

GYNAEMIGHT!

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

editorial

Hello to all and a very Happy New Year!!

At the end of my previous editorial, I stated that "with knowledge we are empowered" but it occurs to me that knowledge is not the only thing that empowers us. Support also empowers us, both in receiving, and giving it.

GAIN encapsulates this idea in the same way that all the many thousands of support groups out there do. Just as getting medical treatment or advice is a sign of strength rather than weakness, so is joining a support group.

Many people join such groups at a time of feeling overwhelmed by despair, grief, weakness, if you like. Only to find that within a remarkably short space of time, they have gained so much strength from the support of others, that they are able to then give support rather than receive it.

Of course, just as "no man is an island" no support group is either. The world is a series of giant networks, physically, emotionally and spiritually. Support groups also operate in networks, intentionally or not.

Chair's Report - February 2004

Happy New Year to all of our members – here's hoping it is a happy, healthy and prosperous year for you.

The Committee has considered starting a regular support group and we would be very interested in hearing your thoughts on this. There is also a busy calendar of events, listed later in this issue.

In addition, GAIN will continue to be represented on, and form alliances with, state and national women's and medical associations and hopes to be putting forth a recommendation to the Australian Society of Gynaecologists, at their AGM in April.

Enjoy reading your newsletter and my thanks again to members Vicki O'Dwyer and Donna Cameron for putting it all together. Extra special thanks also to our outgoing 'web mistress' Donna Milburn for her many years of effort, and a warm welcome to our new 'web master' Dean Usher.

Natalie Jenkins

In the same way that web pages on the Internet list "links" to similar or related information, members of support groups such as GAIN, offer informal "links" to their fellow members. These result in each member sooner or later developing wider and wider networks. These networks may be social, medical, psychological - to name a few characteristics

And just as humans are not static, neither are support groups, or the networks of which they are a part.

GAIN is a relatively new support group. It will evolve, possibly in ways that none of us can currently foresee. This is not something to be concerned about, but to embrace.

Most of us who have been drawn to GAIN have had to deal with the fear that comes from feeling, through lack of information, that our lives are out of control.

Support groups such as GAIN can increase our knowledge and also remove our sense of isolation. While we can never have total control over our lives, being part of a supportive network can do a great deal to ease our fears and expand our horizons.

Vicki



GAIN Christmas Party, Tarts Cafe.

www.gynsupport.com

inside
ISSUE 7 - FEB 2004

Member's Story - Donna Milburn

HPV Medical Issues
Hit the Press in the USA

Cancer Claims
Hong Kong's Madonna

Meet GAIN Secretary Lyn Oliver

CALENDAR OF
events

27th February - 11.30 am
Momentum Women's Forum
Luncheon at the Sheraton Hotel
Kath and Natalie to be guest speakers
alongside Dr Fiona Wood. \$80 per head.
RSVP to Barbara on 0417 824 619 or
email momentumwf@westnet.com.au.
Door prizes and fashion parade included.

24th March - 8pm
Theatre Night Fundraiser "Bench"
at the Rechabites Hall, Northbridge
\$30 per head (see separate news item
for more details).

20th May - 10.30 am
"Hands that Help" at St Lawrence's
Church Dalkeith. GAIN guest speaker.

11th - 13th June - 9.30am to 5pm
Everywoman Expo, Burswood Dome

10th September - National
Gynaecological Day. Venue TBA.

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

2004 MEETING DATES:

18th February, 31st March,
12th May, 23rd June.

"With Knowledge We Are Empowered"

Member's Story from Donna Milburn

Most women know how many children they have been mother to. I am not so fortunate. The line between being a mother and not being a mother is a little clouded for me. I was a mother, then I wasn't, then I was again. Here's my story:

In 1982 my first children, identical twins, were born prematurely in their 25th week due to TTS¹. I went into early labour after the onset of acute polyhydramnios². Michael passed away immediately after the birth and Steven joined him a few hours later.

Afterwards, a social worker at King Edward Hospital told me about SANDS³ and I attended several meetings before feeling up to trying for a baby again. In 1984 I lost my daughter's fraternal twin at 3 months gestation. To my delight, my daughter Emily was born perfectly healthy and will be 20 this year.

In 1985 I lost another set of twins at 3 months gestation. I have no idea why - the babies just stopped growing and died in utero. A D&C (dilatation and curettage of the uterus) was required.

In 1986 I miscarried at 6 weeks. In 1987 my son Sam was born healthy after a completely uneventful pregnancy. His birth however, was by Caesarean section. He will be 17 in February.

In 1992 Sophie and Joe, fraternal twins, were also born prematurely in their 25th week. Ironically, this time I suffered oligohydramnios⁴ for the length of the pregnancy which had first threatened to abort at 9 weeks. I repeatedly lost amniotic fluid after the membranes ruptured several times. The birth was long, difficult and hazardous and both children passed away within 5 hours of being born. I attended more SANDS meetings and decided that I was more in a position to help than to be helped.

In 1993 I was contacted by some other members of SANDS who were looking to set up a support group for women who planned pregnancies subsequent to a loss. The support needs of parents braving a post-loss pregnancy were different to the support needed by the newly bereaved, so together we founded PALS⁵.

PALS has since been merged with SANDS, which itself has merged with SIDS⁶ in WA and the issue of support for parents braving more pregnancies has been addressed satisfactorily. Little steps, one at a time, are the paths to recovery!

During the time we were launching PALS, I was pregnant with my last

child, Wes. I had lost his twin somewhere between 6 and 9 weeks and I was later diagnosed with a Grade 4 Placenta Praevia⁷. After my third haemorrhage whilst being bed rested at home I was admitted to King Edward Maternity Hospital at 20 weeks gestation in a desperate attempt to get the pregnancy past 28 weeks.

I was eventually transferred to Attadale Hospital (closer to home) at 34 weeks, expecting to have a planned Caesarean delivery but had to have an emergency Caesarean section at 35 weeks when the placenta ruptured for the final time. I imagine Dr Molloy still remembers the Golf Tournament he was pulled from that Sunday ... I do hope he wasn't telling the truth about leading the field. Wes was gorgeous and healthy and has just turned 10 years old.

More pregnancies would have been dangerous and with recurring polyyps, I had a hysterectomy in 1996⁸. Of course this is a very clinical description of the biggest emotional roller coaster I have ever been on. The reality for me of those years just can't be put into words.

I'm one of the lucky ones and I owe a lot to all the family, friends, doctors, nurses and aides, radiologists, haematologists, pathologists and support people who helped me to achieve the family I now have and one day I may become a grandmother with no pain at all. Thank You. My involvement with PALS and now GAIN was born of a need to give something back.

Donna Milburn, GAIN Website Design and Management.



FOOTNOTES:

1. What is TTS? Twin-to-Twin Transfusion Syndrome, or TTS, is a condition that may occur in identical twins or higher multiple pregnancies. The disease results when blood passes disproportionately between one baby and another through connecting blood vessels in their shared placenta. The babies are normal. The abnormalities are in the placenta. Ref: <http://www.twinhope.com/facts.html>
2. What is Polyhydramnios? Polyhydramnios (many waters) is excessive amniotic fluid. At the end of a normal gestation period the amount should measure approximately 600ml. Due to the TTS I was carrying approximately 7500ml of amniotic fluid. The space this took allowed no room for further growth of the babies and premature labour was forced. Ref: http://www.marchofdimes.com/aboutus/681_4536.asp
3. What is SANDS? Stillbirth and Neonatal Death Support - a group which offers support to newly bereaved parents. They offer support for both antenatal (before the birth) and postnatal (after the birth) losses. I found this service of great value in my grieving process. It was also comforting to know that I wasn't as alone as I had imagined. I believe that SANDS WA has now become part of SIDS (Sudden Infant Death Syndrome) WA. Ref: <http://www.sandswa.org.au>
4. What is Oligohydramnios? Oligohydramnios is a lack of amniotic fluid. Ref: http://www.marchofdimes.com/aboutus/681_4536.asp
5. What is PALS? Pregnancy After Loss-Support - a group which offered support to bereaved parents planning or enduring a subsequent pregnancy. Support offered was particularly useful to parents prone to have children with often-fatal genetic conditions, but also for other conditions causing repeated losses. PALS are now part of the SANDS group, which is part of the SIDS group in Western Australia.
6. What is SIDS? Sudden Infant Death Syndrome - a group which offers support to parents who have lost a child up to the age of 2.
7. What is Placenta Praevia? This term is applied to a placenta that is placed over the exit - the cervix. A grade 4 praevia completely covers the cervix and prevents a normal birth. Caesarean section is the only remedy for a live birth with this degree of obstruction. Lower grades of praevia denote less obstruction of the cervix. Ref: <http://www.babycentre.co.uk/refcap/830.html>
8. What is a Hysterectomy? Hysterectomy is surgical removal of the uterus. No more periods and tampon purchases - but a radical way to lose half a kilo. Ref: <http://www.health.state.ny.us/nysdoh/consumer/women/hyster.htm>

A NIGHT AT THE THEATRE
(and GAIN Fundraiser)

bench
written by Helle Turner
directed by Alan Decher
with Laura Black, Jenny Davis
and Rosemary Barr
(From the hit production -
The Vagina Monologues)

A chance meeting on a park bench results in an old sow, a lame rooster and a crazy ballerina battling for territory as they struggle to hold on to their various versions of reality.

A poignant and poetic comedy, Bench illuminates our notions of time, memory and friendship.

"Winner of the Best Script Award - 2003 WA Premier's Award"

Wednesday 24 March at 8pm
Rechabites Hall, Northbridge

Tickets \$30ea - (\$10 from each ticket goes to GAIN)

Bring along your friends, family and partners for a great night out, and help raise money for GAIN!

ptc
PERTH THEATRE COMPANY

Book with Chris at PTC on 9323 3433
Bookings close Wed 17 March
Payment must accompany booking

CANCER CLAIMS HONG KONG'S MADONNA

Canto-pop diva and actress Anita Mui, whose voice captivated the Chinese-speaking world, died early yesterday after a battle with cervical cancer. She was 40. Mui, known to Chinese across the globe as the Asian Madonna, died at Hong Kong's Sanatorium and Hospital after suffering lung complications caused by cervical cancer, according to fellow stars.

Actor Jackie Chan eulogized the veteran entertainer, who many referred to affectionately as Sister Mui. "She didn't belong to the entertainment industry. She belonged to all Hong Kong people," Chan said. Mui appeared with Chan in Rumble in the Bronx. She launched her career by winning a local singing contest in 1982. Her unusually deep voice caught further notice with a soulful delivery of acclaimed song Homecoming.

Mui's frequent makeovers drew comparisons to Madonna. In 1987, she held a then record breaking 28 concerts in Hong Kong, titled Ever-changing Anita. She proved equally impressive on screen, winning Taiwan's Golden

Horse award for best actress in 1987 for her role as a tormented ghost in the movie, Rogue.

In September, Mui confirmed media reports that she had cervical cancer, but vowed to beat the disease. "I am not a weak person... I can tell you that I have never had any fears and I will win this fight," she said. Although physically frail, Mui completed another concert series in November after her cancer announcement.

Canto-pop refers to hits sung in Cantonese, a Chinese dialect that is widely spoken in Hong Kong and in many overseas Chinese communities. Mui, who was not married, also actively took part in charity work. She established the Anita Mui Charity Foundation in the early 1990s. Her elder sister, Mui Oi Fong, died in 2000, also from cancer.

(from "The West Australian" 31 December 2003, Associated Press)

For the Bookworms - Some Suggested Reading

"The Hysterectomy Hoax" by Dr Stanley West.

This book details why 99% of hysterectomies are unnecessary, in the author's opinion, and what the alternatives are. Medical guidance that educates and empowers women faced with difficult choices at times of great stress.

"Desert Flower" by Waris Dirie.

The true story of one woman's incredible flight from her country in the wake of female genital mutilation as a child, to becoming an international model in Europe.

"The Hospital by the River" by Dr Catherine Hamlin.

The story of an extraordinary couple and their work with women in Ethiopia suffering from birth injury, in particular the condition fistula.

"Sex for One" by Betty Dodson.

A book on learning to be comfortable with your own body.

"Anatomy of the Spirit" by Caroline Myss.

One for the spiritually inclined. Explores the relationship between spiritual maturity and physical wholeness.

TART'S PARTY REPORT FROM NATALIE JENKINS

The inaugural Christmas gathering was a great success and all those who attended enjoyed the occasion. Everyone commented on how nice it was to have a purely social event and it was also great to meet the very supportive partners and friends of our members. My thanks to Helen Pearson who organised this event and chose such a lovely venue.



The GAIN Committee intends to write to the Australian Society of Gynaecological Oncology seeking a working partnership between the ASGO and the gynaecological health consumers of Australia.

GAIN is grateful for the moral support of Dr Gabrielle Caspar, Dr Joanne Samer, and Prof Michael Quinn We hope to build strong avenues of communication with many more members of the medical profession over time.

Your Suggestions/Contributions are Most Welcome!!

If you have any suggestions for future Newsletter items, or a "member story" that you would like to share, don't be shy! Contact Newsletter Editor Vicki O'Dwyer by email at: davicjon@eon.net.au. Alternatively write to her at 1/53 Malcolm Street, West Perth 6005.

While no promises can be made as to exactly when your suggestion or contribution will appear, they are certainly appreciated and will be treated with respect.

Meet GAIN Secretary - Lyn Oliver



Hi my name is Lyn Oliver. I am 45, married and have a seven-year-old son and I work part-time at Woodside Energy.

I have known Kath Mazzella for about ten years and met her through a mutual friend. I felt very sorry for Kath when she went through her diagnosis and surgery but did not get to know her very well until after these events. I wanted to help Kath with her ideas right from the beginning. My goal was to give Kath some

administrative assistance with her goals – even when they were not as well defined as they are today through GAIN.

I felt that there was a need for women to be able to have a consumer-based group who could do something to help other women. I have helped GAIN with a variety of tasks including organise seminars, social and fundraising

events, chair meetings and take minutes (my current role is Secretary). I have particularly enjoyed meeting so many interesting and knowledgeable people through my association with GAIN. My stand out favourite is Catherine Hamlin whose work in Ethiopia I admire so much.

The areas of women's health that particularly interest me are mental health, childbirth injury and continence issues. Childbirth injury is of particular interest as I experienced a severe injury when my son was born. Thankfully I have fully recovered but for a couple of years it was quite a journey.

One of the main sources of solace and distraction, apart from having such a beautiful baby, was to fully 'reinvent' my front garden and subsequently win a local garden award. It was a total metaphor for my recovery and gave me a lot of fun and satisfaction. It also gave me the opportunity to meet a lot of local people in the community. It has been great to be a part of GAIN's journey and I really enjoy the milestones and first's that GAIN has achieved.

HPV MEDICAL ISSUES HIT THE PRESS IN THE USA

On December 23 2003 Cheryl Wetzstein reported in *The Washington Times*:

" A House Republican Leader has charged two federal agencies with failing to provide aggressive public education about a sexually transmitted disease linked to cervical cancer.

Officials with the Centers of Disease Control and Prevention and the Food and Drug Administration have asked to appear at a January 28 hearing to discuss issues pertaining to the human papillomavirus (HPV), said aides within the House Government Reform subcommittee on criminal justice, drug policy and human resources.

'We are deeply concerned whenever a federal agency fails to abide by the law, but especially so when the public's health is threatened.' Said Rep. Mark Souder, Indiana Republican and subcommittee chairman.

Under a law signed by President Clinton in 2000, the CDC was to issue a report by this past Sunday on the best strategies to prevent the spread of HPV, a virus linked to cervical cancer. HPV is often called genital warts.

Separately, the FDA was to re-examine condom labels to ensure that they are 'medically accurate' concerning their ability to block transmission of diseases, including HPV.

Neither agency has complied with these legal mandates, Mr Souder said. CDC spokeswoman Kathy Harben said yesterday that the agency was completing its HPV report and would issue it in January. The CDC has posted HPV information on its Web site and given HPV presentations to health care workers, she said.

'The FDA has also undertaken enormous review of the literature related

to prevention of (sexually transmitted diseases), and are evaluating the labelling issue' said an FDA spokeswoman.

HPV is a concern because of its large infection rates – an estimated 20 million people in the United States have HPV and a further 5.5 million become infected each year - and it is linked to cervical cancer. HPV is believed to be the primary cause of the cancer, which is diagnosed in 12,000 women a year and takes the lives of 4,100 women per year.

Moreover, HPV is a complicated disease. It is incurable, but only a few of the may HPV strains are cancer related. This means that HPV infections are often benign. On the other hand, most women are unaware of their HPV infection or its links to cancer until they receive an abnormal Pap test

The Eagle Forum and other groups have urged Health and Human Services Secretary Tommy G Thompson to highlight HPV education, including the fact that condoms do not provide effective protection against infection. Tamara Kreinen, president of the Sexuality Information and Education Council of the United States, called yesterday for more education about all sexually transmitted diseases.

I don't think we, in any way, want to do anything that will frighten people from using condoms or going to the doctor and getting tested,' said Miss Kreinen. 'The bottom line message always needs to be that most STD's are treatable, and it's important to get tested... early'"

A very high proportion of women with cervical cancer have had HPV at some stage, research seems to suggest. In the light of this there is room to wonder if the high profile woman mentioned in the report on the previous page was as well informed as she might have been...

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.



GAIN website by **Dean Usher Web Design**
www.deanusher.com (previously by Page Me Web Design)



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



GAIN artwork by **Donna Cameron Design**
Telephone: 08 9337 6494

PROUD SPONSORS OF GAIN INC.