasts, womb and ovaries. Your breasts, ovaries and womb have both alpha and beta receptors.

Isoflavones, as found in chickpeas, lentils and soya, stimulate the beta receptors which helps prevent the overstimulation of the alpha receptors in the breasts, ovaries and womb. So they can help protect you from breast, ovary and womb cancers and yet also help keep your brain and bones healthy. Isoflavones can even help to block the foreign oestrogens, called xenoestrogens, coming in from the environment and prevent them from locking on to your cells. These foods are also good to include in your diet even if you are on HRT.

Add in a good multivitamin and mineral designed for the menopause which will have higher levels of “bone” nutrients like calcium, magnesium and vitamin D3 but will also give you good levels of antioxidants, etc. See my menopause action plan at www.naturalhealthpractice.com, for example. Take omega 3 fish oil supplements as these are anti-inflammatory and will generally help to keep your skin and hair soft.

And the other important point is to remember to exercise. It is “use it or lose it” with your bone health, so make sure that you include good weight-bearing exercise like walking, dancing, etc.

For more information on what to eat to keep yourself healthy, see my book *Natural Solutions to the Menopause.*
Chrissie Hosking is an experienced, accredited integrative counsellor and psychotherapist (MA, CTA). She has a special interest in the psychological impact of premature ovarian insufficiency and infertility. She runs her own independent therapy practice in the Midlands. Chrissie is also available to talk to if you take advantage of the Daisy Network tele-counselling.

Dani Singer is a psychotherapist and counsellor (UKCP Reg./MBACP Senior Accr.). She specialises in women’s health, particularly in the area of ovarian insufficiency, is actively involved in research on this topic and often gives talks on the psychological impact of POI to health professionals.

Dr Marilyn Glenville (PhD) is the UK’s leading nutritionist specialising in women’s health, with gynaecology clinics in London and Kent. She is former President of the Royal Society of Medicine’s Food and Health Forum and a Daisy Network patron. Formerly an observer on the Food Standards Agency’s Expert Group on the safety of vitamins and minerals, Dr Glenville is a member of the British Menopause Society, British Fertility Society and National Osteoporosis Society.

Nick Panay (BSc, MBBS, MRCOG, MFFP) has worked in obstetrics and gynaecology for more than ten years. As director of the West London Menopause & PMS Centre at Queen Charlotte’s & Chelsea and Chelsea & Westminster Hospitals, he heads a busy clinical and research team that publishes widely. He also presents at scientific meetings, trains health professionals at all levels and is an honorary senior lecturer at Imperial College London.

Dr Gerard Conway is clinical lead in endocrinology at University College London Hospital. Dr Conway’s research into ovarian function has formed the basis of more than 120 academic publications. His research focuses on the causes of ovarian insufficiency and his clinical research projects include studying the cardiovascular effects of oestrogen in young women. Dr Conway has been involved with the Daisy Network since its inaugural meeting in 1995.

Nigel Denby is the UK’s proclaimed GDA (Guideline Daily Amount) Diet Doctor. He now runs his own private practice in Harley Street specialising in weight management, PMS/POI, menopause, irritable bowel syndrome and food intolerance.
TIME FOR A LITTLE TLC

Menopause symptoms such as hot flushes are well known. But hormonal changes can have other consequences which you may not be expecting. As your oestrogen levels fall, you may find that your skin and hair become drier. The North American Menopause Society says that collagen loss is at its fastest in the first few years of menopause. So what can you do to keep your face looking fresh and your hair healthy? Here are ten top tips.

1. **Eat well.** Fatty acids help to maintain your skin’s natural oil barrier; so make sure you’re eating foods rich in omega 3s, such as flaxseeds, walnuts, salmon and sardines. If you find it difficult to include enough of these foods in your diet, consider a supplement. Evening primrose oil can also help to alleviate dry skin.

2. **Stop smoking.** Tobacco reduces the level of oestrogen in your body. Research also suggests that smoking can cause the early onset of menopause and make symptoms worse.

3. **Be gentle.** Some soaps can be harsh, stripping your skin of its natural oils and making it drier and itchier. Choose an unscented or lightly scented cleanser instead.

4. **Use warm water.** Hot water can be harsh on your skin and dry it out further. Use warm water and don’t linger too long in the bath or shower.

5. **Moisturise.** Look out for skincare products with vitamins A and C, known for their antioxidant properties, and cream containing collagen, which can keep skin firm and younger-looking. Shea butter, hyaluronic acid and lactic acid can help too. Lots of brands offer free samples or inexpensive travel-size packs, so experiment to find something that works for you.

6. **Use sunscreen.** The Great British weather may not make it necessary at this time of year, but it’s worth investing in a good sun cream with UVA and UVB protection.

7. **Hydrate your hair.** If you suffer from a dry scalp, shampoos containing zinc or selenium can help to deal with dandruff. Dry hair may also benefit from a deep conditioner. Cutting down how often you wash your hair, blow-dry and use other moisture-stripping appliances like straighteners will help too.

8. **Relax.** Stress can reduce your oestrogen and thyroid hormone levels even further. Set aside some me-time or try something like yoga or t’ai chi, which can help you unwind.

9. **Drink more water.** It’s no good lathering moisturiser on your skin if you’re dehydrated inside. Simply making sure you’re drinking enough water can really help.

10. **Talk to your GP.** Other health issues can cause dry skin, such as thyroid problems, fungal infections and vitamin deficiencies. If you think you’re doing everything right but the problem persists, ask your doctor to run some tests.
LOCAL GET-TOGETHERS

Meeting other Daisy members can be a great way to talk to women who understand what it’s like to be diagnosed with POI. We actively encourage you to get together and meet fellow Daisy members in your local area, and there is a section of our forum dedicated to regional groups.

If anyone would like to organise a regional get-together, such as a new year’s dinner, please post a message in the forum. Our membership manager Erica has offered to facilitate a social in central Manchester towards the end of January, so please email daisy@daisynetwork.org.uk if you are interested in this. We are also looking for people who would like to organise occasional meet-ups in their local area and someone to coordinate these regional volunteers.

Please contact us using the email address above if you can help Daisy in either of these ways.

CALLING ALL RUNNERS

Why not burn off some of those Christmas calories and raise funds for Daisy in the new year? We have several places for runners to enter the British 10K London Run on Sunday 12 July 2015. The route passes some of London’s most iconic sights, including St Paul’s Cathedral, Big Ben and the London Eye. We could even set up a Daisy running club if enough people are interested.

If you’d like to run for us, please contact daisy@daisynetwork.org.uk.

For more details about the event, go to www.thebritish10klondon.co.uk.

New Year’s Resolutions

• Eat healthily
• Do more exercise
• Stop smoking
• Make me-time

New Year’s Resolutions
Over 35,000 donor-conceived children have been born in the UK since 1991, when records began. Scientists’ understanding of genetics has increased enormously in this time.

An event held at University College London in May looked at how people’s attitudes towards donor conception have changed and their understanding of what it means to be a family. Do Genes Matter? Families and Donor Conception examined a host of issues – from the legal definition of parenthood to what having a donor-conceived child means for parents, grandparents and the children themselves.

Solicitor Natalie Gamble kicked off the event by talking about the role genetics plays when family courts make rulings on legal parenthood. Arguing that the law is inconsistent and out of date, she put forward the view that although biology matters to a certain extent, the intentions of all those involved and their role in the child’s life should be given much more weight.

Erika Tranfield, co-founder of the Pride Angel website, took to the podium next. She talked about the results of a Cambridge University study conducted among over 1,000 users of the non-profit website, which helps single, same-sex and infertile couples to have a family using donor conception or co-parenting. While most donors said that they did not have a relationship with any children conceived using their donated egg/sperm, most prospective donors replied that they might like some form of relationship.

Meanwhile, one would-be parent said that: “I would like the child to understand that the donor is its biological father, but not really to call him dad.” One donor-conceived child surveyed wrote that it was important for them to know who their biological father was, while another was grateful to their mother’s sperm donor, saying that “without him I would have not been born”.

Erika Tranfield argued that it was crucial for all those involved in the process to understand what was expected of them once the child had been born. She believes that it is important to put everything in writing for the sake of both the adults and the child. Even though this is not legally binding in the case of a dispute, it helps if everyone puts their preferences down on paper. Most members of the audience also felt that children should be told how they were conceived, but opinions were
divided on how and when to go about this.

Next, the event touched on how genes influence our physical health and traits. Anneke Lucassen, Professor of Clinical Genetics at the University of Southampton, said that although scientists know how a small number of our 25,000 or so genes affect our characteristics, the role of the vast majority is either too complex or as yet not fully understood. With this in mind, she explained that a donor’s family history could be at least as important as screening for inherited conditions. However, she felt that there would be very few cases in which families would benefit from being told if the donor they had used was subsequently diagnosed with a condition which could have been passed on to the child.

Carol Smart, Professor of Sociology at the University of Manchester and co-author of the book Relative Strangers, then spoke about a recent study of donor-conceived children’s parents and grandparents. As well as examining how family members’ attitudes to donor conception and adoption differ, she concluded that many people were unsure exactly what genetics means. Most respondents felt that genes mattered but only to a certain extent.

The research presented and input from the audience made it clear that many people do not have a clearly defined view of what genes are and how they work. Ultimately, the event concluded that there is no simple answer to the question “Do genes matter?”. It is up to each individual to decide for themselves.

For a podcast of the event, visit www.progress.org.uk/genesmatter.

Have your say: Do genes matter? Go to the Daisy Network forum to leave your comments or share your experiences.

46-YEAR-OLD MOTHER GIVES BIRTH USING OWN FRESH EGGS

An American woman has become the oldest known woman to have a baby through IVF using her own fresh eggs. Although women have successfully given birth using frozen eggs into their 60s, Belinda Slaughter made the record books because of the age of the egg used. Dr Richard Paulson, a fertility expert at the University of Southern California, explained: “What’s remarkable about this case is not the age of the mother so much as the age of the egg, which was 46 years old.”

He added that: “If a woman freezes her eggs at age 40, and at age 47 has those eggs implanted through in vitro fertilisation and has a baby, that would not be as scientifically remarkable as if she got pregnant using an egg harvested at that day and age.”
Nicole Evans from the New Zealand Early Menopause Support Group kindly contacted the Daisy Network recently with some material she presented at the Australasian Menopause Society Congress. Like us, she is working hard to provide support for women diagnosed with POI and raise awareness of the condition.

In 2012, a survey was conducted among members of the Australia and New Zealand support groups. It showed that more than half of respondents found the infertility aspect of their diagnosis hardest to deal with. Over 70% of those surveyed did not have children prior to being diagnosed with POI and therefore felt this was no longer an option. More than half of the women who took part in the survey were dissatisfied with the way their diagnosis was given to them, echoing feelings which are often voiced by Daisy Network members here in the UK. Studies have shown that women with POI are more likely to suffer from anxiety, depression and somatisation (psychological issues manifesting themselves in physical symptoms) along with lower self-esteem and overall life satisfaction than their peers.

In a separate survey, members of the NZ Early Menopause Support Group were asked about their diagnosis experience. Over two thirds of those surveyed said that they were dissatisfied or extremely dissatisfied with almost all aspects of the way their diagnosis was delivered. The survey identified failings in the way doctors ascertained what patients already knew, gauged how much information they wanted or were able to absorb, used language they could understand, addressed the emotional repercussions of the diagnosis, and managed the condition. Almost three quarters of the patients asked said that they felt their doctor was not knowledgeable enough about premature ovarian insufficiency to help them deal with the short and long-term health issues, such as bone and cardiovascular health, sexual function and psychological impact.

The group in New Zealand recommends healthcare providers use a six-step approach known as SPIKES to deliver bad news: S – SETTING up the interview P – Assessing the patient’s PERCEPTION I – Obtaining the patient’s INVITATION K – Giving KNOWLEDGE and information E – Addressing the patient’s EMOTIONS S – STRATEGY and SUMMARY

Check out the support group’s website at www.earlymenopause.org.nz for lots of information aimed at women with POI.

The Human Fertilisation and Embryology Authority (HFEA) is an independent body which regulates all UK fertility clinics and research involving human embryos. It is also a source of information for the public. Its website features a search tool which helps patients to choose a fertility clinic. This online database is set to be improved over the course of next year to make it more informative and user-friendly. Following the overhaul, patients will be able to access details including clinics’ success rates, the treatments they offer, their performance in inspections and costs.

As well as modernising the whole HFEA website and making it more intuitive, the aim is to simplify how statistics like pregnancy rates are presented, incorporate more information about the different types of clinics both in the UK and abroad, and feature patients’ feedback as part of the Choose a Fertility Clinic tool. A consultation is currently under way with the improvements due to be implemented in 2015.
GOING IT ALONE

There is an increase in women choosing to take on motherhood alone. Numbers have been steadily rising and have doubled in the last five years. IVF and donor insemination are increasingly being seen as an option for single women who want to start a family by themselves and a growing number are seeking fertility treatment as the route to motherhood.

Since the introduction of the 2008 Human Fertilisation and Embryology Act, it has been easier for women to have treatment without the need for a partner, as long as they have “supportive parenting”, according to the HFEA. Professor Dr Geeta Nargund, Medical Director of Create Fertility, said：“It’s not taken very lightly by the woman or by the clinic. There are very responsible rules.” In the UK there are nearly two million single parents, though most through separation of partners.

NEW QUALITY STANDARD FOR FERTILITY SERVICES

The National Institute for Health and Care Excellence (NICE) issues national guidance and advice with the aim of improving health and social care in the UK. It recently published a quality standard designed to end the “postcode lottery” that women currently face when it comes to fertility services.

The fertility guideline issued by NICE in 2013 recommends that eligible women under the age of 40 should be entitled to three full cycles of IVF funded by the NHS and women aged 40 to 42 who meet a specific set of criteria should receive one. At present, less than 20% of Clinical Commissioning Groups (CCGs) – the bodies responsible for deciding which services are needed at local level and making sure these are delivered – fully comply with this guidance. Although CCGs do not have to follow NICE’s recommendations, they are obliged to provide good reasons for not doing so.

Sir Andrew Dillon, Chief Executive of NICE, said: “Infertility affects more people than you might think; around one in seven. It is a recognised medical condition that can occur at any age and for a variety of reasons, such as endometriosis, polycystic ovary syndrome or naturally low ovarian reserve. Whatever the cause, we know fertility problems can have a potentially devastating effect on people’s lives; causing significant distress, depression and possibly leading to the breakdown of relationships.” It is hoped that the new standard will bring an end to the current discrepancies in the fertility treatment available on the NHS around the country.
MEMBER’S STORY

It was a five-minute appointment in the specialist’s office when I was told I couldn’t have children. I think the actual phrase was: “We would recommend assisted reproduction.”

After four years of more or less regular periods, my periods began to become sporadic. At sixteen, I was tested for anaemia, diabetes, thyroid problems – all of which came back negative – and told not to worry; that lots of teenagers have irregular periods.

My doctor said he had never heard of POI in his twenty-five years of practice.

Another year of sixth form, a year of university and only a handful of periods later, I returned to the GP. I used to get quite low and experienced hot flushes on a regular basis. I was sent for a number of blood tests, testing my hormone levels. My oestrogen level was slightly low, but my FSH was extremely high. To see why the signal to release eggs was being ignored, I had an ultrasound of my ovaries. I received a letter saying there were no irregularities. I was consequently feeling hopeful when I turned up at the specialist’s office.

It took another year and another two specialists, along with a lot of misleading information, before I fully understood the condition, and that the chances of having my own child were extremely low. I was put on Femodene, the contraceptive pill. This does control the hot flushes and gives me a monthly bleed. After diagnosis, I was sent for more tests. A bone densitometry scan showed I had slight osteopenia in my back. I had a genetic test to ensure I had no underlying genetic condition, and one final test to confirm low ovarian reserves which I am still waiting to hear from.

I feel frustrated that there was little support or even correct information from the NHS. My doctor said he had never heard of POI in his twenty-five years of practice. I think informing GPs is crucial to ensuring other people don’t feel the same way. I have found the diagnosis heart-breaking and quite overwhelming at times. It has changed the way I see my life, but I’m learning that “we can’t direct the wind but we can adjust the sails”. I’ve recently joined the Daisy Network and appreciate that there is something practical I can do, as well as meeting other people and hearing their stories.

I have found the diagnosis heart-breaking and quite overwhelming.
POI (Young Menopause) FORUMS

Come along, meet up, share ideas and experience

Northwick Park Hospital
9.30–10.30am
8 January, 5 February, 5 March, 2 April 2015

ALL WELCOME

The forums include a chance to meet with a member of the hospital’s multi-disciplinary team for questions and answers, such as our specialist GP, specialist nurse or specialist pharmacist. They are open to everyone who has experienced POI (early menopause). You should ideally be aged under 40 (and definitely under 45). There is no lower age limit.

Please put the dates in your diary and feel free to turn up. Or, if you prefer, contact Dani (who facilitates the forums) in advance at: d.singer@nhs.net or call and leave a message on 020 8235 4034.

Northwick Park Hospital
Gynaecological Outpatient Dept. (ask at reception), then please wait in the waiting area
Watford Road
Harrow
HA1 3UJ

FREE COUNSELLING FOR DAISY NETWORK MEMBERS

Tele-counselling: help is only a phone call away

Tele-counselling is our scheme offering the chance to have half an hour of counselling over the phone with Chrissie Hosking. We offer this service free of charge to our members. The Daisy Network pays Chrissie for her time.

27 January, 24 February, 24 March 2015
Sessions at 6.30, 7.15 and 8.00pm.

Send your name, address and phone number, either to the PO Box or by email to daisy@daisynetwork.org.uk. A slot will be allocated to you and Chrissie will call you.

BARGAIN BOOKS

We have a limited number of menopause books available at heavily reduced prices. Postage is free for members. If you would like to buy any of these, please send a cheque to The Daisy Network, PO Box 183, Rossendale, BB4 6WZ, with a note stating which book(s) you would like.

The Menopause, HRT and You by Caroline Hawkridge, RRP £7.99, now £3
The Premature Menopause Book by Kathryn Petras, RRP £11.99, now £8, LAST COPY!
Beyond Childlessness by Rachel Black and Louise Scull, RRP £12.99, now £6, LAST COPY!
Healthy Eating for the Menopause by Marilyn Glenville, RRP £12.99, now £8
Osteoporosis – the Silent Epidemic by Marilyn Glenville, RRP £10.99, now £6
The Nutritional Health Handbook by Marilyn Glenville, RRP £18.99, now £8
Natural Solutions to Menopause by Marilyn Glenville, RRP £12.99, now £8, LAST COPY!
Understanding Osteoporosis by Dr Juliet Compston, RRP £4.75, now £2
Understanding Menopause and HRT by Dr Annie MacGregor, RRP £4.75, now £2
Understanding Depression by Kwame McKenzie, RRP £4.75, now £2
The Menopause: What You Need to Know (second edition) edited by Margaret Rees, David Purdie and Sally Hope, RRP £10.95, now £6
Fast Facts Menopause by David H. Barlow and Barry G. Wren, RRP £15, now £8
Management of Menopause, RRP £5, now £4

Osteoporosis – the Silent Epidemic by Marilyn Glenville, RRP £10.99, now £6

Understanding Menopause and HRT by Dr Annie MacGregor, RRP £4.75, now £2

Understanding Depression by Kwame McKenzie, RRP £4.75, now £2

The Menopause: What You Need to Know (second edition) edited by Margaret Rees, David Purdie and Sally Hope, RRP £10.95, now £6

Fast Facts Menopause by David H. Barlow and Barry G. Wren, RRP £15, now £8

Management of Menopause, RRP £5, now £4
The networkers are members of the Daisy Network who are happy to take phone calls from other members. You don’t need a particular reason to call – they are here to offer a friendly ear. You might have a query you don’t want to trouble your doctor with or you might just feel a bit down. Please note that these numbers are for members only. Please do not pass them on to anyone else without the prior consent of the networker concerned.

**MEDICAL AND SURGICAL**

**Angela, Kent**  
POI in 30s following cancer treatment.  
01959 561 620, early evening.

**Jasbir, Hertfordshire**  
Ovarian cancer at 21. Three children. POI at 32, then problems with HRT, then hysterectomy. Implant.  
01462 629 463, evenings and weekends.  
jjaswal@ntlworld.com

**Sarah, West Midlands**  
Total hysterectomy, uses HRT implants. No children.  
07894 033 315, any time.  
first55@aol.com

**TEENAGE DIAGNOSIS**

**Joyce, Fife**  
POI at 16. Successful and unsuccessful egg donation attempts.  
01577 830 067, 7–9pm Mon–Fri, or any time at weekends.

**Lisa, Northumberland**  
POI at 14, now in 30s. Successful egg donation.  
01670 514 750, any time.  
lisajonathan2001@yahoo.co.uk

**Louise, Somerset**  
POI at 17, reason unknown. Takes combined pill as HRT.  
07816 399 203, after 7pm but not Tuesdays.  
louise.k.baker@googlemail.com

**ADOPTION**

**Jacqueline, Devon**  
POI at 34. Four failed egg donations. Adopted two siblings. Spontaneous return of periods then normal pregnancy. Rediagnosed as resistant ovary syndrome.  
01752 290 648, 7–9pm Mon–Fri and any time at weekends.  
jacqueinehouslander@gmail.com

**OTHERS’ POINTS OF VIEW:**

**Brian, Gloucestershire**  
Egg donation and psychological impact.  
07802 490 563, any time.

**Martin, Hampshire**  
Unsuccessful IVF. Adopted two children.  
02380 849 602, after 7pm.  
martin.chill@sky.com

**EGG DONATION**

**Caroline, West Midlands**  
Diagnosed at 32, now 39. Successful egg donation in USA. Positive experience of HRT.  
01926 733 411, after 7pm.

c.kuzemko@yahoo.co.uk

**Karen, Wiltshire**  
POI in early 30s. Been on HRT for 12 years without problems. Successful egg donation – twins.  
01985 211 494, evenings after 7pm.

**Pamela, Surrey**  
POI due to resistant ovary syndrome. Successful egg donations.  
0208 669 0508, 7–9 pm.  
palhillton@btinternet.com

**Nicola, Worcestershire**  
POI at 35. Successful/unsuccessful egg donation abroad. Takes HRT.  
01905 457 480, evenings after 7.30pm and any time at weekends.  
armpete2@yahoo.co.uk

**MISCELLANEOUS**

**Gemma, Northern Ireland**  
POI at 33, now 44. Spontaneous pregnancy in 2004.  
02838 343 291, after 6pm.  
gemma@gemau03.orange-home.co.uk

**Kate, Cheshire**  
POI at 28, now early 40s. No children. Positive about HRT and life post-menopause.  
07974 754 901, any time.  
km_palmer@btinternet.com

**Patricia, Roxburghshire**  
POI in early 30s, now in 40s. Single. Difficulties with various types of HRT. Interested in bone health (has osteopenia).  
01573 224 604, 5.30–7pm

**Thea, Kent**  
POI at 27. Conceived naturally. Problems with HRT, especially tiredness.  
01795 538 014, 6–8pm

**Jane, Hertfordshire**  
POI at 28. Successful egg donation. Reasonable success with HRT.  
01727 370 723, any time.  
janehuntess@hotmail.com

**Jemma, Kent**  
POI at 26, reason unknown but autoimmune in close family. Two young children. Takes HRT.  
07977 464 682, after 5 pm weekdays and Saturday only.  
jemma.crisp@btinternet.com