

GYNAEMIGHT!

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

Introducing GAIN's new Chair - Natalie Jenkins -

Natalie is currently General Manager of Perth Theatre Company and first came to know GAIN through PTC's highly successful production of The Vagina Monologues. Kath had read about the production and contacted the company to see if GAIN could be promoted in any way. PTC obliged by including GAIN flyers in the show programmes and also helping to promote the Gynae Might forum that was held in 2001. Natalie was so impressed by Kath and the work that GAIN was doing that she decided that she would like to become involved in the organisation. Having no real understanding of gynaecological issues that faced some of the members (apart from having the important credentials of being a woman!), Natalie felt that she could offer support in the business side of GAIN – that being her prime area of expertise. After coming on board in late 2002, Natalie helped with the strategic planning process and then helped co-ordinate the National Gynaecological Day. Natalie was elected Chair at the AGM in September.



A message from the new Chairperson...

I am very pleased to have taken on the role of Chair of GAIN although, I do feel that I have a lot to learn from all the incredibly supportive members of GAIN. I believe that after 10 years of hard work, GAIN is now in a position to really grow and build its important role within the community. The foundations have been well and truly laid and I thank all of the members who have worked so hard to do this. In particular, I have to express deepest admiration to Kath Mazzella who I think is an incredible lady with a great passion to 'fight the cause'.

The work that Kath and all of the GAIN supporters have done over the past 10 years are the building blocks of GAIN and I can't thank them enough for doing everything that they have. I'd like to thank the outgoing committee members, in particular Tony Mazzella and Trish Krauss and welcome in the new Committee members who are: Vice Chair - Marilyn Kench; Treasurer - Kath Mazzella; Secretary - Lyn Oliver; Committee Members - Melissa Beeck, Elaine Embleton, and Vicki O'Dwyer. I am confident that this is a strong committee who will take GAIN into its next era.

I would also like to thank the two Donnas: Donna Cameron who looks after all of our graphic design work and Donna Milburn who takes care of our website. Without these two roles, it would be extremely difficult for us to communicate as effectively with our members and to present such a professional image for our advocacy efforts. Thanks also to our new newsletter Editor, Vicki O'Dwyer.

Additionally, can I thank Helen Pearson who I know is an excellent support for Kath with all of the events that GAIN holds. Helen will be organising our Christmas function (details in the newsletter) and regular social get togethers for members in 2004.

Finally, can I say that establishing organisations such as GAIN is a long and slow process but many small steps eventually turn into big steps and they are so worth it in the end!

Natalie Jenkins

Farewell Statement from outgoing Chair...

It gives me great pleasure to announce that after realising my dream of creating GAIN and being Chair for 2 years and seeing its growth to such an important organisation, our newly elected Chair is Natalie Jenkins.

Natalie has vast experience with non-profit organisations and has a wonderful business rapport and I am sure will bring in new initiatives and insights not only to GAIN members but all women and their families.

It almost brings a tear to my eyes. I remain on the Committee and offer all my support to Natalie and her team.

Kath Mazzella

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GAIN CHRISTMAS PARTY

Time to celebrate GAIN with Christmas drinks and nibbles. Bring along your friends for a fun, relaxing after work chat.

Date: Wed 3rd December 2003

Venue: Tarts Café, 212 Lake Street, Northbridge. Tel: 9328 6607

Time: 5.30pm - 8.30pm

Cost: \$15 per person
(drinks provided)

RSVP: 24/11/03 to Helen Pearson
on 9380 4101, 0402 243 852
or ppear@optusnet.com.au

GAIN Meetings are held every 6 weeks on Wednesdays from 6.30 to 8.30 pm at the National Council of Women (NCW) 25 Irwin Street Perth. Parking available at rear of building. All are welcome.

2004 MEETING DATES:

**14th January, 25th February,
7th April, 19th May, 30th June.**

"With Knowledge We Are Empowered"

National Gynaecological Awareness Day 2003

The Inaugural National Gynaecological Day was held on September 10, 2003. The signature event was a breakfast held at Altitude 9 in the city, with guest speaker Sexologist, Dr Gabrielle Morrissey. In addition, Dr Ian Hammond, Gynaecologic Oncologist launched the inaugural day. He spoke about the need for early diagnosis and more awareness in the community thus, supporting the work of GAIN.

Eighty-five people attended the breakfast. Many people attended from different sections of the community including: the National Council of Women of WA, Australian Medical Association – Gynaecological representative, Cancer Foundation of WA, King Edward Memorial Hospital and Soroptimists International. All showed great interest in GAIN's objective of raising a higher profile for gynaecological health. Attendees came from all walks of life and included health workers and clinicians, doctors, relationship counsellors, single women, mothers, older and younger women and male partners. The GAIN committee was very pleased to see such a broad range of attendees.

Our guest speaker, Dr Gabrielle Morrissey delivered an address entitled "What Women Urge to Know" and covered sexual health as it relates to gynaecological issues. Gabrielle is passionate about raising a higher profile of gynaecological health in the community and she stressed the importance of sharing our gynaecological concerns with others. Gabrielle's talk introduced a sense of fun and intrigue in the way she presented. The responses from the people who attended were very positive.

GAIN Founder Kath Mazzella talked about GAIN, our objectives and the services we offer. GAIN information packs and our latest newsletter were on all tables so that attendees could take them away. The Cancer Foundation supported the event and had some information materials at the venue. Cytyc Corporation also supported the event and as such had an information display about smear testing. We sincerely thank Cytyc for continuing to support the activities of GAIN.

Amongst the attendees was Ms Louise Pratt MLC who was also very active in promoting the event to her parliamentary colleagues. GAIN also invited (but who sent their apologies), the Hon. Sheila McHale MLA and Barbara Scott MLC, as well as all female federal government senators and members of parliament. Many elected state members promoted the day through their constituencies and to their parliamentary colleagues. Some also printed fliers for their newsletters.

The promotion of the event was undertaken far and wide and included distribution of fliers and e-fliers by all of our partner

organisations (e.g. Cancer Foundation of WA, Curtin University, ECU, Family Planning, King Edward Hospital, Genetic Society, Health Consumers Council, Women's Policy Office, Soroptimists and the National Council of Women WA. A media release was distributed to all media and one of our members spoke on radio promoting the event. GAIN also utilised our newsletter and website to promote the event and the importance of a raising the profile of gynaecological health.

In conjunction with the breakfast, King Edward Memorial Hospital hosted a gynaecological display during the week of the National Day. There were also a number of smaller and less formal events held around the country: GAIN members in Esperance held a morning tea, as did members in Tasmania.

Outcomes of the National Gynaecological Awareness Day

The national day served to put gynaecological issues on the agenda for many of our community sectors. It also strengthened community and health professional relationships with GAIN (one of our objectives). GAIN will be working hard to continue these relationships.

The promotion of our day increased awareness and curiosity about GAIN and what we stand for. Sometimes we do not see the impact we have on the community, as it is such a sensitive issue however, we know by the feedback from this day that we are creating an impact.

As a direct result of the National Day, gynaecologic oncologist Prof. Michael Quinn from the Royal Women's Hospital in Melbourne has suggested we put forward a submission to the Australian Gynaecological Society Annual General Meeting in May 2004. He has indicated that he would be very supportive of our initiatives at this meeting. This is very exciting news and represents big inroads for our organisation aims.

The event also indicated a clear demand for more open public forums on gynaecological issues in WA in the future. GAIN intends to hold more of

these. GAIN also attracted thirty-seven new members. This is an excellent outcome

Overall, the inaugural national day was a great success and GAIN plans to ensure it grows every year. Our thanks to the WA Women's Policy Office for supporting this important initiative and the women who comprise GAIN Inc. A vote of appreciation also goes to Altitude 9 for looking after us. Finally, a big thank you also to all members who attended the event and to those who helped organise the day and set up the event – as usual, our wonderful members and supporters came out in full force!



Dr Gabrielle Morrissey, Kath Mazzella and Dr Ian Hammond at the 2003 National Gynaecological Day Breakfast



editorial

As your new Newsletter Editor, I thought I should introduce myself. My name is Vicki O'Dwyer, and I have been involved with GAIN for only a relatively brief period. I discovered the existence of GAIN by accident, while searching for information about Dr Joanne Samer, who is now my doctor.

It's a long story, but suffice to say that I decided on the spot that GAIN was an organisation worth being involved with.

My own journey has involved battling endometriosis and fibroids. From the time I was 12 years old, I frequently had to be sent home from school with excruciating period pain. Apart from holding a hot water bottle against my tummy, the only treatment was to take the contraceptive pill, which did nothing but mask the symptoms.

At age 19, I underwent a laparotomy, major abdominal surgery, in an attempt to remove the unbound endometrial tissue that was packed into my pelvis, completely blocking both fallopian tubes, and which was also adhered to my bowel.

I was told that it was so bad that I had at most, a 30% chance of ever becoming pregnant. I did become a mother, and although my first child was tragically stillborn, I do have two adult sons. This in itself is nothing short of a miracle.

Despite having been told that a pregnancy would cure the condition, my endometriosis returned with a vengeance after a few years, and as time went by, fibroids decided to enter the picture as well. These two conditions, both singularly and in combination, are the major causes of infertility in women.

I have had many surgeries to deal with these gynaecological problems, so many in fact that I developed incisional hernias, i.e. the muscles in my groin collapsed

from being cut so many times. The solution? More surgery!

Throughout this roller coaster ride, I have had to deal with making medical decisions based on limited information and with feelings of isolation and fear. Endometriosis still seems to be a mystery to the medical profession and the treatment for it and for fibroids are still, in my personal opinion, somewhat barbaric. Hysterectomy seems to be preferred solution in the eyes of the majority within the profession, especially once you reach a "certain" age.

After reading "The Hysterectomy Hoax", a wonderful book by a dissenting doctor whose name I cannot now recall, I felt much more confident about dealing with doctors and standing my ground.

The bottom line is... knowledge is power, and we need to have as much knowledge as we can, and share it as widely as possible.

This is my first effort as Editor, so please be gentle with me, and I hope you enjoy the remainder!!! Vicki

Outgoing Chairperson's Report by Kath Mazzella

Each year upon writing my report I can see the growth and success of GAIN. When we look back it is amazing the ground that we have covered. Yet there is still so much work to be done in raising gynaecological awareness in our community, locally, nationally and internationally.

National Gynaecological Awareness Day 2003:

See report on previous page.

International Profile:

See report below.

GAIN's Vision, Mission and Goals:

- A National Gynaecological Health Support and Advocacy Network providing a powerful voice for the community.
- To be a central point to collect, coordinate and disseminate information on the support available on gynaecological issues.
- Foster community awareness of women's gynaecological issues.
- Provide information to empower individuals to develop responsibility towards gynaecological health.
- Promote the importance of a holistic approach to gynaecological health.
- Promote preventative gynaecological health activities and attitudes.
- Have a positive impact on the psychosocial outcomes of gynaecological issues.

(As per dossier - thanks to Karon Church and Natalie Jenkins).

Strategic Initiatives 2003 - 2008:

- Establish an ongoing National Gynaecological Day on the 10th September.
- Establish a working partnership with medical professional associations.
- Establish a working partnership with relevant community groups and NGOs.
- Lobby all levels of government to secure funds for research, projects and organisational core funds.
- Resource GAIN financially and physically.

Some of the exciting achievements the past 12 months were:

ARTICLES

1 Feb Victorian Cancer Newsletter - Alongside Prof. M Quinn - Royal Women's Hospital

2 July HPV article Australian Health Consumer - Rural Women Network Victoria - Alongside Prof. Marion Pitts La Trobe University

3 Aug Women's Imaging USA

CONFERENCES 2002/2003

"Viva la Vulva" Forum Melbourne - Spons - Prof. M Quinn Royal Women's Melbourne

"Women Speak" Canberra - Spons - Office Status Women
Mental Health Sexual Health - Spons - Health Consumers
International National Council of Women - Perth WA
National Council of Women Triennial - Perth WA

SPEAKING ENGAGEMENTS

Avon Health Service; Rocky Bay Village - Disability Women;
Shell Corporation ; WA Sexology Society ; Avon Cancer Support (Rural)

GAIN SEMINARS & EXPOS

National Gynaecological Day 2002 - Linq Restaurant 8/9/02
National Gynaecological Day 2003 - Altitude 9 Restaurant 10/9/03
"You Are What You Absorb" Karon Sibbritt
"Reflexology Day" Melissa Beeck
"Conscious Living Expo" GAIN Display
National Gynaecological Day Display - King Edward Memorial Hospital

Liaison:

GAIN is in contact with a Gynaecologist who is very interested in supporting the initiatives of GAIN with a suggestion that we submit a proposal to the Annual General Meeting of the Australian Gynaecology Association in May 2004.

Financial Balance:

Financial balance of GAIN Inc as at 31 July 2003 is \$2,733.99.

Looking forward, we need public discussions and liaising in regards to all gynaecological issues to help not only women themselves but also their partners and families. The cost to the government would decrease with people understanding more about their bodies and also being able to share with others. We need a more open approach to these issues and GAIN is paving the way.

I wish to thank most sincerely the support of the GAIN committee and members who have devoted their time energy and initiatives for without these people behind GAIN this would never have come to fruition.

I would like to make a special mention of my husband Tony, without whose patience and support this would never have come together.

Love and Good Health to you all.

INTERNATIONAL GYNAECOLOGICAL INTEREST

In September 2003 I was lucky to have experienced the International Council of Women General Assembly in Perth Western Australia and the separate conference - Australian National Council of Women Triennial.

During the International Conference I met the new International President Anamah Tan - from Singapore who wishes to bring in new ideas and is very open to suggestions.

She was amazed at how GAIN had paved the way and was very interested in some of the women's stories that had come through GAIN. I suggested to her that these stories must be heard so that research and funding changes can be made.

It was through her suggestion and interest that International National Council of Women could work toward an International Gynaecological Workshop to assist in raising a higher profile of gynaecological health. What an opportunity this would be for women of the world to GAIN better knowledge.

I was honoured to have the opportunity to have experienced such diversity, to create an interest with international women about global gynaecological issues and it was personally a great learning curve for myself and the future of GAIN Inc.

I worked alongside the then President Judith Parker and the NCWA Committee who was very supportive in GAIN's initiative of the National Gynaecological Day 10/9/03.

I have now finished my position as Australian Secretary National Council of Women and hope to use the contacts and knowledge from here to take GAIN to a higher level in the community.

Life never ceases to amaze me.

Kath Mazzella



Kath Mazzella with outgoing President Phinina Hertzog and incoming President Anamh Tan of International Council of Women.

GAIN MEMBER JO TAYLOR SHARES HER EXPERIENCE

VVS (*Vulval Vestibulitis Syndrome*)

The first time I experienced vulval pain was in 1984. It came out of the blue with the beginning of a relationship, stayed for three mystifying and excruciating months and then suddenly vanished. Nobody knew what it was, why I had it or why it went and I set about forgetting this unpleasant time as quickly as possible.

At the beginning of 2000, I was again at the beginning of a relationship. I was a single mum with two active sons and I had a rapidly growing private practice in psychotherapy. I also taught students in counselling and psychotherapy training programmes. I felt at the peak of my life; full of energy and ambition. Again, suddenly and shockingly, I developed generalised vulval pain along with a urinary tract infection. The pain stayed after the infection cleared.

The pain was so unrelenting and debilitating that I was forced to surrender my work commitments. (I am still on a disability pension). I lay for months as the world went by without me, at times barely able to move at all. My family, friends and partner provided ongoing and practical support. Nevertheless, I rapidly lost my sense of self-worth. Though I didn't want to die, the vulval pain was so acute and so unchanging that at times I felt I could no longer live. My partner remained caring and constant, though it was hard for both of us in different ways. My whole genital area felt so sore and inflamed that I could bear no touch, no arousal.

It was a relief to be diagnosed with **VVS (Vulval Vestibulitis Syndrome)** months down the track after unintentional mismanagement by many doctors. Any topical treatment had only increased the pain. It took about a year for this pain to gradually improve with a regime of amitriptyline (an anti-depressant), supplements and general nurturing.

There has been no substantial improvement over the last one and a half years and so I am currently trying a new approach. At its best, I have a little discomfort, especially after urinating. At its worst I have a raw, aching sensation and piercing pains up into my body, which prevent comfortable movement. There is never a time when vulval pain is completely absent. My life revolves around its management: how I urinate, how I sit, what I eat, the activities I can participate in, are all dictated by it.

It is hard to remain optimistic when nothing you try helps; hard, on a bad day, to keep faith and hope alive. On good days, however, I sense meaning and purpose in this experience. I have been led to act in entirely different ways and to interact with people I would have, otherwise, had no contact. I feel that my future may well involve ways of being I could never have formerly imagined.

VVS / VVD Support Group

On 12th October 2003, Melissa Beeck and I, with the support of GAIN and Melissa's mother Barb, organised an afternoon tea for women with Vulval Vestibulitis Syndrome and/or Vulvodynia. We were thrilled with the number of women - and one supportive man - who attended. It was obviously a relief for them to be with others who know their pain (physical and emotional) and to hear each other's stories. It was also terrific to have - through their attendance - the support of practitioners in this field.

With women from that initial meeting, I am organising an ongoing support group for women with vulval pain. If anyone is interested in this they are welcome to contact me on 9305 2650. If necessary we can form several groups.

Jo Taylor BA(Hons); AdDip(Psychotherapy)

Explaining HPV (Human Papilloma Virus)

Human Papilloma Virus (HPV) is the clinical name for a common wart virus. Sometimes the warts are visible as raised growths, in other cases they are only visible under the microscope.

Viruses affecting genital areas are usually sexually transmitted. The lifetime risk of being exposed to the virus is around 85%, although only about 10 - 20% of people will have an active infection at any one time.

Once a person has been exposed to the virus it can take up to a year for a wart to develop and some people never develop visible warts even though the virus is present. Most people are not aware that they carry the virus.

The vast majority of people clear the virus with in a few months. However, some women do not clear the virus and it is these women who are at risk of developing **cervical cancer** at some point in the future.

On a global scale, **cervical cancer** is the second most common cancer of women. In Australia approximately 900 new cases of cervical cancer are diagnosed each year. Cervical cancer has only relatively recently been associated with HPV. The association is **extremely strong** and appears to be independent of other risk factors.

HPV is the most common viral sexually transmitted agent and the relationship between cervical cancer and HPV is stronger than for any other environmental agent and a human cancer – greater, for example, than the association between cigarette smoking and lung cancer.

Between 8% and 12% of women aged 18 to 24 and between 2% and 5% of women over the age of 35 may have the virus at any one time. Infections persist in older women, are more stable and show a closer association with cervical cancer.

The virus needs to be treated if it infects the cells of the cervix and produces abnormalities. In most cases a woman's immune system can fight abnormalities caused by the wart virus and no extra treatment will be required. However, it is not possible to predict whether abnormalities will progress to cervical cancer so moderate to serious abnormalities are always treated.

In 2000 together with Tracey Clarke, the author carried out a study of all female staff members of a small university in the UK. They ranged in age from 19 to 64. We asked these women a series of questions about themselves and their knowledge of cervical cancer and HPV.

Only 30% of the women in our study had heard of HPV, and even those who had heard of the virus did not know how HPV is contracted. Forty-five women (11%) correctly identified a potential link between HPV and the development of cervical cancer in the long term.

Studies such as those discussed here show that there are major gaps in women's knowledge and understanding of the role of HPV in cervical abnormalities. The topics of cervical cancer, and HPV in particular have yet to permeate the health sections magazines and newspapers or to feature on television program.

The challenge to public health is to develop ways of communicating accurate information about HPV and the associated risks within cervical screening initiatives such that women (and men) understand both the prevention and management issues associated with these viruses.

(Pitts, M.K. and Clarke. T. (2002) Human Papilloma virus infections and risk of cervical cancer: What do women Know? Health Education Research: Theory and Practice, 17 (6) 706-714 **condensed.**

GAIN MEMBERSHIPS DUE

A number of valued members are overdue with their annual subscriptions. Please complete and return the enclosed form to renew your subscription and help us continue this valuable service into the future.

GAIN thanks you for your continued support.



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