

GYNAEMIGHT!

THE QUARTERLY NEWSLETTER OF GAIN INC.
(GYNAECOLOGICAL AWARENESS INFORMATION NETWORK INC.)

Chair's Report

September 10 is *National Gynaecological Day* and here's how you can celebrate:

- Attend the **Great Gynae Debate** on Thursday 9th September at the Subiaco Theatre Centre. Tickets are \$35, which includes a drink on arrival and post-show cocktail function. All funds raised go to help GAIN continue our important work. The Great Gynae Debate is going to be an entertaining and informative night! See the enclosed flier for more information.
- Attend the **National Gynaecological Day Art Exhibition** at the Left Bank Bar & Café in East Fremantle on Wednesday 8th September from 7pm. This exhibition celebrating women features four talented local artists and music 'unplugged' by the sensational Natalie Gillespie. All of the artwork will be for sale and entry is free. As a special offer, The Left Bank have a 'buy one get one free' deal on meals in the restaurant. Bookings for this can be made on 9319 1116 (offer needs to be mentioned on booking).

The Left Bank Bar and Café supports National Gynaecological Awareness Day.



- Celebrate in your own business, workplace or home. I encourage all of our Eastern States and regional WA members to have their own

celebratory event – even if it's just getting your friends around for a cup of tea and a cake! Last year, the Women's Surgical Health unit at The Mater Hospital in Brisbane held an information day with resource videos, clinical nurses and give away bags full of goodies (sanitary napkins, aromatherapy products, cosmetics and chocolates). We hope that others can do the same. E-mail your event details to mazzella@bigpond.com.au, so we can keep a record of how you are celebrating.

Be sure to celebrate National Gynaecological Day on September 10, 2004!

Natalie Jenkins,
Chairperson.



Kath Mazzella and Natalie Jenkins with Norma Jamieson - Founder of "Hands that Help" during a Fundraiser for GAIN. Thanks to Norma and her Committee for arranging the day. It was most successful and the donation was graciously received.

editorial

Hello again to all.

It has been said many times that we live today in a world of information overload. Sharing information is one of the primary reasons for the existence of GAIN.

Not all of us will see things the same way. Sometimes this newsletter may publish information which causes controversy, even outrage. This is of course, not done intentionally.

The area of health care is one in which there will often be differing viewpoints. Given that human

knowledge is constantly expanding and evolving, exponentially so in fact, this is not surprising.

Because of this, it is wise for us all to keep open minds, and to listen to "both sides of the story".

It is in this spirit that we publish in this edition, a "rebuttal" to the view put in the article "Kathy's Story" regarding ovarian cancer and the CA 125 test, published in the previous edition.

In doing so GAIN makes no judgement about either viewpoint, rather accepts the desirability of consciously working towards being as even handed as possible. It is then up to our members and readers to make their own judgements at any given time.

Vicki.

www.gynsupport.com

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GAIN Committee Meetings are held every 6 weeks on Wednesdays from 6pm to 8.30pm. Please call 08 9279 7773 for venue details.

2004 MEETING DATES:
15th September, 27th October,
8th December.

stop press!

GAIN wishes to congratulate Dr Gaye Casper - President Australian National Federation of Medical Women, who is currently in Japan being installed as the International President of the International Federation of Medical Women.

**CELEBRATE NATIONAL
GYNAECOLOGICAL
DAY ~ SEPTEMBER 10!**

"With Knowledge We Are Empowered"

FOLLOW UP TO KATHY'S STORY FROM ISSUE 8

(In answer to last edition's story, the following is taken and condensed from the website www.womenofcolorobgyn.com)

There are several versions of a popular email circulating that encourages all women to have a CA-125 blood test yearly as a screening test for ovarian cancer. This particular email implies that the CA-125 test is a widely kept secret from the female public and that physicians or insurance carriers typically discourage female patients from taking this potentially, life-saving test.

THE FACTS

Yes, there does exist a test or "tumour marker" called CA-125. The level of CA-125 is usually elevated in women with ovarian cancer and in primary peritoneal cancer. It is NOT however, a "screening test" for ovarian, or any other type of cancer.

In reality, there is no good screening test for ovarian cancer nor are there any "classic symptoms" for ovarian cancer. In fact, ovarian cancer is most often without symptoms until it is in later stages. Even then these symptoms are often very vague, such as bloating or general

gastrointestinal discomfort. It is this lack of specific symptoms and adequate screening tests that makes early diagnosis and treatment of ovarian cancer extremely difficult.

WHAT IS A SCREENING TEST?

There are several characteristics of a good screening test:

- 1 It must be sensitive (able to detect a particular problem or if the condition exists).
- 2 It must also be specific (levels are elevated exclusively in the disease or condition you are looking for).
- 3 It must have a low number of false positive results (a positive result means you actually have the disease).
- 4 It must be safe, cost effective and widely available.
- 5 Most importantly, it must be shown to improve survival rates for the disease you are screening for because it allows for earlier detection and treatment.

At one time the CA-125 tumour marker created quite a buzz in medical circles, because it was

thought to have great potential for becoming a screening test for ovarian cancer. However, several large studies have since revealed that a CA-125 test fails miserably as a screening tool. The CA-125 level is only elevated in 50% of ovarian cancers, and many times it doesn't become elevated until the cancer has already spread. Therefore, a negative test does not necessarily mean that you are free from ovarian cancer.

The CA-125 test has a high rate of false positive results. Numerous false positive results would result in expensive additional testing and risky exploratory surgeries searching for a potential cancer that most likely isn't there. CA-125 testing as a screening tool has never been shown to improve survival in ovarian cancer.

Used properly, the CA-125 is a good test. If one has been diagnosed with ovarian cancer and has an elevated CA-125, it is extremely useful in monitoring the response to treatment. A decrease in the level means chemotherapy is working, an increase in the level can signify the recurrence of the cancer.

Andrea N. Price MD FACOG

For the Bookworms - Some Suggested Reading

The Gynaecological Cancer Guide: Sex, Sanity, Survival and Gynaecological Cancers by Margaret Heffernan.



The book, written by a cancer survivor, Margaret Heffernan with one of the world's leading gynaecological cancer specialists and researchers, Professor Michael Quinn, provides information on:

- What gynaecological cancer patients and their family and friends experience
- The range of gynaecological cancers
- How the cancers are diagnosed and treated
- Complementary medicine
- Coping with the Psychological and sexual impact of cancer
- Lesbians and cancer
- Reaction to your diagnosis by family and friends
- Helping children to cope with your diagnosis
- Practical support services
- Questions to ask your doctor

Ms Heffernan said: "Cancer is something which it is almost impossible to speak about without

fear, denial or evasion. This book aims to counter the fear, the unpredictability and the lack of knowledge. It also reinforces that the range of reactions that women and their loved ones experience after a cancer diagnosis is normal, and usually last for a short time only."

The book provides both detailed easy-to-understand practical information relating to intimacy and sexuality; psycho-social impacts and coping post treatment. It gives descriptions of the personal experiences of a diverse group of women who have survived cancer. The founder of GAIN Kath Mazzella has also made an invaluable contribution to the book on aspects of vulvar cancer. The authors are available for interviews and briefings on the book and all aspects of gynaecological cancers. NOTE: All royalties from the book are being donated to gynaecological cancer projects.

Published by Michelle Anderson Publishing Pty Ltd, PO Box 6032, Chapel Street North, South Yarra, Victoria, 3141. Cost \$24.95.

Giving up the Ghost by Hilary Mantel.

Hilary Mantel is the British author of nine novels. This book describes her childhood and her experience as a sufferer of endometriosis. It

starkly outlines the effect of the disease and its misdiagnosis, on her life – from pain and childlessness, to being suspected of insanity, or at the very least, malingering.

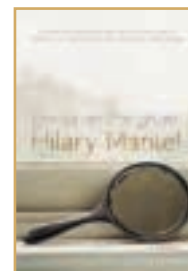
The scars are clearly both mental and physical. The "ghosts" include those of her never born children and her unrealised aspirations as a lawyer.

A brief quote "I have been so mauled by medical procedures, so sabotaged and made over, so thin and so fat, that sometimes I feel that each morning it is necessary to write myself into being... to locate myself, if not within a body, then in the narrow space between one line and the next".

The "so thin and so fat" refers to the bloating of her entire body that occurred when Mantel's endometriosis returned following the hysterectomy that she was led to believe would result in its eradication.

A further quote with which many of us would relate "...when you're in pain, you're vulnerable, and there's something profoundly shaming about being a gynaecological patient"

Published by Harper Perennial, cost \$22.95.



DISCLAIMER: Information appearing in *Gynaemight* is offered as a service to increase the general awareness of women with regard to gynaecological issues. Such information reflects the experiences and opinions of GAIN members as well as many other individuals who have expressed themselves in a variety of fora. Such information in no way constitutes medical advice, for which readers should at all times consult their qualified Health Professional. GAIN Inc 4 Boronia Court, Morley WA 6062. Telephone 08 9279 7773.

MEMBER'S STORY BY ROSETTA CLARKE



Hello, my name is Rosetta, and in April this year I was diagnosed with vulvar vestibulitis. I am a retired registered nurse having enjoyed a varied 40-year career in Australia and overseas. In all that

time I do not recall coming across anyone with this condition, or even hearing about it!

This is not surprising because, until the 1980's, there was little if any reporting on the condition. However, close friends, and members of the VVS Support Group constantly remind me, that I and others are in a much stronger position than was possible a decade or even a few years ago. There are specialist practitioners, new treatments, support groups and considerable information available via the Internet.

I consider myself fortunate because I was diagnosed very early. As I have discovered, the condition is complex, and symptoms can vary among individual sufferers. In my case, it occurred suddenly "out of the blue" in November 2003, with a stinging, burning pain in the vulval-vaginal area.

At first I thought it could be postmenopausal,

and after a visit to the local GP, began a course of HRT using Vagifem. After much discomfort and no relief from the pain, I sought a second opinion within weeks. My new practitioner looked at all possibilities, including tests for yeast infection, herpes virus, and urinary tract infection, as well as requesting pelvic ultrasound and colonoscopy.

All of these investigations were negative. I had now discontinued the Vagifem and had commenced on steroid ointment plus an emulsifier twice daily. This gave me some relief, but invariably the pain would return every few days.

As other sufferers have reported, doctors can be diligent and sympathetic, but are often unable to recognise the problem. At this time a dear friend brought to my attention a newspaper article featuring a VVS Support Group member with "her story". I will always bless that person for making her experience known via the media... it was a lifesaver for me! I showed the article to my GP and for her it was the missing clue. I was then quickly referred to a specialist at Perth Sexual Health Centre.

I remember my first consultation. After a discussion of my symptoms followed by an examination, the diagnosis was made... Bingo! At least now I knew what it was, even if I couldn't understand the why or the how?

It is now three months since I was diagnosed. I

am, at this point, about 85-90% pain free. I am enjoying long periods of pain free days with flare-ups occurring less and less. These occur if I overdo activities especially in the garden.

My current treatment includes:

- A low oxalate diet
- Calcium citrate tablets twice a day
- Biomagnesium and Vitamin B6
- Regular physiotherapy
- Emu oil and Oestrogen cream
- A muscle relaxant to reduce spasm in the pelvic area.

This treatment is specific to me. As mentioned earlier, symptoms, and therefore treatments, vary with individuals. I feel I have been lucky in getting an early diagnosis, followed by treatment from compassionate health professionals.

I would say to others, do not be afraid of seeking a second opinion. Remember it is your body. Once diagnosed, join a support group. I have felt reassurance knowing there are others to talk to. The loneliness of the condition will disappear. Also, read as much as possible about the condition. Finally, thank you to the founder of GAIN, all the hard working committee members, and the contacts in the VVS Support Group. God bless you all.

Rosetta Clarke.



GAIN girls strutting gynaecological awareness at the Everywoman Expo - Kate Baker, Arlene Quinn (winner Business Professional Women WA) and Bonnie Barlow.

Everywoman Expo at Burswood

Yet again another successful 3 days at the Burswood Everywoman Expo 11-13 June 2004. Our heartfelt thanks go to Lyn Oliver, Marilyn Kench, Arlene Quinn, Maxine, Marina, Vicki O'Dwyer, David Jones, Natalie Jenkins, Elaine Embleton, Nicole Gray, and the many others who contributed.

GAIN has had a display at this Expo for many years now. When we first exhibited there were very few displays on gynaecological issues.

I must say it was very exciting to see many more gynaecological displays on infertility, endometriosis, cancers, menopause, complimentary therapies and even "the elusive orgasm", thus giving women information and also most importantly, giving them choices and enabling them to share their stories with others.

GAIN is clearly able to move mountains and is gathering great momentum through this Expo and it is easy to see it has been recognised as a very professional organisation.

Fundraising Offer Repeated by Vicki O'Dwyer

GAIN is a purely volunteer not for profit organisation always in need of more funds. As some of you may remember I made an offer some time ago to donate to GAIN 50% of the profits of any Esteem Jewellery presentation hosted by any GAIN member or their families or friends. I am repeating this offer on an indefinite basis.

Esteem Jewellery is high quality fashion jewellery at reasonable prices, available in gold and silver and with a lifetime manufacturing warranty. A catalogue CD can be supplied or it can be viewed at <http://www.esteem.com.au>. To book a presentation call me on 9322 1171 or 0419 918 211.

I recently held a presentation at the home of GAIN member Suellen Edwards, it was fun for all, and GAIN benefited to the tune of \$100.00. Many thanks Suellen!!

When will YOU hold your presentation???



Looking happy and gorgeous at the Pamper Day run by Emily Milburn on July 25, 2004, where GAIN members got to relax and enjoy some well-deserved complimentary pampering.

Vulvodinia Support Group News

Our Vulvodinia Support Group meets regularly at each others' houses. We have a wonderful time sharing not only invaluable information but also emotional support and plenty of laughs. As we were getting rather large, a second support group has also begun meeting.

There are several upcoming events with which we are involved. One is a workshop with Marek Jantos - a specialist in psychophysiology who many of us are working with - looking at muscle stretching and relaxation. This will be held on Sunday, August 29th. A meeting is also being planned by Lyn David, who is a physiotherapist at King Edward (date to be decided). This session will look at the work that physiotherapists do with women with vulvodinia, especially focusing on the different equipment that is used in this type of physiotherapy. Both events are free and open to any woman with vulvodinia whether they are patients or not. We look forward to learning more about our muscles and how we can re-educate them in order to reduce or eliminate pain.

If anyone is interested in these events, joining a support group, or is simply seeking more information about vulvodinia, contact with me is welcomed on (08) 9305 2650 or jogreygum@aol.com. Information is also available from the Vulval Pain Information Package compiled by myself and Melissa Beeck on the GAIN Inc website: www.gainsupport.com Jo Taylor.



Images from the first Vulvodinia Support Group meeting at the home of Melissa Beeck in October last year.

ON A LIGHTER NOTE: *The Seven Dwarves of Menopause*

The Seven Dwarves of Menopause arrived at my door without warning: **Itchy, Bitchy, Sweaty, Sleepy, Bloated, Forgetful** and **All-Dried-Up**. One by one they crept into my own private cottage in the woods and started to take over my life. The first to arrive was **Itchy**. I developed this itch on my right calf that was so irritating, I wanted to scratch the skin right off my body. Then **Bitchy** came to my door. No longer was my PMS contained to one or two days a month-- it felt like constant PMS. Then I would swing from **Bitchy** to **Weepy** for God's sake, what was wrong with me? Ding-dong...It's the middle of the night and **Sweaty** has crawled into bed with me. Oh, yes, **Sweaty** brought embarrassing hot flashes and introduced me to night sweats where it seemed as if a faucet had been attached between my breasts. Of course **Sweaty** brought about **Sleepy**, because I was tired all the time. I would wake up so many times in the night and not be able to get back to sleep. **Bloated** crept in slowly, my once-svelte figure got thick through the middle section, even though I was following my weight-loss program that had worked so well for so many years! I can't quite remember when **Forgetful** arrived, but one day my brain stopped working. I considered myself a pretty focused woman until **Forgetful** came, and I could not keep a coherent thought in my brain. Am I getting Alzheimer's I wondered? Last, **All-Dried-Up** slowly encroached upon my happy marriage. This was probably the most unpleasant of the dwarf family. Sex was no longer on the top of my list...or on my list at all. My husband would give me that knowing look, and I would think, "Frankly, I'd rather have a smoothie." *Author Unknown.*



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GAIN website hosting by **Generation IT** www.git.com.au



GAIN artwork by **Donna Cameron Design** Telephone: 08 9844 8267

PROUD SPONSORS OF GAIN INC.

Memberships became due and payable on 30th of June 2004. Your continued support is greatly valued and is vital to the ongoing success of GAIN. Please complete and return the below form as soon as possible.

GAIN MEMBERSHIP FORM

Please support GAIN by becoming a member (annual fee \$20.00). Just fill out this form and send with your cheque for \$20.00 made payable to GAIN Inc. 4 Boronia Court, Morley WA 6062

Name of Individual / Organisation (circle one): _____

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Signature: _____ Date: _____

Suggestions / Ideas: _____
