

GO FUND

News on the GO

JUNE 2006

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Nicole Kidman A.C.



• Research • Treatment • Awareness • Prevention of Gynaecological Cancer

*Supporting a collaboration between the Royal Hospital for Women
and the Garvan Institute for Medical Research*

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Senate inquiry into ovarian cancer

Senator Jeannie Ferris knew nothing about ovarian cancer until she was diagnosed with it in October 2005. Now she is organising a Senate enquiry into funding to fight the disease.

Tiredness is something everybody faces at some time in their life. But Jeannie Ferris sensed that the tiredness she felt late last year was abnormal. At first she thought that the trips to Russia and Italy as part of a Government delegation were the reason. There had been a lot of travel and some lengthy flights and it seemed logical that the trips had taken their toll.

When the tiredness did not abate, Jeannie went to the doctor, who thought it was glandular fever. When the blood tests showed it was not, the

next thought was that it was chronic fatigue syndrome. So Jeannie took herself to Canberra Hospital where they ran a series of tests. They told her there was nothing wrong with her.

At this point, Jeannie insisted on a CAT Scan. The resident medical officer told her "We don't think you should have one. They're very expensive," to which Jeannie replied "I'm valuable!" She refused to leave until she had one. The scan showed she had an ovarian tumour which was putting pressure on her left kidney.

"It was all a surprise," said Jeannie, "It was like being hit by a speeding train."

Jeannie found it difficult to believe because she had always been so healthy. She was sent to the Royal Hospital for Women in Sydney on the Monday and was in the operating

theatre on the Tuesday. What amazed her was that until the doctors operate, they don't really know what they will find. This is due to the fact that there is no specific test for ovarian cancer.

When Jeannie heard that the GO Fund was looking for a blood test to diagnose the disease, she

decided to help. She is involved in drafting some terms of reference for a Senate inquiry into funding for gynaecological cancer. A key issue will be the level of funding for ovarian cancer research and education.

"I think this is one of the less understood cancers. It kills a lot of people because of the insidious nature of it. We're optimistic we'll get that inquiry underway in the next three months. The witnesses will enable us to get a really powerful point of reference into ovarian cancer in Australia, which we can then use to determine what needs to be done."

Although Jeannie had been actively involved in furthering the breast cancer cause, including attending a big breast cancer forum two weeks before her diagnosis, she knew nothing about ovarian cancer. In her 10 days at the Royal she experienced fantastic treatment from a very caring network of staff. It could have been an alien time for her being away from family and friends, but she found it to be the reverse.

Recently Jeannie was interviewed by an Adelaide newspaper. The story which appeared on the front page carried her message "Pursue your diagnosis." Later she received a call from a woman who had read her story and could relate personally to Jeannie's symptoms. The woman went back to her doctor and insisted on a CAT Scan and was diagnosed with ovarian cancer. She told Jeannie "Thank you for saving my life."



Senator Jeannie Ferris (left), with Leo Sayer and six year ovarian cancer survivor, Lisle Fortescue, at the GO Fund's Cocktails on the GO on March 15

Leo Sayer and the Showgirls wowed the guests at Cocktails on the GO

The guests arrived for the GO Fund's annual cocktail party hoping to support ovarian cancer research. When they left at the end of the evening, they had done exactly that, raising over \$410,000.

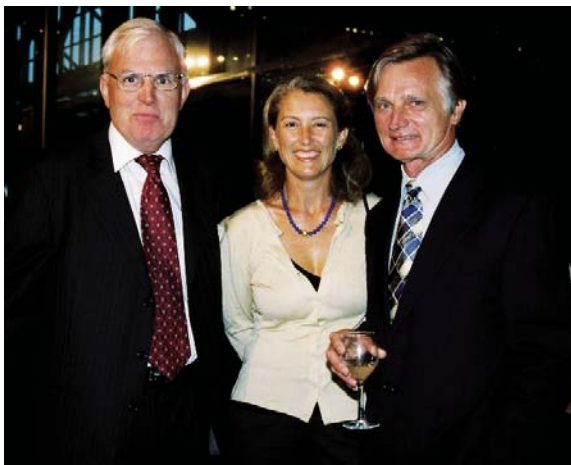
Professor Hacker, who spoke about the research being conducted to find a blood test for the disease, was amazed at the brilliant result. "It was



Professor Hacker

far beyond my expectations. I am so pleased because it means that our research can continue to look for a diagnostic test which will save lives."

As the guests mingled in the foyer at Doltone House, Michael Hope, an accomplished pianist and composer, played numbers from Gershwin and Cole Porter, along with special requests.



Professor Rob Sutherland, Kim McMullen and Jeff McMullen

The special guest speaker for the evening, Kathleen Thornton, a lawyer with Baker & McKenzie, was unable to attend, as ovarian cancer had progressed to the stage where she was totally bedridden in the Royal Hospital for Women. Professor Hacker read out a message from Kathleen to the guests, while slides showed Kathleen's marriage a couple of weeks beforehand to her fiancée, Philip de Semlyen.

The Showgirls, Rachel Beck, Danielle Barnes and Mandy Carnie, burst onto the stage in dazzling red outfits and entertained the guests with numbers such as Hey Big Spender, to encourage them to bid on auction items.

The MC for the evening, acting Woollahra Council Mayor, Marcus Ehrlich, launched the Karen Campaign, named in honour of his mother, Karen Ehrlich. There were some major law firms represented in the room who will become fundraisers for the Karen Campaign in 2006 as part of the campaign amongst the legal profession in NSW.

The hit of the night was Leo Sayer singing his numbers from the 70s. He danced with, cuddled, and kissed women in the audience, while he belted out his chart winners. People waved their arms in tune to the music. The whole place was swinging. And, as



The Showgirls - Danielle Barnes, Mandy Carnie and Rachael Beck

with the Showgirls and Michael Hope, he donated his performance to the GO Fund, which helped us to raise the amount we did.

The auction, run by master auctioneer, John Stevens, led to some fierce bidding from the guests. The John Olsen painting went for \$110,000 (a great investment for the bidder). Other prizes which received high bids were dinner with the Hon



Miss NSW, Sabrina Houssami, with the Chairman of Miss World Australia, Pauline McFetridge



Retiring Chairman, Steve Eckowitz, with one of the sponsors, Peter Ivany



Raewyn and Bart Doff



Leo Sayer

Malcolm Turnbull at Astral (Star City), lunch for 8 with Bob and Blanche Hawke at Glass Brasserie (Sydney Hilton) and a morning in the studio with Alan Jones at 2GB.

Retiring Chairman, Steve Eckowitz, spoke passionately about the need to continue with the GO Fund's ovarian cancer research program. Steve will continue to work with the GO Fund Committee to raise funds for the project.

The food and venue was great (a big thank you to Doltone House for their support too), and we are also indebted to Brian McGuigan from McGuigans Wines who donated the wine for the evening.

The volunteers who worked in the background

did a wonderful job of helping fundraiser, Jenny Mansell-Black, make sure the evening was a success. We also thank those who donated prizes for the evening, for without them it would not have been the success it was.

We are now looking forward to the awards dinner for the Karen Campaign - Food on the GO - which will be held in October.

Farewell



Jenny Mansell-Black

After 3 1/2 years of dedicated commitment to the GO Fund, Mrs Jenny Mansell-Black is leaving to pursue a career as a Consultant. Since joining as the Fundraising Manager, Jenny has raised over \$1.3 million for our research program.

Jenny's position will be taken by Ms Carmen Duncan. Jenny will continue as a Consultant for the Fund. We thank her for her great contribution and wish her every success in her future endeavours.

Mr Steven Eckowitz has retired as Chairman of the GO Fund, although he will remain a member of the Committee. Steve has been our major benefactor for many years, and we thank him sincerely for his outstanding support. His role as Chairman will be taken by Mr Aleco Vrisakis, who has been on the Committee for the past two years.



Sharon and Warren Cloud

Kathleen's memory lives on



Philip and Kathleen in happier times

Many people have been saddened by the death of Kathleen (Thornton) de Semlyen after her battle with ovarian cancer. Her friends and family recall some of the wonderful things about Kathleen and how she made the most of her short life.



Kathleen and Philip married on March 4

It was little more than a year between Kathleen's diagnosis and ovarian cancer claiming her at 32.

Her colleagues, friends and family are still coming to terms with it all. Originally from New Zealand, Kathleen was a Senior Associate with

Baker & McKenzie law firm when she was diagnosed. We printed her story in our December 2005 newsletter when she was determined to ignore the prognosis and carry on with life.

Kathleen lived her life to the full. She left out nothing in her pursuit of the things she thought important in life which included her family and friends, her career in law, and her interest in music and travel.

The most impressive thing about Kathleen was her inner strength, manifested in her independence and self-sufficiency. Two weeks after being diagnosed, she ran the City to Surf half marathon, beating her previous personal best by nine minutes. She then began a course of chemotherapy, never once complaining. Kathleen confronted ovarian cancer as simply one more challenge.

She was incredibly giving and generous of her time to her family and friends. Her friends describe her as honest, intelligent and insightful, with an innate ability to bring out the best in those around her.

Her strength was bolstered by the

support from her then boyfriend, now husband, Philip de Semlyen whom she met in London in 2003. Instead of becoming insular, her house was a hive of activity as Kath encouraged and revelled in having people around, giving them the courage to be with her on her final journey. Her friend, Ruth, says "sometimes it felt like she was caring for us rather than us for her."

On 4th March, Kathleen and Philip married. Surrounded by those she loved, Kathleen looked beautiful and stylish.

Baker & McKenzie are donating a sporting trophy in Kathleen's name to be awarded within the firm at the annual City to Surf run. They are also fundraising for the GO Fund as part of this year's Karen Campaign, with Kathleen very much in mind.

Sparke Helmore staff volunteer

As part of their Community Support Program known as SHARE, Sparke Helmore assisted the GO Fund again this year by providing staff resources to send out mail for the Karen Campaign to the NSW legal profession.

Margie O'Brien, who organises the mailout at Sparke Helmore's Newcastle office, was inundated with 8,000 GO Fund brochures, envelopes and labels. She set up two



Margie and Leo

workstations and motivated the staff to get the job done in record time.

When the Karen Campaign was launched on March 15, Margie was there with Sparke Helmore's Pro Bono & Community Programs Director, Michael Rosenfeld. As Leo Sayer was singing one of his 70's hits, he approached Margie and sang right next to her. Michael was able to capture the moment in true paparazzi style.

Thank you to the staff at Sparke Helmore for their valued help with such a large project.



Sparke Helmore staff getting into the swing of the mailout



Lisa Banfield with her twin sons, Joshua and Lucas, as they wait to go onto Channel 7's "Where are they now" which aired on Mother's Day. Lisa's amazing story of overcoming cervical cancer and finally being able to have twin boys by a surrogate mother in America has been written up in our June 2003 and January 2005 newsletters. You can read the story and the newsletters on our web site: www.gofund.org.au.

Knowing your family history can help

A discovery that Dawn Donnellan has the BRCA2 gene has helped her understand her battle with both ovarian and breast cancer.

In 1998, Dawn, and her husband Kevin, were packing up to go on a caravan trip. "We have travelled to many places in Australia, but we always wanted to do a trip up through the centre of the country," said Dawn.

Before they left, she decided to have a Pap smear and thorough check-up. Her gynaecologist did a biopsy which was clear, but Dawn was told she had a prolapsed womb which was understandable, considering she had had four children.

So Dawn and Kevin set off down the coast from Ulladulla in their caravan looking forward to their trip. But Dawn's feet had started to swell, she was constantly heading to the toilet and her tummy was swollen, so they decided to go home.

Dawn's GP suggested an ultrasound of the legs, but nothing showed up. He also sent her for a chest X-ray and blood test, also with negative results. That weekend, Dawn felt around her tummy and discovered a lump just above the hair line. Her GP confirmed that there was indeed a huge cyst and he sent her off for a CAT scan which showed a large tumor the size of a grapefruit on one ovary.

Dawn's gynaecologist was surprised. "I gave you a thorough internal three months ago and it was all clear," he said. The tumor had grown aggressively in that time and her gynaecologist was up front. "Dawn, this is cancer. It will be a major operation. Your life is on the line.

Will you give it a go?"

"We were all devastated," added Dawn, "but I kept a positive attitude." Dawn's surgeon was concerned that the tumor may be attached to other areas and as a precaution, she was referred to Professor Hacker. "The Professor and his team are incredible. They really looked after me."

Dawn had radical surgery and the tumor was removed, followed by chemotherapy treatments closer to home in Wollongong. Some of her lymph nodes enlarged eight months later, so she had another operation, which was followed by radiotherapy.

Three years later Dawn and Kevin did do their big trip to Alice Springs, Uluru, Kings Canyon and the McDonnell Ranges.

Then in 2003 they decided to sell their home as the children had moved out, and Dawn went for a mammogram and blood test. The mammogram showed a lump in the left breast and a needle biopsy meant that Dawn was back in hospital with breast cancer. Following the lumpectomy, Dawn's brother died and she felt that her world was crumbling. But her husband brought her back to life with his humorous comment: "You can't die yet; I'd starve to death!"

It has been her family support that has kept Dawn going over the years.



Dawn had a lovely day whale watching at Hervey Bay in Queensland

When her mother commented that Dawn's grandmother had died of ovarian cancer, a genetic test was ordered and it was then that they discovered the BRCA2 gene.

"I've explained it to my cousins and now we know that three of them have the gene," said Dawn. "At least the family is now aware and can carefully monitor their health." Having either of the cancers detected early will give them all a better chance of survival.



Dawn (right) enjoys a luncheon with her girlfriends



Enjoying the scenery at Kalbari, WA, with her husband, Kevin

Barbara's persistence pays off

For about 18 months, Barbara Farrant had not been feeling well. But although she was reassured by several doctors that nothing was wrong, and at times was told she was just being a hypochondriac, she felt that what she was experiencing was not normal. She changed doctors several times looking for another opinion, but nobody could tell her what the problem was.

Then in 1995 she was referred to Professor Neville Hacker and Dr Greg Robertson, when the Royal was situated at Paddington. Barbara was sent for tests and was told she needed surgery. The doctors told her she had a very rare cancer and they did not know if it had spread from the source - the fallopian tube.

Barbara feels she was the luckiest person alive. The doctors managed to get it all despite the fact that the cancer had spread a little. The operation in June of that year coincided with her daughter, Rebecca, being chosen to play for Australia at the World Series Softball Championships in Illinois, USA. So Barbara's husband, "Smokey", took one of their sons to watch Rebecca play.

The Farrants lived at Shelly Beach, which meant that her son, Mark, had

to travel hundreds of kilometres every day from work to see Barbara.

"It was an incredible time," recalls Barbara. "One minute I was working from home in the family business which employs 25 people, and the next minute I'm told I have a rare cancer and the prognosis is not good. I was devastated.

"The bottom line is that you have to be responsible for your own health. I knew something was wrong. At 49, I could not understand why I would become incontinent.

"The treatment is the same as if you have ovarian cancer - chemotherapy. I was told that the odds may not be that good - a 50-50 chance. You've got to take every day and live your life. Each day is special!

"I was very tired for a long time. After a year I joined the golf club and I continue to play. I guess I was looking for hope and decided I just had to make the most of every single day.



Barbara nurses the latest addition to the family, Olivia, with cousins Ben and Sarah watching

"It has been 11 years and I thank God for everyone there at the Royal. Mary [Ryan] was my rock and the doctors were delightful. Dr Robertson gave me so many words of wisdom to keep me going. I was lucky that I did not get lymphoedema.

"The members of my family stood by me and encouraged me too. Family support is what you need. At the time, none of the kids were married, so now that Mark, Scott and Rebecca are married, it's nice to see the grand kids growing up."

Barbara's final words? "I wouldn't be around if I had not been persistent!"

A daily focus on survival

In 2002, Daphne Sauvage was at the height of her career and thoroughly enjoying her work. At 38 she was one of the top 10 real estate agents for Ray White and was having her best year in business. Suddenly, without warning, she was diagnosed with ovarian cancer.

Daphne felt she was too busy to be sick. There was no cancer in her family, she had always worked out and watched what she ate. She didn't smoke. In her own words she was a "health freak".

"I was feeling terribly tired and went

through periods of bloating and stomach cramps, but I put it down to too much hard work," she recounted. Her GP told her she was low in iron and needed more sleep. When the cramps became too much and she ended up in hospital, blood tests and examinations failed to pick anything up.

Eventually Daphne went to St Vincents Hospital, had a CAT scan, fluid taken, an ultrasound and further tests. They told her it was cancer, maybe stomach or bowel, but that she was too young to have ovarian cancer.

She was referred to a medical



Daphne Sauvage

oncologist, Professor Robyn Ward, who diagnosed Stage III ovarian cancer. The following day the chemotherapy treatments were started to reduce the bloating, and in preparation for an operation. It was too late to save Daphne's ovaries for pregnancy.

"I was in shock," she recalls. "I didn't want to know any details or hear the statistics." Daphne knew the mortality rates were high, but she just wanted to focus on day to day survival.

In October of that year, Daphne was operated on by Professor Marsden at the Royal Hospital for Women. Following the operation she was transferred to acute care and underwent a blood transfusion. "I

was so tired; it was like wearing lead boots." Daphne left hospital 14 kg lighter.

While in hospital, Daphne made friends with a woman across the room from her. As time and treatments moved on, her friend's cancer returned. Daphne also had another friend who had breast cancer with an 80% chance of survival, but that friend also died. But Daphne refused to allow the cancer to become part of her. In her own mind "it was going".

What Daphne had not allowed for, was the feeling of fragility and the fear of the cancer returning. She returned to work too quickly, and despite the wonderful support she

received from Ray White, she could not cope. So she took a trip overseas. "I had to adjust mentally and not let fear take over. Now it's interesting to look back on my anger at getting cancer and the challenges I overcame to survive."

Three and a half years on, Daphne's tumor markers are normal. Now she says she takes nothing for granted. "Life is so precious. I met the most beautiful people in my life during that time." One of her friends gave her the Lance Armstrong book and she felt that if he could do it, she could too.

Her message to others: "Ignore the statistics and be positive."

When in doubt, check it out!

Judith Alderman recalls how her symptoms could have been ovarian cancer



Judith Alderman

For about six months, I'd been going to Weight Watchers. My weight fluctuated and then suddenly something happened that made

me not care about my weight any more: My son, Derek died. He was 22 and it was leukaemia. He fell ill in the March and was gone a month later.

I felt like giving up on everything and over the next three or four months, although my stomach continued to balloon and seemed to get bigger by the week, I was so consumed with grief, I paid no attention. Even when I looked as if I was ten months pregnant and could barely walk, I didn't do anything about it until one day my younger son, Mark came to me and burst into tears.

"Please Mum, Dad and I are worried about you," he said. "We've already lost one family member. Please don't let us lose another one."

Mark is a kid in a million. I knew he was as upset about his brother as I was and had even refused to have a 21st birthday party because the

person he most wanted to be there was absent. He was so devastated I felt really guilty and I went to see my GP immediately. "You could have a bit of wind," he said but, as a nurse, I knew it was more than that and told him I'd had bowel problems as well and suffered nausea and reflux. Also my stomach had turned a bluey colour.

"It's time to face reality," I said and to be honest, I was terrified I had ovarian cancer. I wasn't in pain and knew that ovarian cancer was known as "the silent killer".

"I want to follow through with this," I insisted, so my GP organised an abdominal x-ray followed by a pelvic ultrasound which showed a large white-out area on my right side. I then had a CT scan which suggested it might be a benign ovarian cyst.

I went to see a gynaecologist, Dr David Eisenberg. He was amazed at the size of my tummy. "It has to be a cyst and it has to be benign because of the size of it," he said and finally, I was referred to Professor Neville Hacker at the Royal Women's Hospital at Randwick.

He was just fantastic and also agreed the cyst must be benign - I'd be lucky to still be alive otherwise - but said it had to be removed and so I was booked in for surgery in September 2004. "I'll assist," Dr Eisenberg said. "I want to see what comes out!"

What did come out amazed everyone:

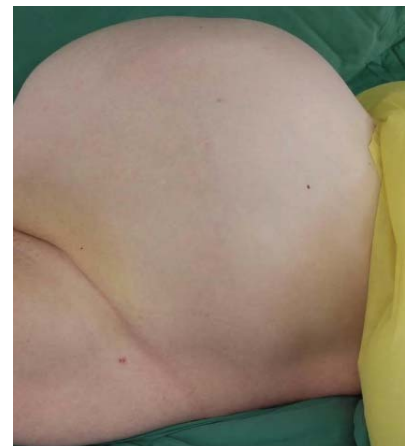
It was a cyst weighing 27 kgs and containing 15 litres of mucky brown fluid.

I went in weighing 101 kg and the day after surgery, I weighed 82 kg. I felt like skipping out of that hospital, I felt so light and happy.

I was also very, very relieved. I am not a religious person but I believe Derek was looking after me and said: "It's not time for Mum to join me yet. Dad and Mark need her."

For the next few weeks, I was the talk of Weight Watchers. No-one could believe I'd lost so much weight overnight.

But I'd advise anyone with a bloated stomach to get an ultrasound to check it out. It could save your life.



Judith's stomach before the operation

Iran follows Australian example

The inaugural meeting of the Iranian Society of Gynaecological Oncology was held in Tehran recently, and Professor Neville Hacker was their keynote speaker. The very successful meeting attracted 300 registrants from all over Iran, and was held at the Imam Khomeine Hospital, a large general hospital in the centre of Tehran.

While in Tehran, Professor Hacker was invited to conduct a teaching ward round at the Mizra Koochak Khan Hospital, the major Women's Hospital at Tehran University. The Director of Gynaecological Oncology at the hospital is Associate Professor Zahra Eftekhar, who spent 12 months training in the Gynaecological Cancer Centre at the Royal Hospital for Women in 2001.

Asked for his impressions of his visit

to Tehran, Professor Hacker said, "I saw a lot of patients with advanced ovarian cancer, and because there is no screening program, there is also quite a high incidence of cervical cancer in Iran. I did not have a chance to observe any surgery, but they have all the best chemotherapy available. The problems confronting women with gynaecological cancer and those caring for them are the same the world over, and we are very fortunate to have such a great team here at the Royal. By contrast, there is very little palliative care or psychosocial support for the patients in Iran."

Professor Hacker said that the Iranians were very anxious to learn all they could, and requested a more formal collaboration with the Gynaecological Cancer Centre. He has agreed to spend two weeks teaching and operating in Tehran next year.



Nurses and doctors during the ward round at the Mizra Koochak Khan Hospital. Dr Zahra Eftekhar is on Professor Hacker's left.

Thank you to those who have donated in memory of:

- Kathleen Thornton / de Semlyen*
- Gillian MacLachlan*
- Lorna Negrine*
- Joan Patterson*
- Helen Emanuele*
- Margaret Johnson*
- Suzanne Turner*
- Kerrie Denning*



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JUNE 2006

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