



Hi ladies!

This newsletter comes with a warning: be careful where you get information on the internet. Anyone can set up a website these days and it is up to you to be your own spam filter.

A U.S. group calling themselves 'Project Aware' and claiming to be consumer advocates is clearly misrepresenting their affiliations with the 'natural hormone' industry. Details inside.

The lesson: just because someone claims to have your best interests at heart, doesn't mean they do. Do your research, try to find out who sponsors the site and always check their references. If you're only getting one angle, you're not getting the full story. Thanks to everyone for a great weekend in Rotorua last month - see below for more...!

Nicole x

Group news

June Meeting a huge success!

I just wanted to report back on what a great time we had at our girls' weekend away. Most of us had never met before and, although I've had a fair bit of email contact with the attendees, I think I speak for everyone when I say it was so nice to finally be able to put a face to everybody's name. About half the group gathered at Polynesian Spa for a quick lunch before the Saturday afternoon programme began which was a good opportunity to get to know one another. It was a huge relief to me that everyone seemed really comfortable to talk and laugh together so early on.

We all trickled in to the hotel and at 1pm we were just about all in the conference room, so I said a few words of welcome, including a brief history of the group and then handed over to our first speakers, Dr Megan Ogilvie and Dr Susannah O'Sullivan, two of the only three reproductive endocrinologists in

the country. They shared with us their vast knowledge of POF and we certainly made the most of the time we had with them. They presented a very interesting series of topics, allowing for question time at the end of each, which really helped us digest each topic. They covered diagnosis and testing; HRT; fertility issues; bone health; relationships & libido; and androgen replacement. Not everyone present had taken the POF road to early menopause, but we were all dealing with the same aftermath:

- *hot flushes
- *night sweats
- *infertility - whether primary or secondary
- *relationship difficulties
- *peer group difficulties
- *which treatment option is best for me now and in the future?

Regardless of our own personal histories, and despite our obvious differences, we discovered that the things we had in common united us. And that was the theme of the whole weekend. Our differences gave us all a wider understanding of the early menopause experience, while our similarities helped us forge a unique and very special bond that I'm sure we'll all treasure for a long time to come.

After bidding our generous speakers farewell, we headed across the road to Polynesian Spa for some pampering. This was a huge part of the reason I chose Rotorua as our destination and I'm pretty sure everyone had a good time there. I know I really needed my massage even though my brain was still working a million miles an hour making sure I was on top of what was still to come. We all met up again for dinner at the hotel restaurant and had a great time doing more of what girls do best: talk!

Dr. Andrew Shelling from the University of Auckland joined us on Sunday morning and shared with us his scientific knowledge of the genetic

cause of POF and of how HRT works within us and did his best to answer our many questions. It was nice to learn a bit more about how ovaries work and the different theories for why humans are the only species that live past the end of the reproductive years. His knowledge added a lot to what we had covered yesterday and helped us to further understand what's going on in our bodies.

Dr. Shelling founded this group while doing research into a genetic cause of POF and gave us a more detailed history of the group that stretches back about 10-12 years. He's always interested in what we're up to and, although he's very pleased we run the group ourselves now, I took great comfort when he said he'll always be around for us. I strongly believe this group needs to exist and while I hope to be here for a long time to come, there may come a time when I need to move on for whatever reason, so it's good to know Andrew can help maintain that continuity with whoever steps up to the plate.

Andrew joined us for lunch, as did our afternoon speaker, Jane Catherine Severn and it was a good chance for everyone to chat more informally.

After we all said goodbye to Andrew - who was obviously very happy to hang out with us girls and in no hurry to leave! - we headed back to the conference room for our final afternoon together. Jane Catherine Severn is a psychotherapist and also calls herself a menstruality educator. She coined the term 'menstruality' when she became aware the English language had no term to describe a woman's lifecycle from the onset of periods through to post-menopause. She divided her session into two parts. The first was about discovering what we'd gained from this journey into premature menopause (which ended up an extremely impressive list including strength, compassion and resilience), while in the second she



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June meeting cont.

tried to help us reclaim our lost femininity and reconnect with ourselves.

This was the toughest session for me, because although I still sometimes struggle with the medicine and the science, in comparison, I feel I've not really dealt with the emotional side of this journey at all well. I discovered that I still have a lot of pain to deal with going right back to the day of my diagnosis, not to mention all the other complications that have crossed my

path since then to do with my relationship and our dreams of starting a family.

Through sharing our experiences, we learned that this is something that will be with us all for the rest of our lives and this gave me some relief that I don't have to have all the answers right now. Some questions are unanswered at the moment, but I have confidence that with patience I'll discover the answers for me. As will we all.

To end, I'd like to thank everyone who had anything to do with this weekend,

from the sponsors and suppliers, to the speakers and of course our wonderful attendees. Everyone simply wanted to be there and it was truly humbling to be graced with the presence of our professionals who freely give us their time and to watch the group get on so well that by Monday morning no-one wanted to leave. You are all beautiful, courageous women with so much to offer this world. I feel honoured to have been a part of this weekend and I very much look forward to the next one.

Nicole x

EGG AND SPERM DONATION

“Cabinet is expected to make a decision soon on whether to allow women wanting a baby to use donor eggs as well as donor sperm.

The *Herald on Sunday* understands the Government's Advisory Committee on Assisted Reproductive Technology (ACART) has recommended approving the procedure to Health Minister Tony Ryall.”

http://www.nzherald.co.nz/health/news/article.cfm?c_id=204&objectid=10654725

My name is Liz and I am trying to get the Minister of Health to approve the use of donor egg with donor sperm in New Zealand. A friend of mine used to be a policy advisor for government and he has been coaching me how to get the Minister's attention.

Dr Johnson, of Fertility Plus, put me in touch with a journalist who wrote an article that appeared in *The Herald on Sunday* last month – follow the link above to read more.

The next step is sending a letter to the Minister telling him that a number of people are waiting on his approval before they can have a child. Apparently it's a numbers game and the more people we can say are waiting, the more chance we have of getting the minister's attention. So far four people have contacted me. Crazy what we have to do to get a baby – I never thought sweet talking a Minister would be part of the journey!

Is this an option that would help you build your family?

Do you want to join with others lobbying the government to approve this treatment option?

If so, please send Liz an email on nzdonor@gmail.com to be added to the next letter to the minister.



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Group news cont.

New members

Our national meeting attracted quite a few new members. I advertised it on our website, our forum, the Fertility NZ newsletter and the everybody.co.nz menopause chat room. I'm not sure which avenue was the most successful, but a third of our attendees were not already members beforehand – two of them lived in Australia! I don't know whether it was something in particular, or the combination, but the promotion worked. I'm so glad they found us and were able to come along and meet others dealing with similar challenges.

New look forum

At the beginning of the week [our new-look forum](#) went live. If you are a member already you may need to check your password still works. If you're not, please take this opportunity to have a look around, read the posts from others in the group and consider joining up yourself. It's a great way to learn from other people, share your own experiences and feel part of a larger community of women all dealing with similar issues.

We've had one new member post a message on our forum since our last newsletter:

After struggling with fertility issues (and substandard fertility care) for years, [Trish](#) is now more concerned with HRT and her long-term health. She's in her mid-40s and would love to hear some different perspectives on this topic. If you can help her by sharing some of your experiences or just popping in to say hi to her, I'm sure she'd appreciate hearing from you. I'd be happy to send her your email reply as well, if you're not yet signed up on the forum.

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

[Some tests you should know about](#)

One of the recurring themes I hear from new members of the group is how their doctor has let them down when it comes to basic general health care leading up to and following a diagnosis of POF / Early menopause. I thought it'd be good to have a reference list of tests on our forum (and perhaps in future on our website) so that women know the care they should be receiving and make sure they find a doctor who will take their health concerns seriously. So I contacted my specialist and here is the list she recommended.

Blood tests to make the diagnosis:

- Follicle Stimulating Hormone at least two, a month apart
- Luteinising Hormone
- Oestradiol (E2 oestrogen)

Once the diagnosis is made:

- DEXA Scan to measure baseline bone density and to monitor for bone loss
- More bloods: iron levels, vitamin D, glucose, lipids, cortisol, thyroid and antibodies - adrenal, antiendomysial, thyroid, testosterone.

Women with spontaneous Premature Ovarian Failure are at increased risk for a number of other conditions, particularly:

- Hypothyroidism – low thyroid function can slow the metabolism, leading to mental and physical sluggishness
- Addison's Disease – a condition where the body attacks the adrenal glands which are important for coping with stressful events such as severe illness, injury or surgery
- Fragile X Syndrome – a genetic condition that leads to learning disabilities.

Regular testing means your overall health is adequately monitored for these and other health concerns.

[Rotorua Feedback](#)

We've had lots of lovely comments from women who attended our national meeting in Rotorua that I thought I'd share with you here. I really hope we get to do it again soon.

"What a great weekend! Thanks to Nicole for organising such a fantastic event and to all of the wonderful ladies who attended and made the weekend an incredible experience. Hope you all had a safe trip home."

-Tina

"Thanks Nicole for organising our fantastic weekend away with a great bunch of girls. It was awesome to meet you all."

-Lee

"I had a great weekend with you and learned a lot from you and the group."

-Shaz

"Thank you for an awesome weekend. I returned home feeling energised to keep moving forward and with a feeling of peace that I haven't had for [a] long time."

-Tanya

Getting together & Expansion!

Well, there are currently no future get-togethers organised, but that can and will certainly change!

We're not a huge group, but we are pretty well spread throughout the country and if you'd like to meet other women experiencing similar challenges, I'd be very happy to help you arrange to meet others living near you. Or at least hook you up via email. I've found the best support through just being able to chat to other women who 'get it'.

Please email me if you have ideas for future meetings, or if you'd like to get involved in promoting the group among NZ's medical professionals. We need more volunteers to help as we do this mainly by phoning and writing letters. No face-to-face contact required, but it does take a fair bit of time!

My epiphany

I've been through a lot in the 5 years since my earth-shattering POF diagnosis. I've learned a lot about myself, my husband and our relationship. I think the biggest thing I've learned is the resilience of the human soul.

I thought I'd never recover from my infertility blow, but DH and I did our grieving and then we began our inevitable foray into donor egg IVF. Two very good friends tried to help us create a family and we'll be forever grateful to them for those chances, but in the end it was not to be.

Earlier this year, a couple of months after we'd decided we couldn't afford a third cycle, a friend came round with her 6 month-old baby boy. It seemed like a normal visit to me, but my epiphany came later that night as I was telling DH that I hadn't had the 'Oh I wish I had a baby' feeling I usually got whenever they visited. I was writing it off to being simply one of my 'good days' when he stopped me mid-sentence. He got me to repeat myself and as I did I actually heard what I'd said. It really surprised me to realise that I'd subconsciously closed that door and that I was ok with it.

And I feel the best I've felt in a long time. Our focus is now on what we have rather than what we don't have. Our private parts are private again. We are free to dream again. It is liberating to have found a sort of peace with our situation, but I think the loss will always be felt.

IVF is different for everyone. We each are in unique situations, and have our own breaking points. After 2 cycles, 8 embryos, 3 transfers and all the invasive procedures, I lost the ability to cope with treatment. I truly admire those who can keep chasing that dream for 3, 4, 5 cycles. But no matter where you're at on your journey, I just want you to know that you will survive and your resilient soul will find its happy place again.

Nicole x

Health news

Calcium & osteoporosis

Researchers at Harvard University have found no evidence that women who consume one to three servings daily of milk or other calcium-rich foods—like cheese or yogurt—reduce their risk of hip fractures, the standard measure for osteoporosis. Vitamin D appears to be much more important than calcium in preventing fractures. Interestingly, countries with lowest rates of dairy & calcium consumption (like those in Africa & Asia) have the lowest rates of osteoporosis.

Their recommendations:

- Eat lots dark green leafy vegetables, sea vegetables, canned salmon or sardines with bones, sesame seeds and nuts. Calcium supplements are a good option.
- Exercise frequently and supplement with at least 2,000 IUs of vitamin D. Get your vitamin D levels checked!!

<http://www.care2.com/greenliving/milk-to-prevent-osteoporosis.html>

International news

Give me a second

www.givemeasecond.com

Second opinions are good for your health!

This site was set up to encourage women to seek second opinions before a hysterectomy or any life changing surgery. Especially for women facing gynaecological health concerns or disease, second opinions may result in fewer invasive surgeries, fewer hysterectomies, an increase in alternative treatments and improved quality of life for women.

As the website says: "Three important things can happen when we get a second opinion:

1. We get more information
2. We may gain a new perspective
3. We will gain peace of mind"

We women too often put ourselves at the bottom of our priority list, so take a second and go and have a look. And don't forget to pass it on!

Project Aware – Be Aware

www.project-aware.org

"A website by women, for women... offering objective and comprehensive health information, especially related to menopause, perimenopause, and post-menopause."

I found this site the other day and, at first glance, I could only fault their lack of info on the subject of POF/Early Menopause. I wrote to them suggesting they provide more because the sites they link to require money for their services and I struggle with that idea. However, I've now become concerned with the ethics of the site. I found a page of contact details for compounding pharmacists and the ones at the top of the list were labelled site sponsors. So I've written to them about their bias towards 'natural' HRT and how I feel they're hiding their affiliations to the people who sell them. I'm not very hopeful they'll listen to my original suggestions anymore, but this is a lesson in consumer diligence – anyone can set up a website these days and they're not always being up front!



Special Topic

Where did my libido go?

I found this article on the great US website www.care2.com.

Our doctors addressed the subject of libido at our weekend in Rotorua last month. And Jane Catherine Severn, the psychotherapist who ran a workshop at the weekend, offered to do a workshop for us on this topic. Many of us were keen to learn ways of coping with the distressing loss of libido that comes with unbalanced hormones, invasive IVF treatments and the loss of personal identity an early menopause can bring. If you're interested in taking part, please let me know. Nicole.

Libido is the sexual marker for wellness. The question of libido is a complicated one, yet often is framed in a simple black and white of "do you have any libido?" Our drive to be sexual is impacted by a complex interaction between our physical health, mental health, emotional connection and our own individual tendency/preferences about our sexuality.

The range of physical health problems that impact libido comprise a long list. Chronic illness and diseases like high-blood pressure, arthritis, and diabetes, to name just a few, often contribute to low libido. Also, a wide range of prescription drugs, including anti-depressants, blood pressure drugs and even antihistamines can take a toll on your sex drive. Yet more often than serious illness, many people as they age do not maintain the eating, exercise and sleep habits that keep us well. Over 55 percent of women are overweight to some degree in this country.

Our hormones are the cocktail that drives our passion in life. Normal life events like pregnancy, nursing and perimenopausal to menopausal shifts can make big impacts on the libido mechanism. Although low libido is common to most women (over 40 percent) at some point in their lives, ongoing and persistent lack of sex drive may well respond to hormonal treatments. Hormones are an interesting and vital part of what it takes for both sexual and overall wellness. Hormones are worthy of you and your doctor's attention.

For many women, the libido function is deeply tied to their psychological and emotional life. The brain is the sexiest organ in the body; the arousal function starts there, so if you are plagued with emotional issues like low self-esteem, poor body image, depression, anxiety or even constant stress, it is not surprising that you can't find your libido. These issues are just as legitimate as any biological ones and, for many women, more tenacious.

Mental and emotional struggles often get wrapped up and manifest in ongoing relationship issues. Many couples are challenged with communication problems and ongoing conflict. Issues of commitment and infidelity can be deal breakers. Not feeling connected to your partner is enough for many women to have no access to their libido. The link between feeling bad about yourself and then feeling bad about your partner is a bit of a chicken and egg problem—hard to know which one initiates the other. The important thing is to stop the cycle. Usually that begins with self love.

Certainly not the only reason, but a great one to inspire a fresh look at your lifestyle habits is that the healthier and happier you are, the more room you give your libido to wake up.

It is amazing how changing small daily habits can turn our health around quickly. Include exercise and choose fresh and whole foods every day. Learn to meditate or take short walks and learn to shut off the chatter in your mind. Turn off the gadgets and television and cultivate the art of conversation. Sleep when you are tired.

Learning how to communicate is the currency of your relationship's capacity for intimacy: physically, emotionally and mentally. Prioritize shared enjoyment and learn to fight fair when conflicts arise. Schedule time to connect physically. Intimacy can be as non-threatening as mutual back rubs, but what is important is to rebuild your capacity to have physical conversations. Go slowly and consider this a practice of discovering the sensual aspects of sharing a life with someone.

A great resource on your journey is *Reclaiming Desire* by Marianne Brandon, PHD and Andrew Goldstein, MD. I like this book because it doesn't pathologize the issue of libido but offers a wide range of holistic solutions to address it. I spoke with Marianne recently on her radio show and was excited to find this resource that provides so many reasonable and doable solutions for women.

I congratulate you for wanting to deal with this issue in your life. As challenging as it may be to find the mix of solutions that works for you and your partner, I guarantee that the effort will pay you back, both in the increased connection you build in your relationship but also, and more importantly, in the confidence you gain from finding your centre.

Wendy Strgar is a loveologist ... [She] helps couples tackle the questions and concerns of intimacy and relationships, providing honest answers and innovative advice.

<http://www.care2.com/greenliving/ask-the-loveologist-where-did-my-libido-go.html>



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We need your story!

For our newsletter or website - or both! Newly diagnosed women get so much from hearing the experiences of others. It could be your whole story or just some part of it that you felt able to share. And it can be anonymous if that makes you more comfortable.

I've found it can be very cathartic to write down your experiences, so not only can you help someone else, you're almost certain to help yourself in the process. Send me an email if you'd like to do this.

WHAT'S ON GUIDE

Fertility NZ Contact Groups

NB. If your area isn't on this list, please email support@fertilitynz.org.nz to see if one is likely to start.

Auckland

Six courses per year, each 3 weeks long.
Next one starts July 27.
Contact: cg.fnzauckland@gmail.com

Hawke's Bay

Contact: support@fertilitynz.org.nz

Wellington

No date as yet, but hope to run one later in the year.
Contact: wellingtonfnz@gmail.com

Hamilton

Contact: karenandmarcus@yahoo.co.uk

Palmerston North

Contact: support@fertilitynz.org.nz

Christchurch

Contact: support@fertilitynz.org.nz

Tauranga

Contact: support@fertilitynz.org.nz

Nelson

First Wednesday of the month.
Hour-long meetings followed by supper. Women only.
Contact: lyndajessentye@clear.net.nz

Dunedin

Contact: support@fertilitynz.org.nz

Rotorua:

Contact: support@fertilitynz.org.nz

INTERNATIONAL EVENTS

Australasian Menopause Society 14th Annual Congress

September 26-29, 2010
Sydney, Australia

Including sessions on 'early menopause', 'female sexual dysfunction', 'skeletal health' and 'managing the menopause'.
The Early Menopause session covers psychological consequences, clinical consequences and fertility issues.

North American Menopause Society 21st Annual Meeting

October 6-9, 2010
Chicago, Illinois

Including a session entitled 'Primary Ovarian Insufficiency is not an early menopause.'