

The GO FUND Newsletter

• Research • Treatment • Awareness • Prevention
of Gynaecological Cancer

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

NOVEMBER 2003

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Circle for Life

**'OK boys and girls, mums
and dads, friends and
gems. Time to go.' They
were the final words of Suzie
Striessnig. She was 41.**

Two years on, her husband John Worrell is about to 'go' himself – on an epic journey around NSW to raise awareness of ovarian cancer – the disease which took Suzie.

John, 43, of Manly, NSW, will be kayaking and cycling 4,000 km up the coast and along the rivers and tracks of the state, talking and giving interviews along the way.

The Ovarian Cancer Project, a joint collaboration between the Royal Hospital for Women and the Garvan Medical Research Institute is trying to find a simple blood test which could be used to screen healthy women

for early ovarian cancer. However, the GO Fund needs all the financial help it can get – hence the reason for this trip.

During his journey, which will take around four months and go through some of the most rugged and inhospitable terrain in Australia, John will talk to women about the importance of looking after their health and the early warning signs that may indicate ovarian cancer.

Thanks to Sydney Harbour Kayaks, he will also be raising funds for research. They have donated his canoe and equipment and will be auctioning it off at the end of the trip which has been timed to coincide with Ovarian Cancer Awareness Week in February.

The Sydney Harbour Kayak's team is also training John to prepare him for the ocean conditions.

John decided to do the trip for several reasons. He explained: 'I was Suzie's full-time carer for the last three years of her life, and during that time I learned to take life one step at a time and to never give up, because you never know what might be around the corner.'

The massive physical endeavour is also a tribute to Suzie's spirit. 'She was a keen cyclist because you had to work hard to get where you want to go, but in the process you see so much,' he said.

'She was the only person I have known who actually loved the challenge of cycling up a huge hill. 'Similarly, even

when she was very ill, she learned to go on exploring life. If she couldn't cycle – well then, she'd fish.'

John hopes that by sharing the story of Suzie's spirit, he will encourage others who have had cancer to take hope, but also share their stories of hope and survival.

He admits that it is an arduous trip – one that has never been attempted before – and that it will be a tough call to complete it.

However, he says: 'Another thing I learned from Suzie is that anything is worth trying. And even if we only get as far as Port Stephens a lot more people will know about ovarian cancer and maybe a few more lives saved in the process.'

John will be joined on the trip by former *That's Life!* editor Bev Hadgraft. Their story will be followed by *That's Life!* and also by UK magazine *Take a Break*.

THE ROUTE

The trip will leave on October 29 from Manly. They will kayak up the coast to Tweed Heads; follow the river inland to Murwillumbah, through Walgett and Bourke, along the Darling River to Wilcannia, Kinchega National Park, Wentworth, Mildura, to the Murray River. Then he heads to Albury and Wodonga before cycling over the snowfields of Kosciusko to Eden. He will paddle up through Jervis Bay and finish at Sydney Harbour Kayaks at Spit Bridge.

We look forward to reporting on this epic journey in our next newsletter and wish John and Bev a safe and successful trip.



John Worrell and Bev Hadgraft
planning their trip

Chipping away at Ovarian Cancer

Jenny Mansell reports on the latest findings from the GO Funded research.

On June 12, the GO Fund and the Garvan Institute of Medical Research presented their latest research findings at a cocktail party at the Institute titled, "Chipping Away at Ovarian Cancer".

The team at the Garvan, headed by Dr Philippa O'Brien, and overseen by Professors Rob Sutherland and Neville Hacker, are enthusiastic about their subject and keen to find the answers to the "silent killer" – ovarian cancer.

The biggest problem with diagnosing ovarian cancer – the 5th highest cancer killer in women – is the lack of early warning signs. Therefore, 75% of women present with advanced stage disease. Despite some improvement in 5-year survival rates over the past 20 years, the outlook is still poor, the overall survival being only 40%, about half that of breast cancer.

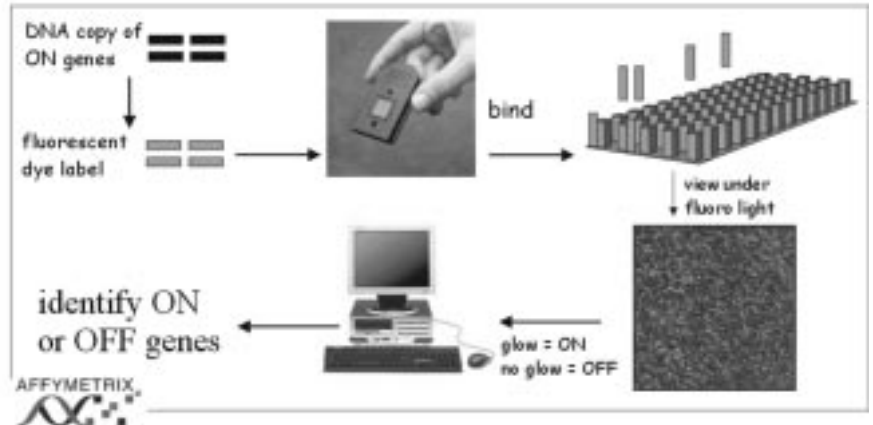
Hence the main goal for the GO Fund is to find a simple blood test that



From left: Professor Rob Sutherland (Garvan Institute), Mick Mathers, Roslyn Bowen-Day, Tony McKerrow



From left: John Banfield, Lisa Banfield, Dr Stefan Ivanov (Gynaecological Cancer Centre)



could identify the disease in the early stages, when the chances of cure are 80-90%. In addition to the blood test, results from the research may help to devise new, targeted treatments.

Aims of Research

The aims of the research are:

1. To identify which genes are involved in the development and progression of ovarian cancer.
2. To identify a test that would allow screening of healthy women for early ovarian cancer.
3. To identify ways to predict disease progression or recurrence, and new ways to specifically treat ovarian cancer.

Many of us have read about the Human Genome Project, which began in 1990. The aim of the project was to produce a molecular blueprint of all the genes in the human body. A draft sequence was issued in 2001 and is proving to be a boon to researchers. The project is expected to be completed this year.

We have known for some years that cancer is a disease that is controlled by our genes and how they are turned on and off. Normal

cells maintain a balance between cell division and cell death. Cancer cells have alterations in the genes that control this division, and resemble a car out of control with no brakes.

GENE CHIPPING: Genetic profiling of cancer

The researchers take an extract from the cells of ovarian cancer tissue, which is a copy of the DNA that is turned on in those cells, and label it with a fluorescent dye. They then pass it over a gene chip. The DNA copy will bind to their complementary DNA partners on the chip.

When fluorescent light is applied to a chip, a glow signal is obtained where those genes that are turned on have bound. Using computer software, it is possible to determine which genes are turned on or off in different tumours.

We have now profiled 51 ovarian cancers using GeneChips. Our GeneChips are the most advanced available, in that they contain DNA that corresponds to over 90% of all human genes.

When compared to normal ovaries we have identified over 250 genes that are turned ON, and over 150

genes that are turned OFF in ovarian cancer. Now the challenge is to work out which of these genes have potential in a clinical setting so that we can develop a blood test for early detection.

The more money the GO Fund can raise, the more researchers we can employ, the sooner the answers will come.



From left: Princess Taofi Atoa, Sylvia Emmett (GO Fund Committee)

"My priorities have changed"

After 14 years on the high seas, Kelly Ryan and Gil Quesada, entertainers on the Princess Cruise Lines, made their first visit to Australia. Little did they realise they would be staying longer than they planned.



While on their latest cruise from Sydney to Auckland, Kelly suddenly developed a clot in her leg. After visiting the ship's doctor, Kelly was encouraged by friends to seek further medical advice. She was eventually referred to Professor Hacker at the Royal Hospital for Women and was diagnosed with ovarian cancer.

It was a shock for both Kelly and Gil. In a

5-hour operation, Kelly underwent resection of her advanced ovarian cancer, which involved removal of small and large bowel in addition to removal of her uterus, tubes and ovaries. After her chemotherapy, Kelly started losing her hair and lost weight.

Through all this, Gil assumed the role which Kelly had previously taken. "Gil's job was to show up and play the piano, while I sang," recalled Kelly. "I took care of our social and financial life and everything was running smoothly. Now the roles are reversed and Gil is organising everything, including doing the laundry."

However, the biggest change was Kelly's priorities in life. "With shipboard life, you are consumed with work. You are isolated and away from home, so you tend to focus on material things – what you own, what you are wearing, how you look. You tend to let your friendships lapse while you are consumed with your daily life."

Kelly realises that their life has been different, but she says that the whole cancer experience has made her concentrate more on people now. "Losing your hair and finding that your clothes no longer fit, makes you reassess your vanity," she says. "The time I used to waste on things I thought were important, is now being spent on catching up with others."

Once their friends realised what had happened and sent their commiserations, Kelly and Gil started writing to them to renew old friendships and cement new ones. Kelly says she is receiving emails from people who really care and that the reassessment is contagious. People have said "Since you wrote I've been reassessing my life."

"A friend of mine has been putting off visiting the doctor and has now decided to do something about it. When someone asked me 'why didn't you know [you had ovarian cancer]?' I had to point out that having a pap smear is only for cancer of the cervix. People think that after a pap smear, they are safe from any gynaecological cancer."

"Everyone at the Royal Hospital for Women has been so

Ovarian Cancer at 37

Paula East had never had an operation, nor did she have any history of ovarian cancer in her family when she discovered a lump in her stomach in 1997.

Paula was out riding her horse when she noticed her stomach was hitting the saddle. She felt a lump and immediately visited her GP who initially thought it might be a fibroid.

An ultrasound later showed a 10cm cyst on her right ovary. After an operation to remove the cyst, the pathology revealed it was Stage 1, clear cell ovarian cancer.

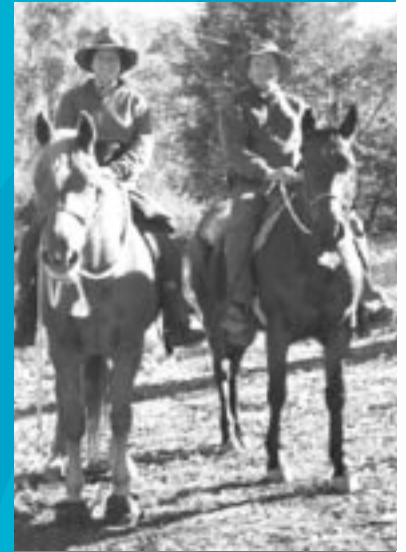
Three weeks later in the Royal Hospital for Women, Paula had a hysterectomy, and removal of her ovaries, omentum and pelvic lymph nodes. This was followed by chemotherapy for 12 weeks.

Paula said the whole exercise was a big shock. "I was always healthy and never expected anything like this." Paula is a nurse at Dubbo Base Hospital and has been working with doctors for the past 20 years. She found Dr Greg Robertson and the staff at the Royal Hospital for Women to be genuine and caring. "They treat you as a person and not as a number. They're not afraid to talk to you."

An additional comfort to Paula was the support she received from her husband and family. "Gary was there for me every day. Even when it became too much and I'd burst into tears, he would be there to comfort me."

Paula and Gary can't have children now, but at least she is still alive. "It's an emotional roller coaster and when you feel a pain it's always in the back of your mind that the cancer may have returned."

Paula has been cancer-free now for 6 years, which augurs well for her being cured. "Finding the cancer early is the key to survival," Paula says.



Paula, left, on her horse, Sovereign, riding with her husband, Gary, on Jez, on their family property at Hartley.

great. They were all concerned with giving me the best treatment," says Kelly.

Kelly has decided to retire back to their home in Palm Desert, California where Kelly will receive ongoing treatment and tests, and Gil will continue to play the piano. Kelly is going to see what she can do to let other women know more about it. "If I had been aware, I would have visited the doctor earlier," she laments.

An Unexpected Golden Wedding Anniversary

When Laurel Greenhalgh started going through menopause her symptoms were severe. They were so severe, that Laurel was considering HRT.



On a visit from their acreage property outside Taree, Laurel recalls what happened 11 years ago. "I went onto HRT and was told to come back in a year. About 6 weeks before the year was up, I felt a lump in my tummy. When I went to the doctor, he picked it up straight away, but thought that it was just a cyst, even though it was as big as an orange.

"I wasn't worried at the time because he didn't seem to think it was cancer. My husband and daughter were with me when I was told that I would need an operation to remove it.

"I came to Sydney where Dr Eden removed, what proved to be, an early ovarian cancer. I was then referred to Professor Hacker at the Royal, and Professor Friedlander administered four lots of chemotherapy.

"I thought I was cured, but about two years later in 1995 I had pain down my right side for three months. After a CT scan, Professor Hacker told me the cancer had recurred in my pelvis and had blocked off my ureter on the right side.

"Professor Hacker was not prepared to give up the fight against the cancer and he performed a resection of the recurrence. This was followed by radiotherapy for two months. The treatment took its toll mentally and physically, and I felt that I could no longer look forward to a long future. It was my faith in God and the power of prayer that was my strength during such uncertain times.

"In July 1999 I developed breast cancer and underwent a lumpectomy. My lymph glands were clear and I had radiotherapy. Ever since then I've had six-monthly tests, including the CA125, and I know that I will have to have these tests for the rest of my life.

"It is now 8 years since that recurrent ovarian cancer, and I am better and stronger than ever. I have had wonderful support throughout from my family, and especially from my husband and my daughter, Carolyn, and I know this has made a big difference. In fact the staff at the Royal keep telling me how well I look. I am fortunate to have such a brilliant Professor looking after me."



The cattle farm keeps Laurel and her husband, Harold, very busy, and Laurel's love of gardening and walking keeps her physically fit. Next year the couple will be looking forward to celebrating 50 years together, a goal she felt she had no hope of achieving when her cancer came back in 1995.

Celebration with a Heart

Anne and George Erber wanted to make the celebration of their 20th wedding anniversary special.

Aware of the urgent need for research into gynaecological cancer, the Erbers decided to use the occasion to raise funds for the GO Fund.

Their anniversary was celebrated amongst friends at Prunier's restaurant in Woollahra, with everyone donating generously to the GO Fund in lieu of a present.

"We preferred to have the money going to the GO Fund in the hope of saving lives," said Anne.



IN MEMORIAM

We gratefully acknowledge donations in memory of the following:

Mereille Sutherland
Gai McKerrow
Karen Ehrlich
Corinne Smith
Gloria Murphy

One Husband's Journey

Tony McKerrow is definite about one thing: A woman is the pivotal part of the family. In the case of his wife, Gai, who lost her battle with a very rare gynaecological cancer in December 2002, she was a much-loved wife, mother, sister and daughter.



Up until Gai was diagnosed with this rare cancer, she had led a very active life raising three children and being very involved in running a sheep property near Coolah, in partnership with her husband. Sadly, she never got to see her two grandchildren. She was a very good horsewoman, enjoyed being outdoors, loved animals and built her own rose garden, insisting on carting most of the river rocks that line the garden on her own.

Amongst the four major and a dozen other minor operations, Tony says he never felt so ineffectual in all his life. "The property became unimportant at the time. I switched off for two years to make things normal for Gai. I just had to concentrate on being strong." He says he was lucky enough to be able to leave their sheep station at Coolah in capable hands, while he spent as much time as he could with Gai. Tony found accommodation in Coogee which meant that their two sons and daughter could spend as much time with them as possible.

The support the family received was greatly appreciated – the neighbour that looked after their property; the real estate people in Coogee; the post office staff who held their mail; Mario, the local butcher, who gave Tony bad horse tips; family and friends who sometimes did not know what to say; people they met during the two years.

Gai McKerrow had a rare cervical cancer known as Adenoma Malignum. Before she was diagnosed, her two pap smears were abnormal, but not cancerous. Upon diagnosis she was referred to a gynaecologist in Dubbo, who subsequently referred her to Professor Hacker. Tony says Gai felt very comfortable right from the start with Professor Hacker and the staff. The continuity of the people during the two years made things easier for Gai and the rest of the family.

Tony says that Gai had hoped that telling her story might help someone else in a similar position. He feels an empathy with the hospital and staff, and appreciates being able to talk to Ros Robertson, the psychologist, and others there at times.

Through his association with the hospital, Tony has become very aware of the need for financial contributions to further research into gynaecological cancer and has become a financial supporter of the GO Fund.



Jenny Mansell, fundraiser for the GO Fund, receives a cheque from Megan Pearson-Craig after the Pearson sisters' successful SisterLink function.



On the night of 23rd August over 150 women of all ages descended upon the Baulkham Hills Sports Club for the first SisterLink Girls Night Out and Awareness Night for Ovarian Cancer.



The Housework Can Wait band keep the housework waiting!

The night, organised by five sisters, Megan Pearson-Craig, Jane McPhie, Kerry Hides-Pearson, Joanne Pearson and Kate Pearson, aimed to provide a fun night out as well as raising awareness of, and funds for, research into Ovarian Cancer.

Those expecting a lecture or boring night of speeches were in for a shock! No sooner had they sat down than the singers "The Housework Can Wait" started up with an infectious mix of jazz, ABBA, and pop which had everybody yelling for more. This was followed by a game of People Bingo where everyone was encouraged to get to know everyone else. The frenzy that ensued was reminiscent of a children's treasure hunt than a dedicated information gathering exercise – Who was wearing the g-string??

Speeches by Simon Lee, Director of the National Ovarian Cancer Network and Joanne Pearson, NUM Oncology Care, Bowral Day Surgery, made the aim for the night 'real' to the guests. These were interspersed

by a silent auction (war was almost declared over the Rugby World Cup tickets), a balloon frenzy (where we lost sight of 5'2" Kerry in the scrum), raffles and lots of singing and fun.

The event raised \$4,500 for the GO Fund.

Any doubts regarding the success of the night were quickly allayed by the number of queries as to "When's the next one going to be? We'll all be there!"

Definitely an experience which will be repeated. ***The GO Fund thanks the Pearson sisters for their inspired event, and the work and planning which went into making it such a success.***

Conference for Rural Doctors & Nurses

On June 6, 2003, the Gynaecological Cancer Centre at the Royal Hospital for Women held their third Rural Network Meeting in the lecture theatre of the Women's Health Institute.

The network consists of gynaecologists from rural New South Wales who regularly refer patients to the Royal for cancer surgery, and oncology nurses who work in regional cancer centres. Approximately half the patients seen in the Gynaecological Cancer Centre are referred from rural New South Wales.

The program of lectures and discussions was organised by Anne Sneddon from Canberra, Martin Baylis from Tamworth and Chris Halloway from Bathurst, and was well received by over 50 attendees.

The network meetings allow doctors and nurses to discuss the best way to optimise care for patients from rural areas.

In the evening, a dinner at the Pier Restaurant at Rose Bay was kindly sponsored by CYTYC Corporation.



**Dr Ron Vaughan (Orange) , Dr Tony Geraghty (Dubbo),
Dr John Tooth (Dubbo)**



**Dr Kieren Phadke (St George), Prof Neville Hacker,
Dr Anne Sneddon (Canberra), Dr Steve Robson (Canberra),
Dr Jing Song (Wagga Wagga), Dr John Curry
(Wagga Wagga), Dr John Matthews (Sutherland)**



**Dr Chris Halloway (Bathurst), Dr Bob Garland
(Coffs Harbour), Dr Joe McCosker (Wollongong)**



**Dr Ian Stewart
(Wagga Wagga),
Dr Greg Robertson
(Royal Hospital
for Women)**



Please visit our web site www.gofund.org.au

"I knew I would be alright"

Adrienne Gorme and her husband were looking forward to their round-the-world trip in 1992, but three days after they left home, Adrienne became ill with a very heavy period. She battled on with the trip and on their return she visited her GP.

Her doctor could not find anything unusual and suggested to Adrienne that it was early menopause. When her doctor was on holidays, Adrienne visited the locum who referred her to Ryde Hospital, but again she was reassured everything was alright and she was sent home.

Sensing that something was wrong, Adrienne contacted her gynaecologist, Dr David McGrath who performed a uterine curettage, then referred her to Professor Hacker with a diagnosis of endometrial cancer.

"I was in shock," said Adrienne. "Pap smears hadn't picked it up and I could not understand why I had the cancer. I felt removed from the whole thing. It affected my husband badly, who immediately thought that I was going to die, and even my 21-year-old daughter found it difficult to come to terms with, although both of them put on a brave face.

"After the surgery, which involved a radical hysterectomy and removal of the pelvic lymph glands, I had this strange disassociation with the disease, but I never thought I was going to die. I was lucky in that I didn't have to undergo chemotherapy or radiotherapy, but a couple of months later I developed lymphedema in my left leg. I had physiotherapy at the hospital and continue to receive treatment twice a year which keeps it under control."

Adrienne has not let the disease control her life. Instead, following her husband's death from kidney cancer three

years ago, she decided to take up golf, a game which her husband had played and which she thought would keep her fit and busy with golfing friends. "Now that I am retiring from high school teaching, I will be able to play more often. Maybe I'll even get back to snow skiing," she said.

Ten years have now passed and there is no sign of a recurrence of the uterine cancer, so Adrienne feels that she is cured. "You're constantly on the alert for any signs, so I guess, in retrospect, it did affect me. I was lucky to have Professor Hacker who is a very gifted man."

Adrienne is also involved with Zonta, raising funds for women's causes. She feels that to support the GO Fund in their quest to find answers to gynaecological cancers, is, indeed, a very worthwhile cause.



Adrienne at Torigate near Hiroshima.

Australia helping Bulgaria

Bulgaria is undergoing great reform in its medical care and Australia is part of that change.

During 2003 a gynaecological oncologist from Sofia in Bulgaria, Dr Stefan Ivanov, has been studying at the Gynaecological Cancer Centre with a view to raising the



standards of surgery, post-operative care and palliative care for women suffering from gynaecological malignancies in Bulgaria. He has taken his knowledge back to Bulgaria to help "westernise" their ways in his field of expertise.

As the third generation of medicos in his family, Dr Ivanov had always wanted to be a doctor. His father is a gynaecologist

and his mother a dentist. When he completed his university studies in 1982, he practised as an obstetrician/gynaecologist in regional areas. For the next five years, he worked at the Medical University of Varna and conducted research in the area of endometrial cancer. In 1987, he was appointed to the staff of the National Cancer Centre, and subsequently, Dr Ivanov met up with Professor Hacker at a conference in Budapest. Later they were both asked to lecture in Turkey.

When Bulgaria became a free country in 1990, health reform was an area that needed to undergo radical change. The World Bank put \$60m into the reform and the Bulgarian government introduced new clinical pathways (the referral system from GP's to specialists), and introduced a health tax on income of 6%, of which 3% is personal and 3% from the employer.

Australia has a high reputation in the field of health care due to our good mixture of private and public patients. During his stay, Dr Ivanov said he had learnt better surgical techniques, better surgical approaches and better post-operative care. Australia also uses more analgesia than Bulgaria and he has also learned a lot about pain relief and palliative care from Professor Norelle Lickiss.

"Professor Hacker is the best surgeon and the best teacher, as well as being a very personable fellow. I have learnt a lot more about gynaecological cancers and the Professor will continue to advise me even on my return to Bulgaria. I want to become the Professor Hacker of Bulgaria.

A Reason to Celebrate



In August 2002, Edith and Keith Campbell celebrated their 50th wedding anniversary at the Kiama Golf Club along with 100 of their friends.

Having lived in Bombo for 40 years, Edith and Keith are well known to the locals, especially those who love fishing. In the summer, they go prawning on Lake Illawarra with a 20ft net, while all year round Edith and Keith go fishing round the rocks.

Edith's case is most unusual, and as Edith says "Professor Hacker calls me the mystery woman." She was first treated with radiation therapy for cancer of the cervix 32 years ago and remained well until last year, when the cancer came back in her cervix. She underwent a radical hysterectomy at this time, but 12 months later, the cancer recurred in the vagina. She then faced a very extensive operation called a total pelvic exenteration.

In spite of the very extensive operation, Edith has recovered well with support from her husband and family of 11 children. She is mentally strong and optimistic for the future.

Keith, who visited Edith daily throughout her hospitalisation, says they can't speak highly enough of



the staff at the Hospital. "From Professor Hacker and his staff, through to the anaesthetists, and all the nurses, clerks and acute care

A First for Serbia

Professor Neville Hacker was invited to be the keynote speaker at the inaugural meeting of the Serbian Society of Gynaecological Oncology in Belgrade in April this year.

In his address, the Professor said that there were many very dedicated doctors working under difficult conditions to try to improve the care of women with gynaecological cancer in Serbia and that the formation of an official society was a significant achievement.



Professor Hacker with Professor Vesna Kesic, who was elected as the first chairperson of the Serbian Society of Gynaecological Oncologists

As a result of his visit, one of the young gynaecologists from Belgrade will come to the Royal Hospital for Women in 2004 to undertake formal training. He will spend at least 2 years in Australia and on his return to Belgrade, will become a key member of the Gynaecological Oncology team, introducing many new ideas he has learnt at the Royal.

staff – the whole lot – they were all wonderful."

Edith concurs: "They would go out of their way to help me. The staff came from all over the hospital just to see me. They were so marvellous and gentle. It was overwhelming."

When Edith and Keith celebrated their anniversary, a friend gave Edith a gold medal for her 50 years with Keith. The strength of their marriage and obvious support for each other has been a great comfort for Edith at this time.



GO FUND

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NOVEMBER 2003

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