



## NZEMail

April 2014

Newsletter for the NZ Early Menopause Support Group

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### Resources for members

#### Available now:

- [NZEM Reference Library](#)
- [NZEM Newsletter Archive](#)

#### Available on request:

- [AMS Newsletters](#)
- [Daisy Network Newsletters](#)
- [NAMS Scientific Reviews](#)

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*Hi ladies,*

*I can't believe it's been 6 months since our last newsletter. Where does the time go? I'm off on a short holiday to Oz soon, but I just wanted to get this out to you before I go. ☺*

*Well, a lot has been going on both locally and internationally with premature menopause and I'm thrilled to be able to bring you this round-up of the bits I've found most interesting.*

*I guess the main news in this neck of the woods is that the Australasian Menopause Society Congress is coming to NZ after an eight year absence. And I plan to make the most of it. I've (somehow!) got myself on the organising committee and I'm enjoying the insights that affords me into how you pull something like this together. If you're going to be in Auckland, let me know if you'd like to attend the consumer info session with me on the final day of the conference (Sunday September 28<sup>th</sup>) and I'd love to catch up for dinner afterwards.*

*As I was writing this newsletter I read in a magazine that Angelina Jolie is preparing to undergo an oophorectomy and hysterectomy, having already had a double mastectomy because she has the BRCA-1 gene mutation. This woman is turning a lot of heads: from doctors suggesting she's sending the wrong message, to women who've been there and are relieved to have a champion, to unaffected men and women everywhere whose eyes are being opened to the stark reality many must face. As a mother, all she's worried about is being around for her kids. I say good on her. I'm sure she has access to the highest quality health care and is making the right decision for herself and her family. Which is all any of us can do.*

*I hope you enjoy the newsletter, and I'd love to hear from you if you're interested in getting involved in any of this year's projects.*

*Nicole x*

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## Group News

### New members

It's been 6 months since our last newsletter and we have grown a bit. Here is a very brief introduction to our newest members. If you identify with any part of their story, they would love to hear from you. If you email me I'll pass on your note to them.

**Aline** is from France. She has lived in NZ for five years, and has been trying to conceive for 2 years. She is a long way from home and struggling to deal with this diagnosis. She would love some new friends who understand.

**Melissa** and her sister **Ange** both live in Auckland. Both have been focussed on trying to conceive, but now they're looking closer at the menopause side. They've had generally good results with alternative treatments and would like to meet others to share ideas about living with POF.

**Fran** lives in Christchurch. She was fortunate enough to have had 2 children before her diagnosis, but she is still struggling with coming to terms with it all. She is unsure about HRT (like most of us are from time to time) and would to meet others who get where she's coming from.

**Rose** is 24 years old, lives in Palmerston North and is keen for contact with others as her recent diagnosis was, understandably, a huge shock to her.

**Carolyn** lives in Auckland. She went through her early menopause about ten years ago and was blessed with a child through donor egg IVF. So the raw emotional pain has somewhat eased for her, but she's still keen to meet others on a similar path.

**Delphine** is in Auckland and was diagnosed about 2 years ago. She has one young son but is grieving she can't give him the sibling he so wants.

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### AMS Submission

The Australasian Menopause Society Congress for 2014 will be held in Auckland and I want to make the most of having these international experts on our doorstep. I've decided to offer a talk on how important it is for a doctor to get the delivery right when telling their patient she has POF. I've heard so many stories from our members about bad ways doctors have told them their diagnosis (over the phone has to be the worst so far!) that I'd like to share the devastating consequences with them: from the obvious emotional shock to the lack of support and information, to the long-term physical and psychological issues at stake.

But to do that I'll need your help. I would like to put together a survey to get some overall stats from the support group as a whole and I'd also like to use individual stories.

If there are inadequacies in this area for the surgically- or medically-induced prematurely menopausal woman, I would be interested in hearing your comments about this also. I know the menopause side of things can take a back seat in the fight to cure the cancer, and that's probably as it should be, but I do think it's wrong to leave a woman to cope with the future physical and psychological ramifications with little or no support.

If you would like to be involved – completely anonymously, I assure you – please let me know.

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## Consumer Update on HRT

We're planning a public information session on the final day of the AMS Congress. Post-WHI we know HRT is not the elixir of youth it was once promoted to be, but we now also know it offers many benefits if we take it carefully. As the 'consumer' voice on the AMS Congress organising committee, I'm keen to get the positive HRT story out to NZ women. The [Sunday](#) programme have already expressed initial interest in our idea to use the early menopause experience as the vehicle to tell the story. If you'd like to know more, or get involved, please let me know.

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## Hot Flash Havoc

This is a humorous documentary from 2012, aiming to remove the social stigma – and associated lack of reliable information – that seems to surround the menopause transition. I think it'll be a great vehicle for GPs to give their patients a basic understanding of what's going on with their bodies and what options they have available to them.

Although the film doesn't directly address the premature menopause experience, I still found it to be very informative and entertaining. It gives a concise overview of the history of HRT and why it has ended up with such an overwhelmingly negative reputation – and gives the other, more positive, side of the story.

The NZ Early Menopause Support Group is an affiliate of the movie, which means we earn a small income when people 'rent' this movie online.

Please have a look via our unique code: <http://ykr.be/24ndbh9mw>

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## Janet's story

"In March 2011, aged 46, I underwent a hysterectomy and BSO (ovarian removal). This was to relieve me of constant, clotted bleeding, ovarian cysts, fibroids and pain associated with severe endometriosis. Thankfully removing my uterus didn't cause me too much grief as I had two daughters in my twenties.

Recovery from the keyhole surgery initially was a breeze. I was relatively healthy, at a good weight, and quite fit. Five days after the operation, menopausal symptoms hit with a vengeance. Flushes were new to me, as were constant migraines and general feelings of 'cloudiness' and anxiety. I held a senior role in a large organisation, and while I had 2 months off post-surgery to recover, I wasn't feeling on top of my game when I returned to work."

[Click here](#) to read more.

Thank you for sharing your story, Janet. ☺

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## NZEM Funds Raised in 2012

After paying for some of my trip to the AMS conference in Melbourne in 2012, we had an excess of \$782 of funds raised, and NZORD are still holding them for us.

I would like to set up an "NZEM Emergency Assistance Fund" for partial or full payment of counselling or specialist appointments to help young kiwi women gain access to the specialist care available to them. I don't have 'criteria' or 'application forms' or anything in place and at the moment I don't think it's a big enough enterprise to warrant it ... yet!

This year I have actually already put \$155 of this money towards this worthy use, helping a newly-diagnosed young member access counselling services. And she has benefited greatly from them. However, it is your money, so I would welcome your input and ideas. We could keep it for conference use (either to attend other ones or to hold our own), or put it towards a national get-together or something like that. Let me know what you think.

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## We Need You!

### We want to hear your story

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. Please get in touch with me if you'd like to contribute your story to our next issue.

### We always need volunteers to keep this support group running.

There are many areas where you could help:

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

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

### National gathering

I propose we get together for dinner on Sunday September 28, following the AMS congress. Those who want to could also attend the consumer update they are proposing to hold that afternoon, so you can pick the experts' brains! Let me know if you're keen to be there.

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## Local news

### Article in the latest FNZ *Dandelion* magazine



I was asked to write an article on the premature menopause experience for the Dandelion newsletter published by consumer group Fertility NZ, and it came out in the February edition. I hope it helps spread the word about this condition and let someone out there know that they're not alone.

"I never could have dreamed my devastating experience of premature ovarian failure at age 30 would end up being such a blessing. My husband and I went through 2 cycles of donor egg IVF that didn't result in the child we so wanted and for a long time I struggled to come to terms with that. It didn't seem fair that all my friends were starting their families while we were being left behind. But it seems our time of trial had a unique purpose."

To read more [click here](#).

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## FNZ Fertility Week: April 7-13, 2014

*Fertility Week: Be Fertility Fit* is a public education campaign being run by Fertility NZ to raise awareness of the impact of five key factors on fertility: age, timing of sex, weight, alcohol and smoking. I'm pretty sure this is a NZ first, so spread the word!

For more info, please visit the website: <http://www.fertilityweek.org.nz/>

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## International news

### Premature Menopause – the experiences of women and their partners.

At the end of 2009, some of our members were involved in some research done at Swinburne University of Technology in Melbourne, towards a degree in Psychology. The researcher, Geraldine Lockley, did interviews with 18 married couples, asking about their individual and shared experiences of premature menopause. It's a really interesting read.

The final thesis was published in 2012, and I've finally found it! It's obviously quite long (200 pages), but I can send you the PDF if you'd like to have a look at it. The main findings are summarised on pages 164-67, then (my favourite bit) advice to the medical community on pages 168-70.

Thank you, Geraldine, for getting our stories out there.

To read the main findings of the research (abridged by me!) [click here](#).

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### Woman's Day USA article – Dec 2013

It's always nice to know the media still have an interest in our plight and will still dedicate room to furthering our cause. I really enjoyed the author's style of writing as she recounted her journey through premature menopause.

To read the full article [click here](#).

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**NAMS** [www.menopause.org](http://www.menopause.org)

### North American Menopause Society 22<sup>nd</sup> Annual Meeting

October 9-12, 2013 – Dallas, Texas

Here are some salient points from the sessions I found most interesting.

#### When ovaries retire too soon

“Given the significance of this diagnosis, particularly in women with amenorrhea, following exclusion of pregnancy, all should be evaluated for POI.”

“Although the use of hormone therapy in appropriate candidates for treatment of vasomotor symptoms, vaginal symptoms, and enhancement of quality of life is nearly universally endorsed, whether the proposed risks of early menopause, particularly cardiovascular disease and osteoporosis, merit specific preventive strategies remains an essential question in the clinical management of these women.”

## Cancer survivorship – with, through and beyond

“Specific concerns related to women’s health, such as premature menopause, fertility preservation, gynaecological and menopause-related symptoms, and bone health will be addressed. High quality survivorship care must attend to these issues, and the cancer care team needs to work collaboratively with primary care providers and women’s health specialists to manage ongoing symptoms and the late effects of treatment.”

If you want to find out more, try the links below.

Info:

<http://www.menopause.org/annual-meetings/2013-meeting/meeting-webcast>

videos:

<http://nams.tri-digital.com/>

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I was very sad to receive an email from the International Premature Ovarian Failure Association in November last year saying they had to shut down the organisation. They’re hoping some new enthusiastic volunteers will pick up the baton, but if no-one comes forward the website will go offline soon.

It’s always difficult keeping volunteer organisations running as they demand a huge time commitment. It’s because I never want to see our little support group ever reach that stage that I ask if others are interested in helping in whatever small way they can. I know everyone’s busy, but I still dream about what we could achieve with a little more ‘manpower’. Ah, one day...! ☺

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## International Facebook Support

A new member, Rose, told me about this avenue for support. The group is called: “*premature ovarian failure (POF): it’s not your mother’s menopause*”. It is a closed group, and offers a bit more online interaction than we do. It’s a safe place to share experiences, so go ahead and look them up!

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## Health news

### Cancer study sheds new light on premature menopause

Around two per cent of women with primary ovarian insufficiency – the medical term for a permanent halt in menstruation occurring naturally before the age of 40 – are affected by changes to a particular gene, a study has shown.

To read more, [click here](#)

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### NZ Fertility Research Review articles

This is a round-up of the latest news from the world of fertility research, prepared by and for NZ doctors.

*Post-oophorectomy pregnancy following ovarian tissue transplant, IVF and ICSI.*

Exciting progress in the fertility preservation arena.

**Reference: Hum Reprod 2013;28(11):2996-9**

[Abstract](#)

*Bed rest after embryo transfer doesn't increase pregnancy rate!*

**Reference: Fertil Steril 2013;100(3):729-35**

[Abstract](#)

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### New Zealand university students' knowledge of fertility decline in woman via natural pregnancy and IVF

(Andrew Shelling, Auckland University)

New Zealand students overestimated the rates of pregnancy for both spontaneous pregnancy and IVF pregnancies. Students are mainly aware of assistive reproductive technologies being available but overestimate their effectiveness. Few students mentioned non-ART or healthy lifestyle as measures to prolong parenthood.

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### Fertility preservation in women

(Belgian research)

In women, ~10% of cancers occur in those <45 years old. Chemotherapy, radiotherapy and bone marrow transplantation can cure >90% of girls and young women with diseases that require such treatments. However, these treatments can result in premature ovarian failure, depending on the follicular reserve, the age of the patient and the type and dose of drugs used. This article discusses the different fertility preservation strategies: medical therapy before chemotherapy; ovarian transposition; embryo cryopreservation; oocyte vitrification; and ovarian tissue cryopreservation. I can send you the full paper if you'd like to have a glimpse into the future of fertility preservation!

And along the same lines...

### Premature Ovarian Failure in Cancer Survivors: New Insights, Looming Concerns

(US editorial article)

An interesting article from 2006: <http://inci.oxfordjournals.org/content/98/13/880.full>

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## First FDA-approved hormone-free treatment for hot flashes

'Brisdelle' (available in NZ) is the first antidepressant approved by the US FDA for treating hot flashes. Apparently it shouldn't be used with Tamoxifen as it could reduce its effectiveness.

For the news article, [click here](#)

For the FDA press release, [click here](#)

In your search to come to terms with your premature menopause, I expect you will have come across many non-hormonal treatments purporting to cure all manner of menopausal symptoms. Oestrogen is still the best option for those who can take it, but for those who can't, it is good news that there is now an approved non-hormonal option for treatment of hot flashes. (Although it worries me that they freely admit they don't know how it works!)

Of course, the prematurely menopausal woman has her long term health to consider, not just symptom control, and should keep up her exercise and healthy diet for the sake of her bones and heart and all-round general health.

My advice, as usual, is to keep talking to your doctor. If your treatment regime isn't working for you, it's up to you to address it. It's your quality of life that suffers, and there are many options available to help you with most symptoms you might be experiencing.

I'm no doctor, but if you'd like to bounce ideas round with me first, I'd love to hear from you!

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## HRT: Could Estrogen Have Saved 50,000 Lives?

(July 2013)

This is an interesting and informative article from *Time* magazine, that proves there's still a LOT of debate in the area of HRT benefits and risks.

The main message of the article is if you've had a hysterectomy, you don't need a progestin, and the health risks are quite different for you than for the woman with an intact uterus who takes a progestin. In the WHI trial that scared everyone off HRT, it was the women who took the progestin who were at increased risk of breast cancer and stroke, not those taking oestrogen alone.

We owe it to ourselves to keep talking to our doctors for information that applies specifically to us.

To read the full article, and check out similar ones, [click here](#)

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## Intimacy Post-Menopause

[Hyster Sisters article](#)

Loss of libido, weakened orgasms, vaginal dryness, this great article addresses it all!

It provides many tips to help you cope with this silent problem. If you identify with anything addressed in the article, please talk to your doctor about it. When I was at my lowest dealing with these issues, I was amazed at how much help is out there.

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## What's On Guide

### Fertility NZ: Fertility Week, April 7-13, 2014

Nationwide events, check the website for more details.

### Daisy Network Annual Conference

June 14, 2014

London, England

### Australasian Menopause Society Annual Congress

September 26 - 28, 2014

Rendezvous Hotel, Auckland

### NZEM National Meeting

Sunday September 28, 2014

Rendezvous Hotel, Auckland

Learn from the AMS experts in the afternoon and share your ideas at our dinner gathering!

### North American Menopause Society Annual Meeting

Oct 15 - 18, 2014

Marriott Gaylord National

Washington, DC

### Fertility NZ Contact Group meetings

Regular get-togethers in the following centres:

**Auckland**

**South Waikato**

**Tauranga**

**Rotorua**

**Hawke's Bay**

**Nelson**

**Wellington**

**Christchurch**

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

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