



NZEMail

December 2011

Newsletter for the NZ Early Menopause Support Group

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Merry Christmas!

I know I'm a bit late, but I hope you won't hold that against me.

This can be a tough time of year for people living with loss, and loss of a dream is as real as any other. Whether you are single or in a relationship, have children or are childfree, went through surgical premature menopause or spontaneous POF, we're all living with loss. And we're all facing vastly different futures from the ones we envisaged as children – the ones our peers are happily living right in front of us.

But, and there's always a but, there is a bright side. Difficult situations provide us with opportunities to re-evaluate our lives in ways our peers can't. The challenge is to embrace these choices and figure out what our new futures will be. Our glorious new futures unhindered by societal expectations.

Often, the greatest desire is to have that much-wanted child. Many of us will attempt to conceive. Some will succeed, some won't. Whatever the outcome, it's another opportunity to embrace the new choices before us.

I've found I have been strengthened in many ways through my struggles with POF. I've found a guiding faith; my relationship with my husband is much richer; I have a new, inspired, driving passion in my life in the form of this support group and also my role with Fertility NZ. I have time I wouldn't have if I had children. I can make a difference to others in ways that I couldn't in the life I originally pictured.

Whatever your situation, I hope you had a wonderful Christmas surrounded by love and laughter - especially our Christchurch members who were rocked, yet again, by a large earthquake on December 23rd. You are in our thoughts and in our hearts. I pray you all get some much-deserved rest over the holiday period.

I hope this support group is living proof of the good that can come out of bad situations. We're all in this together and just knowing you're not alone can really help if you're having a bad day. Remember, we are always here

Contact Us

website:

www.earlymenopause.org.nz

email:

nzem.info@nzord.org.nz

forum:

www.nzordforums.org.nz

and we love to hear your news, so do keep in touch. If you'd like to help us deliver this support, please flick me an email.

I encourage you to pour yourself a cuppa and take a few minutes these holidays to enjoy our latest newsletter. I look forward to the blessings 2012 will reveal to us all!

Nicole xx

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Group News

New members

In 2012 we welcomed 11 new members and I hope we're serving you well and helping you come to terms with this new phase in your life. Please get in touch with me if you have any specific questions or concerns you think we can help you with.

Here is a very brief introduction to our newest member. If you identify with any part of her story, she would love to hear from you. Please email me and I'll pass it on.

Amber went through breast cancer a few years ago, and has had her ovaries removed as a precaution against ovarian cancer. She has a daughter and her menopause experience has a more positive slant than most, but she still struggles with symptoms we all have. Please feel free to get in touch with her through me.

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NZEM HRT Guide

I'm still working on our NZEM HRT Guide website as a way to give NZ women easy access to information that can help them make an informed decision as to what treatment plan is best for them. I'm very grateful to Dr Andrew Shelling at the University of Auckland and Dr Megan Ogilvie at Fertility Associates for their dedication to this project.

I've created a page on our forum where I'm starting to collect information that I'll use to create this guide. You can [view it here](#). If you like to research and analyse data, I would really appreciate some help preparing the information that we will present on this website. Please let me know if you'd like to be involved.

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NZEM on Facebook?

I would love us to have a presence on Facebook, but I know nothing about how it works - nor do I have any time to dedicate to it, unfortunately! If you can see the benefit of being part of this social network, and you'd like to get something up and running, or be involved in keeping it updated, please get in touch with me.

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The screenshot shows the phpBB forum interface for the NZ Early Menopause Support Group. The forum has 75 topics and 249 posts. The latest post is by Nicole on Sat Sep 17, 2011 9:30 pm. The forum is moderated by Nicole.

Forum	Topics	Posts	LAST POST
General discussion For discussion on general Early Menopause/Premature Ovarian Failure topics, whatever stage you're at. <i>Moderator: Nicole</i>	75	249	by Nicole (a) Sat Sep 17, 2011 9:30 pm
Fertility Dealing with infertility as a result of early menopause can be an emotional minefield; share your thoughts and experiences with others here. <i>Moderator: Nicole</i>	37	112	by Nicole (a) Sat Sep 17, 2011 8:57 pm
Parenting/Pregnancy Having an early menopause and being a mother (whether naturally or via DE IVF or adoption) presents many unique challenges; talk to others dealing with similar issues here. <i>Moderator: Nicole</i>	4	18	by Nicole (a) Thu Jun 23, 2011 1:28 pm

Latest posts on our forum

If it's been a while, I strongly encourage you to [check out our forum](#) as there are new posts going up all the time. It's a great way to share information as well as pick up tips from other members. And it's free to join! (But you don't have to join up to read the posts.)

- I found an article: *'Menopause and dry skin: the hormone connection'* that I thought enhanced our discussion on dry skin symptoms. That hormone oestrogen certainly affects a lot of our bodily functions, doesn't it! [Click here](#) to read the full post.
- Debs posted about her recent Hashimoto's disease diagnosis and getting her HRT dose right. [Click here](#) to read more and please reply to her if you have anything to add.
- I recommend all our POF members also check out the post ['Some tests you should know about'](#) to make sure your doctor has any potential long-term health issues covered.

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Publicity in 2011

Media

We had two good publicity achievements this year:

- *Awareness Today* magazine, based in Christchurch, contacted me early in the year to write them an article for their one nationwide issue this year. This ended up being a half-page spread and I think it was really positive.
- The second was my well-timed trip to Avalon studios for work. I met the *Good Morning* resident gynaecologist on the day he happened to be talking about fertility. I, of course, told him about this group hoping he'd pass the details onto his patients. Well, he went a whole lot further than that! A member of the public rang in having gone through POF and he gave her some information as well as our website address – on national television! What a good day that was.

My 2012 hopes include:

- *Good Health* magazine has indicated they'd like to do an article on POF or early menopause in the future. I've been talking with them since June and twice they've told me they'd like to do an article, I just have to somehow pin them down to do it! Don't worry, I shall persevere.
- *Latitude* magazine, based in Canterbury, got in touch a couple of weeks ago. Apparently a reader suggested they contact us and they would like to do a piece promoting menopause awareness. I, of course, jumped at the opportunity and quickly wrote a few ideas to the editor and she's really keen to do something next year. See below for a very timely new contact I've made this year in the Christchurch medical community who will probably be very keen to be involved with this article.

Contacting Medical professionals

In November, I stumbled across an endocrinologist in Christchurch via the AMS website, Dr Anna Fenton, and sent her some flyers about our support group. She told me she was very pleased to hear about us as she has "one of the largest groups of women with premature ovarian insufficiency in the country and [they] are now in fact part of an international database and study following up women long term".

I think it's very positive and exciting that kiwi women are helping global initiatives to devise better treatment protocols for women with POF!

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We Need You!

We always need volunteers to keep this support group running. There are many areas you could help out in:

- Website maintenance (1 or 2 hours per month)
- Forum chat (1 or 2 hours per month)
- Quarterly newsletters - ad hoc contributions gratefully received
- Research round-up (ad hoc)
- Contact with membership (especially newbies)
- Local support co-ordination (1 or 2 hours per month per area)
- Publicity via flyers/specialists/media (1 or 2 hours per month per area)
- Money to donate towards the printing of flyers (or I can send you the PDF and you can get them printed yourself).

I've been amazed how my involvement in this support group has helped me make sense of my own pain by giving back to others. Please email me if you'd like to contribute in some way to the on-going success of this group.

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Getting together

Auckland & Wellington catch-ups



Auckland

December 3rd was a beautiful sunny day and 6 NZEM members met for a lovely lunch at Mecca restaurant in Devonport. Two of us took the ferry the rest drove and we came from far and wide. Members travelled from Whangarei, Massey, Kohimarama, Waiuku and Takanini!

It was a fortuitous mix of people: a mother of twins gave advice to a member expecting twins and we had two breast cancer survivors who got a lot out of meeting each other as well. My heartfelt thanks to everyone who made the effort to come, I really enjoyed catching up with old friends and meeting new ones. It always reminds me of the importance of this group when I see how much we all get from hanging out.

It can be scary to attend an event like this when you may not know anyone else and are unsure of what to expect. I strongly encourage you to come along to one to discover the liberation of being among people who understand what you're going through. We're all a pretty friendly bunch and it can really help knowing a few others who are dealing with similar issues.

Wellington

The following week, while in Wellington for work, I met up with Hilary for a lovely meal and chat in the Back Bencher pub. We shared a platter of tasty morsels while we devised a couple of plans for 2012:

1. Look into ways to lobby government/health boards for HRT, DEXA scans and Mammograms to be subsidised for the prematurely menopausal woman who has to begin these treatments so much earlier. We thought we could use our contact at the NZ Organisation for Rare Disorders who kindly donated our website to us 4 years ago.
2. Increase awareness in the cancer community of our existence. I've heard so many stories of doctors completely overlooking the early menopause experience in their quest to beat the cancer. While I applaud their life preserving priorities, going through a premature menopause is no picnic and has a significant effect on quality of life – as we all know! So we will be looking into ways to get the word out through the NZ Cancer Society.

Thank you for a lovely evening, Hilary, and for your enthusiasm towards improving the lives of NZ women!

Like I said above, we always have a good time at these get-togethers. If you want to arrange something in your area, please let me know and I'll do my best to put you in touch with members living near you.

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National gathering

I haven't made plans for a national get-together in 2012 as I'm busy helping to organise the FNZ Fertility Show in October, but if you'd like to do something over Queen's Birthday weekend (our usual time) let me know and we'll see what we can arrange. I'd be keen for something casual like this year's girls' weekend away, but this time I'll make sure I book a massage before we get there as the Taupo therapists this year were pretty much shut. I was not a happy camper!

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Local news



Menopause the Musical

April 2012

Tickets to Menopause The Musical - In Concert have gone on sale for shows in Wellington, Tauranga, Whangarei, Hamilton, Auckland, New Plymouth, Kapiti, Palmerston North, Hastings, Upper Hutt, Ashburton, Nelson, Blenheim, Christchurch, Oamaru, Dunedin, Invercargill and Gore.

Tickets are available from Ticket Master for Auckland and New Plymouth and from Ticket Direct for the rest.

The show was last here in 2006 and it looks like a great night out, but I can understand that women in this support group might not see the funny side. However, if you do and you'd be keen to go along, let me know and we'll get something organised.

I was thinking there might be a way to heighten awareness of the **early** menopause experience around this event. I'm not exactly sure how, maybe via publicity in the lead-up, maybe via something on the night (flyers? a stall? t-shirts? caps?). At least the people at this show won't be afraid of the 'm' word for this one night... If you have some ideas, please let me know.

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Fertility NZ www.fertilitynz.org.nz

Fertility Show, Auckland, October 27, 2012

I'm on the Auckland committee for FNZ and we hope to tag onto the FSA conference happening in Auckland at that time to make a wide range of specialist speakers available to the Auckland public. It will be a full day event with speakers covering a wide range of topics. Lunch will be provided and it'll be a great opportunity to come together as a community and hopefully raise awareness of fertility issues in NZ.

England holds a Fertility Show each year and we're sort of modelling ours on theirs. I'm sure we'll need extra help closer to the time, so if you're interested in being involved in any way, please let me know.

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International news



AMS www.menopause.org.au

Australasian Menopause Society 15th Annual Congress

September 9-11, 2011

Brisbane, Australia

This conference programme looked like a good general overview of important topics: hormones, quality of life and breast cancer; osteoporosis management; mental health. More interesting to us was their 'meet the experts' session where Dr Nick Panay from the UK spoke about premature ovarian insufficiency and Professor Martha Hickey from Australia discussed management of menopausal symptoms in high risk women.

I don't know the full programme for next year's conference, but I know they're looking at POI in their "pre-congress update" (on the day before the congress proper starts). As this is an Australasian event and there will be both NZ and Australian medical professionals in attendance, I think it would be important for us to be involved in some way. I'll talk to Tanya who co-ordinates the Australian Early Menopause Network and we'll find out what our opportunities are at the conference.

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NAMS www.menopause.org

North American Menopause Society 22nd Annual Meeting

September 21-24, 2011

Washington D.C.

I found some of the topics at this conference very interesting. Especially "Ovarian Aging: Can Science Turn Back The Clock?" Imagine the possibilities this could have for fertility treatment in the future! Maybe even a cure for POF? I have no scientific backing for that last comment, and I know POF and natural menopause are quite different things, triggered by different processes, but the more the scientists understand about the way ovaries work, the better their understanding of POF in the future, right?!

No, I didn't fly to the US to attend the conference, information is on the NAMS website. I've also made some notes on the topics I found most interesting and posted them on our forum for you. [Click here](#) to read more.

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Early/Teenage Infertility Study

You may recall in July I forwarded you an email from a woman in the US who was diagnosed with POF two years ago, age 18. She is now doing a thesis on "The effect of early discovery of infertility on feminine selfhood" and would like our help. She would like to talk to women all over the world who were told at a young age that they were infertile, and who weren't in a long-term relationship like marriage (regardless of their situation now).

I think this is a fantastic project that will improve understanding of the psychological effects of infertility. She is still recruiting study participants and, if you'd like to be involved, her email address is nirena1@babson.edu

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What's On Guide

Fertility NZ Contact Group meetings

Regular get-togethers in the following centres:

Auckland

Hamilton

Tauranga

Nelson

Wellington

Christchurch

See [our forum post](#) for more information

Menopause, The Musical

Nationwide tour

April 2012

North American Menopause Society 22nd Annual Meeting

October 3-6, 2012

Orlando, Florida

Australasian Menopause Society 16th Annual Congress

October 12-14, 2012

Melbourne, Australia

Fertility NZ - Fertility Show

October 27, 2012

Auckland

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