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NZEMail

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Group news

New look newsletter

I hope you like our new look newsletter! I've been wondering how to freshen it up and it'll probably keep evolving until I'm completely happy with it, so be ready for anything! If you have any suggestions for articles you'd like to see in the future or have something you'd like me to include please send me an email; I'd love to hear from you. It could be an exciting announcement, a question, an experience you think others could learn from, your story so far, a poem, a useful tip, an interesting fact, a new discovery, a helpful resource... the list goes on.

New members

We've had four more ladies contact us since my last update. [Susannah](#) has posted a message on our forum. Thank you to everyone who's already been in touch with her. If you have an account, please take a moment to say hi. If not, I encourage you to join up and make the most of chatting with others in the group. Otherwise, if you'd like to simply read her post and reply via me, I'd be happy to pass on your email. It can make all the difference just knowing you're not alone.

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

[My IVF journey](#)

DH and I are half way through our 2nd government-funded DE IVF cycle. Two transfers, no pregnancy, one embryo left. I was losing hope that there was anything they could do to help us get pregnant, but Carlee shared a bit of her story which encouraged me to keep going and I'm so indebted to her for that. As a result, I thought I'd write a brief outline of our IVF journey so far to give hope and encouragement to others.

Group news cont.

Latest posts cont.

[POF Awareness](#)

Rachel's Well is a US-based organisation aiming to improve awareness of POF. As many in this group know, doctors can be quick to write-off menstrual irregularities to stress, and Rachel's Well wants this sort of misdiagnosis to stop. They say that the menstrual cycle should be treated as a vital sign and they've fittingly named their current campaign '[Project Vital Sign](#)'. They want supporters to write to state and federal politicians asking for more recognition and funding for research and health care for this relatively common condition. I know many in this group have lost valuable time as their GP failed to diagnose (or even take seriously) the cause of their erratic cycles. If you'd like to help spread the word here in NZ, we have flyers you can take to your next doctor's appointment (GP or specialist or both!) telling them about POF and our support group.

There are 40 women in this group currently. If 1% of kiwi women are living with this condition, I know we're not reaching anywhere near enough of them. Please help us to change that!

["North & South" article](#)

Research at the Auckland University Liggins Institute suggests IVF children are physically different (in a good way) to naturally conceived children. One of the researchers spoke at the recent Fertility NZ Conference, covered later in this newsletter. If you'd like a copy of the article, I can email it to you.

[Frozen eggs available for IVF](#)

Following new evidence and more public consultation, the government has decided women can now use their frozen eggs for fertility treatment – an exciting development for those who must store their eggs to preserve their fertility for medical or other reasons.

Group news cont.

Latest posts cont.

[Fertility cover](#)

This is an interesting, if controversial, new payment plan available through any Fertility Associates clinic. They claim most (over 80%) of their clients have a child after three IVF cycles. This plan aims to give you a fixed price for three cycles and if you are unsuccessful they'll give you 70% of your money back. You could say they're trying to make the financial side of treatment more palatable.

To read about the different sides of the argument, please follow the link to the post on our forum.

Although the official paperwork still says donor egg treatment is not included, I was told it could probably be arranged if I wanted it, but there may be extra costs involved. So do ask if you think this might be for you.

[BBC radio programme](#)

In May I told you about a BBC radio series 'Am I Normal' which featured an episode on menopause. I found it a really interesting social and medical history of menopause including an interesting new theory on the biological reason women go into menopause: it's all our mother-in-law's fault, apparently! The half hour broadcast is still available to listen to on the [BBC website](#) or I can send you a copy of the typed up transcript.

Call for your experiences!

Our website is ever changing and always needs more personal stories. Newly diagnosed women get so much from hearing the experiences of others. If not your whole story, is there something you've learned that you think might help others on their journey? It can be quite a cathartic thing to write down your experiences, so not only might you help someone else, you're almost certain to help yourself in the process.



Getting together

Auckland region

Some Auckland & Waikato girls got together on Anzac Day to get to know one another a bit better over a leisurely lunch at the Rangiriri Pub and, as always, meeting and chatting with other members of this group was so uplifting! You can read more about it on [our website](#).

We were thinking it was time we did it again and Jackie has generously offered to host a pot luck dinner at her home on August 15th. We'll need to know numbers by August 8th so please email me if you're interested.

National gathering

After the success of the Waiwera weekend last year, it's probably about time we organised another national gathering over the '09/'10 summer. Imagine a fun weekend away, some pampering, some bonding and some emotional healing among women who understand what you're going through. If you have ideas about suitable venues, please let me know.



Local news

www.Everybody.co.nz

This is a great kiwi site for medical information as well as a place to chat to others about health matters. Judging by the number of views, the early menopause topic is obviously very popular. It's been going about 3 years now and there are quite a few women on there talking about their experiences, asking questions and

Local news cont.

helping each other through the ups and downs of what I have to say can be a very confusing condition. There are a couple of references to our website and our forums on there, which is great so women know we're here and how we can help them.

Fertility NZ www.fertilitynz.org.nz

As I told you previously, I went to the Fertility NZ Conference on June 20 and was so impressed with their programme. I'm just sorry I only found out about it three days prior and couldn't let you know about it as I'm sure many of you would've got a lot from the day.

Allyson Gofton shared her IVF journey which is obviously still a very emotional memory for her; I attended a session on 'Coping with infertility' and left with a few new tricks up my sleeve; I learned a whole lot more about **egg, sperm and embryo donation** in NZ; we heard from a scientist at the Liggins Institute about their groundbreaking research into how **IVF children are different** to naturally conceived children – see the "North & South article" entry above for more on that; and to end the day there was a **panel discussion** session between the attendees, Fertility NZ representatives, fertility experts and MPs which became quite heated as you might imagine! The overriding theme was, if you want the government to take notice of your concerns, keep lobbying and keep your issues in the public arena.

It was a fantastic day and I did a lot of networking for our little group, handing out our flyers and discussing our unique concerns with some of the other organisations there.

My notes will be on the 'Infertility' page of our website soon – although I can send you a copy now if you like. I hope you enjoy reading them and can get a real feel for the day.

Local news cont.

FertilityNZ does so much work advocating for everyone affected by infertility and I'm so glad I was able to attend.

Their website is very user-friendly and I was very pleased to see some specific POF information there. The icing on the cake is they're going to put a link to our site on theirs. So that will help increase awareness about our fabulous little group!

NZORD www.nzord.org.nz

The NZ Organisation for Rare Disorders is the generous team that set up our website and forums free of charge so we could reach more women! They do a lot of advocacy work with the government on behalf of rare disorder groups like us.

In their Dec '08 newsletter they mentioned the government's **Long Term Conditions programme**: "This programme led by the Ministry of Health has potential for improvements to clinical care services for those affected by rare disorders. That is, if we can convince the Ministry that the task must go beyond common diseases with big budget implications."

Of course, the government is thinking about chronic illnesses like diabetes, cardiovascular disease, cancer and HIV/AIDS. But if you think about the costs over 20 years for our HRT prescriptions, bone density scans and specialist visits, not to mention our increased risk of osteoporosis and heart disease, I'd say some government help would be very welcome, if not quite necessary.

Please search the [Ministry of Health website](http://www.MinistryofHealth.govt.nz) for more information.

Unfortunately, I heard recently that this programme may have been put on the backburner because of recent funding cuts. If someone would like to look into this for me, I'd be very grateful.



International news

AMS www.menopause.org.au

The Australasian Menopause Society Congress is on Sep 18-20, entitled "Controversies, Challenges, Canberra". The congress begins with a half day "Post Graduate Update" covering the following: Menopause – what is it; HRT: Risks & benefits; Non Hormonal Treatments; Low libido and testosterone. I'd love to attend just this bit just to keep up-to-date with the current thinking, but it's only for medical professionals. Mind you, their information sheets are always current, so I'm sure anything new to come out of the congress will be quickly included.

The rest of the congress will be addressing modern menopause treatments; reduced libido; vaginal health; understanding the latest research evidence; a debate on removal or retention of the ovaries in different circumstances; hair and skin care; women and alcohol; when to use calcium supplements.

NAMS www.menopause.org

The North American Menopause Society's 20th Annual Meeting will be held in San Diego from Sep 30 to Oct 3. It's a very scientific programme covering topics such as: depression and the menopausal transition; the evolution of menopausal medicine; an update on SERMs; nutrition and Vitamin D; postmenopausal osteoporosis; breast cancer; autoimmune disorders. I'm sure they'll be updating their 'Early Menopause Guidebook' should new information be shared here. By the way, you can download this book for free from the 'Consumers' page of their website.

International news cont.

Daisy Network www.daisynetwork.org.uk

They had their annual open day on June 13, so we'll be hearing all about that in their next issue of "Update". Speakers were Nicholas Panay, gynaecologist; Nigel Denby, nutritionist; and Victoria Lehmann, relationship counsellor.

Also coming in the next issue of "Update" will be an article I was asked to write for them, to share the kiwi experience of POF/early menopause. I'm sure this is not so very different to the UK experience, but it was really nice that they wanted to know a bit about us and what our group gets up to. So keep an eye out for that one in among all the other informative and motivating articles they always have in their newsletters.



Health news

Vitamin deficiencies

From the Project Vital Sign website (mentioned earlier) I learned that women with POF are quite often deficient in Vitamin A and Vitamin D. So I looked into this and although I couldn't work out why this might be (maybe you could ask this at your next doctor's visit), I did find out how this could affect us and where to find it.

Vitamin A aids with immunity and vision and is found in carrots, cow's milk and eggs.

Vitamin D is helpful in the battle against diabetes, osteoporosis and heart disease and can be found in oily fish and a daily burst of sunshine.

SOURCE: <http://whfoods.com>

Health news cont.

NAMS "Menopause Flashes"

April issue:

Vulvodynia is a term used to describe chronic pain and discomfort of the vulva (the external parts of the female genitals) when the cause can't be clearly identified. Vulvar symptoms can be related to a number of conditions which must be excluded before a diagnosis of vulvodynia is made. Studies suggest that about 3-15% of women may be affected. Don't put off seeing your doctor; treatments are available, although the goal is to achieve symptom relief as opposed to a "cure."

Medical or surgical menopause (caused by a medical intervention) often results in more severe symptoms than spontaneous menopause. And, like POF, usually requires prolonged treatment for symptom control and long-term health care.

Re-evaluation on a regular basis is of vital importance for women who experience induced menopause to:

- Monitor the condition that resulted in induced menopause
- Ensure adequate symptom relief as needed
- Reassess health status and risks for disease
- Determine optimal disease prevention or treatment strategies.

Vitamin D is associated with a lower risk of breast cancer. Add to this its ability to help our bodies fight osteoporosis and heart disease and I'd say we've found a very important vitamin. So get stuck into those sardines, salmon and eggs and catch some rays, ladies!



Health news cont.

NAMS “Menopause Flashes”

June issue:

Alcohol + menopause don't mix

Have a look at the effects alcohol has on your body: weight gain; breast cancer; heart disease; insomnia; irregular menstruation; osteoporosis; skin and hair complaints; depression; hot flashes. Do these look familiar? Sounds to me like alcohol increases all the symptoms and risks we already face with POF/early menopause. Perhaps not such a good combination. They did mention that light to moderate intake has been shown to have some health benefits, so the choice is yours. The current recommendations are one drink per day.

Did you know that many thyroid problem symptoms may be mistaken for perimenopause-related symptoms?

Hypothyroidism (underactive thyroid gland) symptoms that mimic menopause: forgetfulness; mood swings; weight gain; heavier, longer menstrual cycles.

Hyperthyroidism (overactive thyroid gland) symptoms that mimic menopause: hot flashes; heart palpitations; insomnia; less frequent menstrual cycles.

I know many in this group have had difficulty getting a diagnosis of POF/early menopause. If these symptoms sound familiar it might be worth asking your doctor to check your thyroid function with a blood test measuring levels of TSH (thyroid stimulating hormone).

You will probably have heard in the news lately that **iodised salt** fortification of bread will be mandatory from September this year.

Health news cont.

NZORD said in their Sep '08 newsletter: *“This step will help reduce the incidence of thyroid disease which occurs when iodine levels in the diet are inadequate. This is a growing problem in New Zealand because of generally reduced levels of salt intake and because vegetables, fruits and grains grown in NZ have lower iodine levels than in other parts of the world.”*

Perhaps more controversially, **folic acid** fortification of bread will also begin in September this year, meaning the 800mcg recommended supplement will be reduced and a 400mcg tablet will be available for women planning pregnancy.

See the [Nutrition](#) page of the Ministry of Health website for more on bread fortification.

www.Clinicaltrials.gov

This website shows what research is being done on different health conditions and I thought I'd share with you that there seems to be quite a bit of interest in POF at the moment – mainly from the NICHD in the US. Please visit their [POF website](#) for more on their great work and resources for patients.

Hormone replacement in young women with POF – finished a couple of years ago, so I look forward to reading the results one day.

Steroid therapy in auto-immune POF – they think they might be able to reverse it in some instances.

Ovarian follicle function in patients with POF – some of us do start ovulating again, so it's good to see them trying to understand it.

Feasibility study for development of an early test for ovarian failure – currently, once you have symptoms, there's no turning back the clock, but imagine if we'd known it was coming; we maybe could've had more time to plan things.

Health news cont.

Goserelin in preventing ovarian failure in women receiving chemotherapy for breast cancer – how fantastic if this could help preserve a breast cancer survivor's fertility!



Natural Symptom Relief

Are you suffering from **hot flashes** &/or **night sweats**? Then try increasing phytoestrogens in your diet.

Phytoestrogens are a group of chemicals found in plants that can act like the hormone oestrogen. Phytoestrogens are plant oestrogens that can bind to oestrogen receptors in your body, relieving you of many of your symptoms.

Interestingly, for women who have breast cancer soy foods consumed as part of the diet are not a risk and impart other health benefits. Good sources are flax seed, soy beans, tofu, chick peas, garlic, dried apricots, multigrain bread and winter squash.

Mood swings getting you down? Try increasing your serotonin levels. Carbohydrate consumption naturally stimulates production of serotonin, a chemical that elevates mood and suppresses appetite. When you stop eating carbohydrates, your brain stops regulating serotonin. Good sources are carbohydrate-rich foods like whole-grain breads and cereals.

SOURCES:

www.epigee.org/menopause/diet.html
www.dietaryfiberfood.com/phytoestrogen.php
<http://web.mit.edu/newsoffice/2004/carbs.html>
www.jeanhailes.org.au/content/view/468/589/

The following recipe incorporates many of these food sources. I hope you enjoy them!



Chick Pea Burgers

3C cooked or 2x 400g cans chick peas
450g tofu
2 eggs or 3 egg whites
1T olive oil
1 large chopped onion
3 cloves finely chopped garlic
1 large thinly chopped red bell pepper
4-6T tomato paste
1/2 - 1t ground cumin
2T chopped parsley
salt, pepper, pinch of cayenne (optional)
1/2C whole wheat bread crumbs
ground paprika

Heat the oil and sauté onion and garlic, adding chopped red pepper at the end so it doesn't overcook. Stir in tomato paste, cumin, and parsley and simmer a few minutes.

Drain and rinse chick peas (beware, the canned variety can be quite salty – so rinse well and you still may not need to add salt later) and mash them in a food processor, blender, or with a potato masher. Blend eggs and tofu and add mix to mashed or pureed chick peas. Add sautéed vegetable mix and bread crumbs. Add salt, pepper, and cayenne to taste.

Mix well and refrigerate in a covered container for a few hours.

Mould into large patties with your hands (if too wet, add more breadcrumbs so you have a wet but workable consistency).

Place on a lightly oiled baking sheet and sprinkle paprika on top to promote browning.

Bake at 200 degrees for 30-40 minutes or until firm and browned, flipping them after 20 minutes so both sides are browned.

Makes 8-12 patties.

Serve as burgers on whole-grain buns with condiments you enjoy, or serve plain with baked winter squash or sweet potatoes.