



NZ Early Menopause Support Group
www.earlymenopause.org.nz
nzem.info@nzord.org.nz

NZEMail

November
2009



Hi and welcome...

...to our November newsletter!
I hope life is treating you well.
Well, apparently October was world menopause month. Did you notice it? I sure didn't! And I think that highlights what a low status this transition, which affects every woman on the planet (prematurely or not), has in our western lives. I look forward to the day this is changed and we can all talk freely and find the information and support we need.

We've had five ladies join the group since our last newsletter and while it's sad that they now face this life-changing diagnosis, it pleases me that we're here to offer support to them. I'm sure I speak for every member when I say you're all very welcome here and please just let us know how we can help you.

In this newsletter we look at all the activity that's been happening on our forum; we discuss our national gathering next year; and we review loads of local and international health news and information. Please let me know if you'd like to share some news or a bit of your story in our next edition.

I hope you enjoy this one!
Nicole.

Getting together

In the regions

If you'd like to arrange a face-to-face meeting with other NZEM members in your area (or even just to have email contact), please let me know and I'll do whatever I can to hook you up.

There's really nothing like being able to sit down and have a good old chinwag about problems and frustrations we're all facing. Having a laugh is really therapeutic too and I thoroughly recommend this form of self-help!

National gathering

After the success of the Waiwera weekend last year, I think it's about time we organised another national gathering for 2010.

This will be a fun weekend away, with some mandatory pampering time! You'll make new friends and hopefully heal some emotional wounds while spending time with women who understand what you're going through.

We'll be holding it in Rotorua next **Queen's Birthday weekend: June 5-7.**

If you have any ideas for speakers or activities you'd like to do (like visiting Polynesian Spa, Paradise Valley Springs Wildlife Park, or perhaps even getting some "Zorb" action!) please let me know – we might even get a group discount to some places.

We're looking at getting some sponsorship this time and the bigger the numbers, the more likely it is to be an even bigger and better – and definitely cheaper – event!

Car pooling might also be a fun way to travel and get to know each other a bit better on the way.

To register your interest and reserve your place (&/or offer help!), please email me at nzem.info@nzord.org.nz.

Group news

New members

As I said above, we've had 5 more women contact us since our last newsletter. Women are still mostly finding us via a 'Google' search and I'm so glad our website is there for them.

[Rebecca](#) has very bravely posted a note on our forum with a little background about her situation. She lives in Wellington and she and her husband are hoping to try IVF in the future either with both donated eggs and sperm or a donated embryo. She's really appreciated the contact she's had with members so far.

[Nic](#) has had worrying symptoms for 4 years now, but has only recently received a formal diagnosis. She's also shared her story online to try to find some support. She's newly back in NZ after a few years living in the UK with her DH and two miracle babies.

[Sarah](#) was diagnosed at age 16 with Primary Ovarian Failure. She thinks the full significance of her diagnosis is only now starting to hit her and she would love some support at this difficult time. She'd love to hear from any members, but probably especially from women diagnosed before the age of 20.

I've had the pleasure of meeting two of these lovely ladies and if you have a login, it'd be great if you could take a moment to say hi to them. I'm also happy to pass on an email if that's easier for you.

Anyone can read the posts, but to get the most out of the forum, I encourage you to [join up here](#). Whether you're asking or answering a question, it's great to feel that sense of community around you.

IVFers

A number of our members are currently at some stage of their IVF journey – we have one baby due this month, one pregnancy, a couple of members waiting for egg collection and others still hoping to find a donor. I wish you all the very best and the fortitude to withstand the challenges that lie ahead.

Dave and I are yet to decide on our own next move after two unsuccessful DE cycles. I'm finding it harder to pick myself up each time, knowing there are no guarantees. But we've just had a lovely holiday in Australia to refresh ourselves, so I think we're in a stronger place to think about that decision.

Remember we have a few resources you're most welcome to borrow to help you through IVF. We have a number of books in [our library](#); [Nurture Foundation](#) newsletters; and don't forget to use the forum to ask other members for their advice and support.



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Group news cont.

Going global

I thought you might be quite interested to hear that in July we had an email from a woman in England saying our website was the best one she had come across in her search for support and information! I was pretty chuffed, as Trudie and I have just put it together from the resources we have. Of course, we had specialists check our work, but I thought it was still a huge compliment!

Latest posts on our forum (*please click to follow the links*):

[Vitamin D & premature menopause](#)

Many thanks to new member this year, Janice, for providing so much information on a topic I thought I knew enough about. Vitamin D is being investigated in a number of studies to ascertain its effect on diabetes and heart disease as well as the more obvious osteoporosis.

[Embryo donation](#)

It has been legal since 2005 to adopt embryos for reproductive purposes, but so far only a handful of babies have been born here.

I came across a heart-warming article earlier this year about a couple who now have a beautiful baby girl because a couple generously donated their 'surplus' embryo to them. A link to the article is in this post.

[Infertility Humour](#)

They say a good sense of humour can really help in times of stress, so I thought I'd put a link up to a great kiwi site (www.infertilityinfo.co.nz) that not only shares helpful information about IVF procedures, but also has a section entitled "What would people say to you if you were paraplegic instead of infertile?" As someone who's been on the receiving end of well-meaning but thoughtless infertility comments, I think it's very witty. I hope you enjoy it, too. ☺

[Reproductive Immunology](#)

This is a fascinating topic that I only learned about when Abby loaned me her book "Is Your Body Baby Friendly?" This book is now available to all our members (thanks Abby!) and I thoroughly recommend it if you've been told there's no reason your IVF treatment isn't working.

I was dubious at first, but then I read that they claim an 85% success rate with their patients (who have usually had prior unsuccessful fertility treatment).

Dave and I have always had 'great' looking embryos and the doctors have never known why they haven't gone on to become pregnancies. Well, perhaps my body isn't very 'baby friendly'?

The book outlines the theories and treatments offered by the Alan E Beer Centre for Reproductive Immunology & Genetics. They're in California but will treat international patients. I'm not saying it's right for everyone, but I'm just passing on the knowledge to help you make informed decisions.

Interestingly, the Nov '09 "Next" magazine has an article about a kiwi couple who've successfully completed this programme. The magazine isn't available in the shops anymore, but I have it and will happily send you a copy of the article if you're interested.

NB. There is also a very active RI thread on the everybody.co.nz [communities boards](#).

[Group HRT discussion](#)

It's been on our website for some time now, but I thought it would be handy to have this email discussion available on our forum as well. When you're facing long-term medication, it's invaluable to learn first-hand how others have fared and these women were so open with their experiences. As Paula has always so wisely advised: "listen to your body, do your research, do what feels right for YOU". And remember we're always here to bounce ideas off.



Local news

Fertility NZ www.fertilitynz.org.nz

I joined the Auckland Committee of FNZ last month and I'm very excited about being involved.

They have a lot of processes in place to offer help to those affected by infertility (like information on their website and regular contact groups for personal support) and I look forward to doing what I can to help improve them and reporting back to you about what we're up to.

One of the things we want to re-instate is the regular meetings with the Auckland fertility clinics to give them patient feedback and pass on their news too. These will probably start in the new year and I'll let you know when they're asking for submissions, as I'm sure a lot of you have some feedback for them!

We discussed having a stand at the Girls' Day Out expo (in Auckland this weekend). We all thought it'd be a great idea, so I put forward a proposal to the executive committee who also thought it was a great idea. Unfortunately the board turned it down, but the Chief Executive is keen to make a big drive for next year's event, with ideas for sponsorship and perhaps a joint endeavour with other fertility-related organisations. I just know it'll be a great opportunity to raise awareness about fertility issues and promote the work FNZ does. I think we could really do with our own "[Fertility Show](#)" that they just had in London last week, but I don't think I'm up to organising that one!

My [June conference](#) notes are now on our forum. There's a lot of good stuff in there from "coping with infertility" to learning about the ins and outs of gametes and embryo donation to a very heated debate between attendees, fertility specialists and politicians.



Local news cont.

Fertility NZ cont.

The national office told me they'd like to learn more about NZEM and what we do, so I wrote an article which should appear in the next issue of *Pathways*. I hope to get hold of a few copies to share with you. We also have a link on their website to help visitors find us.

CHRISTMAS CARDS FOR SALE

This year, don't buy any old Christmas cards. FNZ are selling Christmas cards as a fundraising initiative. It's \$10 for a pack of five which is great value for money. And I'm told they're very classy. I'll send out more information on them when it comes to hand.

Donor Conception Network

The DCN has recently been incorporated into FNZ. They support couples and individuals seeking to create a family using donated sperm, eggs or embryos. They also help support the donor-conceived with their queries.

Their future vision is to see groups of the DCN develop throughout all regions. If you'd like to get involved, please email donorconception@fertilitynz.org.nz or visit the Fertility NZ website. (You will need to join FNZ to view this section, but it's free!)

In their newsletter they mention the public consultation earlier this year on creating "*Draft Guidelines on the Use of Donated Eggs in conjunction with Donated Sperm*". ACART (Advisory Committee on Assisted Reproductive Technology) believes that the use of donated eggs with donated sperm should continue to be an assisted reproductive procedure, but guidelines are needed to enable ethics committee approval. They're currently tweaking their draft following public consultation. I can't find any updates on their website yet but I'll let you know when I do.

www.everybody.co.nz

These guys have launched a new website "liveto100" promoting preventive health and wellbeing for Kiwis. As you might expect, it is full of information on all the usual suspects like nutrition, sleep, physical activity and stress management.

But what caught my eye was the 'Personal WOFs' section which suggests things you should be focussing on at your particular age. The tagline: "If you keep your car oiled and greased – why not yourself!"

I was looking around in the "50s" section for menopause-related advice and was interested to learn that recent research has shown calcium supplements may increase cardiovascular disease risk, and it may be safer to eat calcium-rich foods.



International news

AMS www.menopause.org.au

The Australasian Menopause Society Congress was held in September and I have a copy of their booklet: "Postgraduate update in menopause" which has the latest data on the various treatment options available: HRT, testosterone and non-hormonal treatments. It's easy to read – mainly just presentation slides – so let me know if you think you might like a copy.

NAMS www.menopause.org

The North American Menopause Society Congress was also held in September and on their website, free of charge, is a [webcast and podcast](#) of pretty much the entire conference. I didn't see anything specifically for early menopause/POF, but if you want to be kept up-to-date with the latest research, you'll want to check this out!

FSA www.fertilitysociety.com.au

The Fertility Society of Australia held their conference in October and they have some [press releases](#) for public view. The ones that I found most interesting were: "**Poor fertility awareness**"

In a survey on 204 women attending fertility clinics, only 13% had a good knowledge about their monthly 'fertility window' and many were surprised they hadn't been taught this at school "**Emotional response to infertility**" Feelings of anxiety, failure and a loss of self-esteem are common in couples facing infertility and counsellors play a vital role in helping people to understand their anxieties over the inability to conceive.

"Donor issues"

Many children who are informed of their donor conception are turning to the internet to seek information about their genetic background ... because a fundamental part of their identity is missing."

Oz research

It's so exciting; I've now found TWO research studies on POF/Early Menopause currently underway on our back doorstep. There seems to be so little awareness/understanding among medical professionals about how to deal with this condition that these studies can only improve the lot of women in the future.

Kiwi researcher living in Australia Geraldine Lockley is still looking for participants for her "[Women's and partners' experiences of premature menopause](#)" study. It's just an hour long phone interview and nine of our members have taken part so far. I have more information if you're interested.

On the Jean Hailes Foundation [early menopause website](#) I noticed another Australian study recruiting participants: "[Emotional wellbeing and attitudes about health – premature menopause study](#)". I've contacted the researcher (another Kiwi!) and currently they're not accepting international participants. But she would like our input, so I'll let you know if anything changes.



Health news

Bamboo Clothing

In a newsletter I receive from www.minniepauz.com they recommended bamboo clothing for its temperature-regulating and moisture-wicking (drawing it away from the body) properties. I did a little google search and found a couple of NZ suppliers:

www.nzspirit.com

www.nznature.co.nz

The first one provided information on their conservation efforts; the second did not but seemed to have a larger range.

Remember we have more information on our website about symptom control.

NAMS “Menopause Flashes” newsletters

October issue: “Herbs for hot flashes”

Here’s the low-down on some popular botanical hot flash treatments:

Black cohosh (*Actaea racemosa* or *Cimicifuga racemosa*)

This herb has received quite a bit of scientific attention for its possible effects on hot flashes. While results are mixed, some women report that it has helped them. Recent research suggests that black cohosh does not act like oestrogen, as once thought. This fact reduces concerns about its effect on hormone-sensitive tissue such as the uterus and breast. Black cohosh has had a good safety record over a number of years although recent reports linking black cohosh to liver problems are being studied.

Red clover (*Trifolium pratense*)

In five controlled studies, no consistent or conclusive evidence was found that red clover leaf extract reduces hot flashes. AS with black cohosh, however, some women claim that red clover has helped them. Studies report few side effects and no serious health problems with use. But studies in animals have raised concern that red clover might have harmful effects on hormone-sensitive tissue.

Dong quai (*Angelica sinensis*)

Dong quai has been used in Traditional Chinese Medicine to treat gynaecologic conditions for more than 1,200 years. Yet only one randomized clinical study of dong quai has been conducted to determine its effects on hot flashes; it found that dong quai was not effective. Some experts in Chinese medicine pointed out that the preparation studied was not the same as the one commonly used in practice. Due to its possible effect on the blood clotting process, dong quai should never be used by women with fibroids, blood-clotting problems, or by women taking drugs that affect clotting such as warfarin (Coumadin).

Ginseng (*Panax ginseng* or *Panax quinquefolius*)

Although it has been suggested that ginseng may help with some menopausal symptoms, such as mood and sleep disturbances, and with one’s overall sense of well-being, it has not been found to be helpful for hot flashes. Some types of ginseng may affect blood sugar levels, therefore it should be used with caution by people who have diabetes.

Kava (*Piper methysticum*)

Kava may decrease anxiety, but there is no evidence that it decreases hot flashes. The FDA has issued a warning to patients and providers about kava’s potential to damage the liver.

Evening primrose oil (*Oenothera biennis*)

This botanical is also promoted to relieve hot flashes. However, the only randomized, placebo-controlled study (in only 56 women) found no benefit over placebo (mock medication). Reported side effects include inflammation, problems with blood clotting and the immune system, nausea, and diarrhoea. It has been shown to induce seizures in patients diagnosed with schizophrenia who are taking antipsychotic medication.

Evening primrose oil should not be used with anticoagulants or phenothiazines (a type of psychotherapeutic agent). It is thought to be helpful to treat breast tenderness.

Use With Caution

Of course, as with all therapies, there are risks involved. The public usually takes herbal therapies in the form of supplement pills, not as a preparation made directly from the herb by a trained herbalist. Keep in mind that herbal supplements are not as closely regulated as prescription drugs. The amount of herbal product, quality, safety, and purity may vary between brands or even between batches of the same brand. Herbal therapies may also interact with prescription drugs, resulting in dramatic changes in the effect of the botanical, the drug, or both. To be safe, women should tell their healthcare providers about all botanical therapies they are considering and always stop all herbal treatments at least 2 weeks before any planned surgery.

July issue: “Menstrual Mayhem”

OK, so we know our cycle has definitely changed, but do you know what is normal and what isn’t?

Certain irregular bleeding patterns should be investigated by your doctor:

- heavy bleeding, often with clots, especially if this is unusual for you
- periods longer than 7 days (or 2-3 days longer than usual)
- frequent periods – less than 21 days between periods
- spotting/bleeding between periods
- bleeding from the vagina after sex

For us, the cause is most likely our failing ovaries. But other causes may be benign (non-cancerous) conditions like fibroids, infection; medications like blood thinners, tamoxifen, corticosteroids; some illnesses like thyroid dysfunction; or cancerous or pre-cancerous changes. Keeping a menstrual diary ([like this one from NAMS](#)) will help you get to know what is and isn’t normal for you.



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2009**



Health news cont.

www.obgyn.net newsletters

July 7th issue:

[Ovarian transplantation #1](#)

[Ovarian transplantation #2](#)

Researchers are improving their success rates with different ovarian transplant techniques.

In the first article, a woman was pregnant within six months of a new two-stage transplant technique. To improve blood supply to the ovary, the doctors grafted small pieces of the frozen ovarian tissue in the ovarian and peritoneal areas three days before the real transplant.

In the second article, ultra-fast freezing of ovarian tissue before transplant appears to be better than slow freezing. It was also seen to lead to equal success as tissue that was transplanted fresh. Doctors transplanted very thin cortical slices which allows the tissue to be frozen by vitrification (which avoids ice formation), and also accelerates the speed of revascularisation (blood flow) of the ovarian graft. Six of the eight participants have since had at least one successful pregnancy.

[Osteoporosis and diet](#)

In this pioneering study comparing bone growth from supplements and dairy products, results suggest dairy foods are better than calcium supplements for building bigger and stronger bones during growth when compared with calcium carbonate (the most common type of calcium used in supplements).

Aug 25th issue:

[Egg maturation outside of the body?](#)

Researchers have managed to grow egg follicles in the lab for 30 days until the eggs they contained were nearly mature. They are aiming to help cancer patients regain their fertility in the short term, but it may lead to new advances for treating other forms of infertility.

Maybe one day they'll be able to extract some immature eggs from our failing ovaries and give women like us the chance of having our own genetic offspring.

[Tibolone revisited](#)

Tibolone is a synthetic hormone derived from the Mexican yam. It is a valuable treatment option for healthy early postmenopausal women suffering from climacteric complaints and might be preferable to common combined HT products for women with an intact uterus.

While tibolone appears to be safe for the breast in healthy, early postmenopausal women, it remains contra-indicated in women with a history of breast cancer.

"... these recent studies confirm ... that tibolone ... holds a unique place within the large arsenal of currently available postmenopausal therapy options."

[Research plan announced](#)

In July, the National Institutes of Health released a research plan to advance the understanding of fragile X syndrome and its associated conditions: fragile X-associated tremor/ataxia syndrome (FXATS) and fragile X-associated primary ovarian insufficiency (FXPOI) – aka POF.

A major priority of the plan is to investigate the biological processes underlying all three disorders and how to better diagnose and treat them. POI cannot be predicted in a majority of cases, nor can the longitudinal course of ovarian function be defined. Most often, a woman diagnosed with POI has few treatment options. Women who carry the fragile X premutation are at high risk of developing POI and therefore provide an important window to further study mechanisms of POI. Increased knowledge regarding the course of FXPOI may lead to improved health care for all women experiencing POI.

www.Clinicaltrials.gov

This is THE site to visit if you want to know what research studies are happening around the world. As you may've noticed above, I get very excited to find studies on POF. It makes me feel that someone out there cares about what we're going through and wants to help. Here are a couple of new ones I've found:

[Premature Ovarian Failure \(genetic & physiopathologic analysis\)](#)

A French team is searching for possible genetic abnormalities leading to POF. They'll be collecting ovarian tissue from participants to closer examine ovaries and follicle development-involved genes.

[Evaluation of Physiologic & Standard Sex Steroid Replacement Regimens in Women With Premature Ovarian Failure](#)

This Scottish study compares standard HRT with 'physiologic' hormone replacement in women with POF. The researchers are concerned standard HRT may not be the appropriate treatment for us POFers. The study is completed, so I'll pass on the results when I find them!

Funny moment

Finally, we have a man who truly understands what we go through! Dana Jennings, a writer for the New York Times, wrote an article "[My Brief Life as a Woman](#)" about his experiences when going through cancer treatment: *"Even though I only got to spend a brief time on the outer precincts of menopause, it did confirm my lifelong sense that the world of women is hormonal and mysterious, and that we men don't have the semblance of a clue."* I hope you enjoy it! ☺