

ovacome..

August 2005



Congratulations and many, many thanks again to Isla Blatchford (pictured above looking very happy but very tired, with her Dad and brother after finishing the London Marathon). Isla raised over £9,000 for Ovacome through sponsorship forms and the just giving website.

Dates for your diary

Saturday 15th October 2005

Ovacome AGM – see page ? for details and please do consider coming

Saturday 13th May 2006

Ovacome Members' Day 2006

ovacome is nationwide support group for all those concerned with ovarian cancer, involving sufferers, friends, families, carere and health professionals

from the editor

Welcome to the Summer 2005 issue of the Ovacome newsletter. I hope you like the new, fresh look. All of us at Ovacome would be pleased to hear your comments.

In this issue, make sure you read all about our forthcoming AGM, which will be held in Leicester on Saturday 15th October (page 6). All Members are welcome. Please consider coming along.

I would just like to make a plea to all our members regarding two things. First, we are starting to compile a database of self-help groups and hoping to make this a regular item in the newsletter (some appear on page 8). So if anyone belongs to any support group, whether it is purely ovarian, gynaecological or all cancers – please send me the details and I will put the information into the next and future issues.

Second, recently I have noticed that letters to the editor are not as forthcoming as they were in the past. If anyone feels they could contribute to the newsletter via the 'From the Postbag' page – please do. Our letters vary from diagnosis stories, to remission stories, to tips and advice, to comments on other articles in previous issues.

Regarding Christmas Cards (page 13), I know it is only August but I thought it best that you had early sight of our 2005 selection. You can order your cards from now on but we will not be able to post them to you until late September/early October.

Looking forward to seeing you at the AGM.

Jayne

new committee members

Welcome to Karen Ackroyd, Laura Carr and John Walsh who have recently joined the Ovacome Committee. More about them in the Autumn issue.

Ovacome Staff

Louise Bayne, Director
Monday, Tuesday and Thursday

Doreen Jacobs, Office Manager
Monday to Friday, 10am to 3pm

Ruth Payne, Support line/Administrator
Wednesday, Thursday and Friday

Teresa Cramer,
Support line/Administrator
Monday and Tuesday

Jayne Pyper, Newsletter Editor
Works from home but helps out in the office every Monday

Office Hours: Monday to Friday 9.00 a.m. to 4.00 p.m.

Telephone Support line 020 7380 9589
Admin line 020 7380 9877

can you help the BBC?

The BBC Science Department is currently making a major six-part documentary series about assisted reproduction. Presented by Robert Winston, the aim of the series is to give the audience an understanding of the science underpinning assisted reproduction, as well as an insight into what it is like to go through fertility treatment. It will be transmitted in late 2006. Ovacome has been asked to help find people who would be willing to share their stories.

The BBC want to show how women going through ovarian cancer can also be seeking to preserve their future fertility, and how IVF can enable people in difficult circumstances to consider their fertility options.

The BBC hopes to frame the series through the patient's eyes as much as possible, following experiences as they happen. They expect to feature two or three couples in each programme, perhaps using different aspects of their treatment to build up a view of the whole process. Therefore it might not be necessary to film every aspect of the treatment.

This is clearly a sensitive area and the team has a long track record of making programmes about such subjects that are respectful and informative. The filming is mostly observational which means they do their best to follow the treatment and avoid 'sit down' interviews. They hope to establish a relationship with patients that will last over a long period. The BBC knows that for much of this time patients may be under considerable stress. To help this they work in teams of two and do all the filming themselves, so that the patient is always filmed by people that they have had time to get to know and trust.

Six one-hour programmes are a luxury in television terms, and will allow the BBC to look at this important subject in great detail. They are particularly keen to look at the latest assisted reproduction techniques, as well as some of the choices that patients and doctors are faced with. The BBC will be devoting a number of programmes to specific areas of treatment such as the freezing of eggs, embryos or ovarian tissue, IVF treatment using frozen eggs or embryos, or IVF treatment using donated eggs, but will also very much look at standard IVF cases and other areas too.

If you are interested in finding out more, please contact the Ovacome office in the first

This newsletter is produced in memory of Sarah Dickinson, founder of ovacome

a new look for ovacome

Bronwen Edwards and Philip Stevenson, who work for a well-known London design and public relations agency, approached Ovacome, at the end of 2004, offering to help create a new identity for us, in their own time, for free.

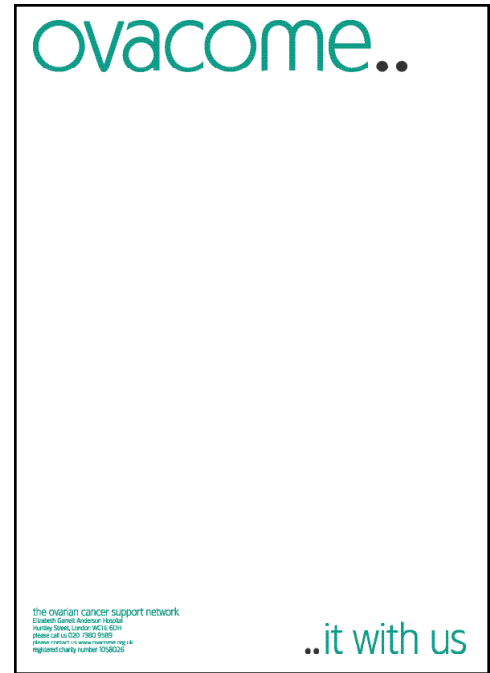
Ovacome's "tree of life" logo was born out of one person's vision for the charity over ten years ago. Today Ovacome represents more than 3000 members countrywide. As Bronwen Edwards explains, "Our challenge was to create an identity that balanced Ovacome's human touch with the gravitas of a serious, well established organisation."

Philip and Bronwen spent time speaking to patients and their family member to understand what they valued most about Ovacome. "Members talked about getting information, of personal contact, emotional support and of encouragement, but Ovacome's existing identity no longer reflected this spirit." adds Philip.

Bronwen explained the big idea. "Ovacome's new identity and logo are based on the idea of dialogue. Whether that's with sufferers, family members, health care professionals or politicians. It is made up of a two parts. The first part builds an "ownable" two pink dot visual equity, representing ovaries, into the Ovacome brand marque. The second part opens up a communication with the audience. Right from the very first moment they come into contact with Ovacome. It rewards the reader with a real experience of the brand's promise: that of dialogue."

You'll already have seen the new design in use in this issue of the newsletter, and on this page you can see some of the new designs we'll be using in future. Unfortunately, our newsletter budget does not allow us to reproduce these here in their actual colours, so we've had to stick with green and black, though all our materials will carry the two pink dot visual that Bronwen mentions.

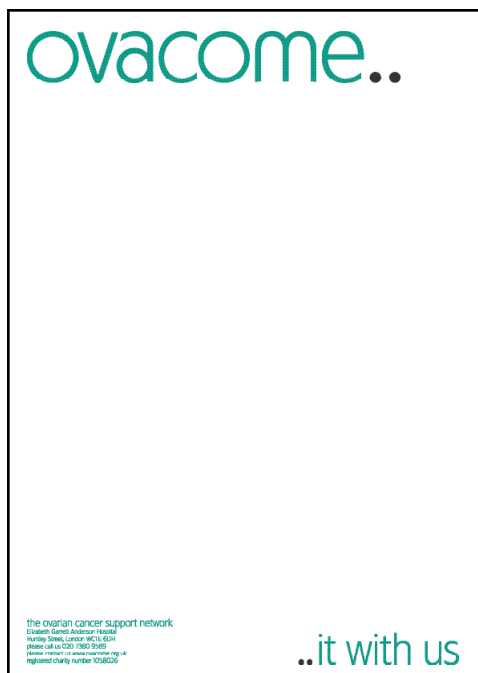
Besides the new look for the newsletter, office stationery, information media and promotional items, all our factsheets are currently being revised and will soon be re-issued in the new livery.



new letterhead



information card



event publicity



complement slip

members' day 2005 report

Members' Day 2005 took place on Saturday 7th May in London. Around 60 members gathered in the beautiful Glaziers' Hall by London Bridge. We were particularly fortunate as the Glaziers' Hall was full of gorgeous flowers because the previous day they had had a promotional photo shoot for the venue!

Ovacome's Chair Noeline Young welcomed everyone.

The first speaker was Professor Ian Jacobs, Director of the Institute of Women's Health at University College Hospital in London. Professor Jacobs' talk was entitled *Signs and Symptoms: finding evidence and moving forward*. He informed the audience that a foolproof screening test would be found for ovarian cancer. He recognised that progress in this area for the majority of ovarian cancer patients seemed slow but emphasised that any screening test had to be 100% foolproof before it is rolled out nationally.

The second speaker was Professor Mike Richards, the Department of Health's Clinical Director for Cancer who reports direct to the Health Minister. His talk, entitled *Ovarian cancer – progress and challenges*, covered facts and figures that

showed amongst other things that 5-year survival rates had increased. He also covered prevention and early detection, diagnosis, treatment, support and care and research. In summary, he said that progress had been made with ovarian cancer over the past 30 years but there is still a great deal to be done to prevent ovarian cancer and to improve outcomes for women who do develop the disease.

The final speaker of the morning was Dr Richard Osborne who is a Consultant Oncologist at the Poole Hospital in Dorset. Dr Osborne's talk was entitled *Life on chemotherapy: managing the side effects*.

It covered the toxicity of chemotherapy and anaemia induced by chemotherapy. He mentioned that side effects of chemotherapy were for the majority lessening and this was due to shorter duration of treatment and improved chemotherapy drugs. He also said that the use of some complementary and alternative medicine – particularly acupuncture and ginger as antiemetics – had also helped some people.

Photocopies of the slides used by Mike Richards and Dr Richard Osborne are available from the office.

The morning closed with a question and answer session to a panel of all three speakers.

In the afternoon, Jenny Vesty, a Complementary Therapist at the Dorset Cancer Centre, gave a demonstration of how to massage the hands as a

stress and anxiety reliever.

Everyone then had an opportunity to have a practice.

Louise Bayne, Ovacome's Director, followed Jenny Vesty by giving a short update of Ovacome's activities over the past year. These are mentioned in the Review of the Year article on page ??

Finally, Jenny Agutter, Ovacome's patron, introduced 'Launch of the new Ovacome logo' and also introduced Bronwen Edwards and Philip Stevenson of Coley Porter Bell, a design company who worked on Ovacome's new look (page 3).

Bronwen and Philip spoke about why they got involved with Ovacome and the process they went through to come up with the finished look and logo. An new Ovacome 'promotional' film which had been produced by ???? followed.

Ovacome would like to thank once again both Bronwen, Philip and the others at Coley Porter Bell and ? at ? who gave all their time on this project completely free of charge.



Members of the speakers' panel



Flowers from the photoshoot and food at the buffet



Members enjoy the chance of an informal get-together

Feedback

Just over half of those who attended the Members' Day completed a feedback form and of those 32% had not attended a Members' Day before. Here are some comments from Ovacome Members who attended:

"Excellent venue and catering." "It could not have been better."

"Best venue to date – more vegetarian food would be appreciated."

Prof. Jacobs talk:

"He was outstanding." "Very relaxing and soothing manner."

"Clear delivery." "Open to other views." "Very sympathetic."

Prof. Mike Richard's talk:

"Lots of facts and figures." "Good to have cancer Tsar involved."

"Thank you for getting him to speak."

"Very helpful to hear about policy and direction of cancer plans."

"Not involved directly in ovarian cancer but caring."

"Not made clear where he was from."

Dr Richard Osborne's talk:

"So good to hear about side effects/toxicity."

"Very interesting, would have liked to hear more about reducing toxicity."

about the panel discussion

Members were asked to write down their own questions and pass them to Ovacome's Chair to read out.

"It would have been better if individuals has asked own questions."

"Could have been longer."

"Written questions allowed for fair distribution."

"It would have been good to have been warned (before the event) about written questions."

"Very helpful (1) to hear women's concerns and (2) to hear caring approach from doctors."

overall rating:

"Pity more Members were not able to attend." "Very good day."

"Professional and informative." "CPB presentation/video – 200%."

"Afternoon sessions as valuable as morning." "Well run."

"Wonderful time." "Lots of new friends." "Positivity restored."

"Would like to have more time to meet others."

Giving a hand with a piece of artwork

One of the last things that Hereford Cancer User and Ovacome member Sandra Woodward and her husband Malcolm expected to be doing was contributing towards a piece of artwork called *Performancelife* by multi-media artist Siglinde Kallnbach from Cologne.

Sandra and Malcolm were in Milan representing their local cancer network in a Masterclass on patient advocacy. Siglinde, herself a cancer survivor, was just one of the representatives from 150 different cancer organisations from 30 countries that Sandra met during the Masterclass.

As Sandra recalls: "One of the most exciting things about the course, apart from the distinguished speakers, was meeting with so many interesting people. They all had their own stories about their own



battle with cancer and about the services available in their own countries. We all left the conference having made many new friends and having a better understanding as to how we can use the political process to improve cancer services. The strongest representation of cancer groups seemed to be from breast and prostate patient information and support groups. Surprisingly there were no gynaecology organisations present.

"I am hoping to be able to be able to put much of what I learnt into practice in order to see best practice in operation in my own cancer network and maybe influence the delivery of services nationally and in Europe.

"In the meantime it is great to think that the artwork that we all helped Siglinde produce will be part of an exhibition featuring the theme of cancer touring Europe. It would be good to think that one day it will be exhibited in the UK."

ovacome AGM 15th October 2005

Our AGM 2005 will take place on Saturday 15th October at the Holiday Inn, 129 St Nicholas Circle, Leicester LE1 5LX. Telephone: 0870 400 9048.

AGM 2005 Programme

Come and join us at the second of Ovacome's annual events. The hotel is conveniently located in the city centre and is about 1 mile from the rail station and is 3 miles from the M1.

To entice you all to Leicester here are some things to see and do before the AGM:

- The Haymarket Theatre is situated close to the hotel. On Friday 14th October, in the main auditorium, there is a special one-off concert called *Strictly Sondheim*. This is an evening of contemporary musical sophistication, which the audience can enjoy with a glass of sparkling wine. Tickets for this show are £15 and £10. Please indicate on your reservation form if you would be interested in going to this show
- The City Gallery on Granby Street is a contemporary art and craft gallery
- The Guildhall on Guildhall Lane is one of the best preserved timber framed halls in the country. It dates back 600 years
- The Guru Nanak Sikh Museum on Holy Bones traces the history of the sikh nation

Leicester also has many shopping opportunities including The Shires, with most of the big name shops, and St Martin's Square and Leicester Lanes, a cosmopolitan area with many independent shops.

More information is available by visiting www.visitleicestershire.com

Reservation Form: AGM 15th October 2005

This meeting is free of charge to Ovacome Members, ovarian cancer patients, their families and friends and costs £50 for Health Professionals.

Name

Address

.....

.....

.....Postcode

Tel (Home) (Work)

If you are a Health Professional please enclose your cheque for £50 payable to Ovacome.

Accommodation is available for the Friday night, 14th October for those travelling a significant distance, i.e. over two hours. Free accommodation is based on two sharing. There is a single room charge of £???.??

Please tick this box if you wish to stay on the Friday night.

Please tick this box if you require a single room.

Please tick this box if you interested in the Haymarket Theatre show *Strictly Sondheim*.

Please return this form to: Ovacome (AGM), EGA Hospital, Huntley Street, London, WC1E 6DH

Review of the year

Ovacome has continued to expand on its role as the main advocacy group for ovarian cancer in the UK. With significant representation from both staff and officers whose lives have been affected by the disease, and coupled with their experience of having the operational responsibility for the charity, we are regularly approached to represent the ovarian cancer community, where we can be a voice for our members.

We again presented to the three main political parties at their annual conferences. Ovacome staff also represent the ovarian cancer population on the National Cancer Research Network (NCRN) – the co-ordinating body for all cancer research work in the UK. We are members of the gynaecological cancer board, the ovarian cancer sub-group and the consumer liaison group. We are also working with other committee members on future investigative procedures in this most important area of research.

We represent the ovarian cancer patient perspective within NICE (National Institute for Clinical Excellence). Ovacome was able to contribute to guidance issued on drugs used for treatment of relapsed disease: Taxol, Caylex and Topotecan. While the final decision did not meet Ovacome's complete recommendations, our input helped to ensure that patients are offered a choice of available treatments.

Ovacome members were represented at a reception at the House of Lords when the charity's patron, Jenny Agutter, was asked to launch Dipex, a comprehensive website resource providing factual and supportive case histories on ovarian cancer on line. Ovacome volunteer members have been interviewed and included in this initiative, and Ovacome received a warm tribute in the accompanying speech for its "professional, caring and sensitive approach".

Fundraising has a considerable impact on our annual operations, along with donations and gifts in memory of those who have lost their personal battle. It is these funds that enable us to continue to support others and to progress the campaign against this deadly disease. This year our

supporters have been very innovative in their fundraising activities, including a garden open day, an Irish evening, a May Ball, an evening extravaganza, a pantomime and the good old quiz night, together with our usual support in the London Marathon and other similar events round the country. Details of significant individual donations and fundraising activities are the Notes to the Financial Statements. Once again we express a big thank you to all our sponsors, donors and benefactors, and to all members and friends for their time and energetic efforts in raising money, no matter how large or small, in so many ways

Many of the events referred to above, as well as up to date information on the medical developments in ovarian cancer and members' own experiences, are published in our quarterly newsletter. While the newsletter represents a significant slice of our annual budget, it is a most valuable resource that reaches all of our members and other affiliated medical professionals. Ovacome received valuable sponsorship towards the production costs for much of the year, for which we express our gratitude to Schering Plough and Lilly Pharmaceuticals for their unrestricted medical grants.

Earlier in the year, staff from Coley Porter Bell, a major Public Relations firm approached Ovacome to offer their services on a pro bono basis. Philip and Bronwyn will be using the resources available to them and working in their own time on a rebranding exercise for the charity. It is hoped that our new image will be launched early in the next financial year, and it was therefore decided to delay the new website until the new look is incorporated.

At the AGM in September, we saw a change of Chairperson. Ovacome acknowledges and is grateful to both past and present post-holders, other trustees, committee members and staff for their time and effort during the year. There have been some changes in staff at the new office where we are now established. This helps us to give a better service to our members, as always our most important resource. Your continued and unselfish efforts help us make a strong

contribution in the coming year ahead on behalf of all whose lives are affected by ovarian cancer.

If 2003/04 was a challenging year from a financial point of view, perhaps 2004/05 could be described as a year of consolidation. Total income rose to £202,932 (2004: £143,466) of which £150,280 (2004: £93,006) was derived from corporate sponsorship, donations and legacies. While income from legacies almost quadrupled to £77,500 (2004: £19,790) and that from unrestricted donations more than doubled to £49,443 (2004: £21,837), corporate sponsorship was well under half that of the previous year at £23,337 (2004: £51,379). Fundraising activities saw a slight decrease to £40,244 (2004: £42,111).

Expenditure saw a significant decrease to £113,791 (2004: £153,403), mainly as a result of the timing of Newsletter publication (three in the financial year instead of the usual four), a reduction in payroll costs (due to a gap between staff departure and replacement, and a case of long-term sickness), and a general effort to control costs.

It is important to regard the surplus for 2004/05 of over £89,000 with more than a modicum of caution. The very large and generous legacy, which the Executive Committee wishes to allocate mainly to specific projects rather than general expenditure, has to be regarded as unlikely to be repeated. It must also be assumed that without sponsorship of the Newsletter its production will continue to be financed out of general funds. On the assumption that both those scenarios apply, that both payroll expenditure and the Newsletter production schedule return to normal, and using the 2004/05 figures as a guide, the effect would be to turn the year's surplus into a deficit of approximately £5,500. From this it is apparent that efforts must be made not just to maintain the level of regular income but to increase it, and that careful financial management will continue to be essential.

It is the Executive Committee's aim to hold free reserves equating to about 9 months of unrestricted expenditure. The total level of funds at 31st March 2005 was £208,570, of which

£204,614 was unrestricted (2004: £119,429), and this represents just over 21 months operating expenditure (2004: 12 months). This does not take into account the situation set out in the paragraph above. If these assumptions are applied to present free reserves and future operating expenditure, the period drops to just over 12 months. While this figure is still above the stated aim, experience over the last few years has shown that income and consequent expenditure are extremely difficult to forecast, making it equally difficult for the Committee to implement its policy of matching expenditure to income. This is exacerbated by the present lack of sponsorship for the Newsletter, an item on which a significant amount of our resources is spent. The Committee is therefore content with the present level of reserves and will continue with its policy of ensuring that, as far as is possible, funds are in place before approving expenditure on future projects or additional resources.

Copies of the Annual Report and Accounts are available on request from the office.

Are you dancing through life?

We take life for granted. We tend to get carried away with life and find ourselves swept along day-by-day busying ourselves with the pressures of work, family and life in general. We rarely stop to check the direction we're travelling in or slow down enough to cherish life. That is until you are thrown a serious challenge, like cancer.

When you are diagnosed with cancer, your world tilts wildly. It's all-consuming, the first thing you think about when you wake and the last thing you think about before sleep. You get through the treatment, survive the emotional ups and downs and look at life as you've never done before. As time passes the emotions steady, life almost seems normal again but doubts and fears remain, albeit to a lesser degree. The fear of reoccurrence is the number one concern for most people who have survived cancer face, even years after the illness was initially diagnosed and successfully treated. There are no guarantees, but there is a lot that you can do to help yourself.

Changes to your diet and lifestyle (some a lot easier than others!) will help you to stay healthy but I'm talking about being in control of your life. Being proactive about moving forward rather than reacting to life's events gives you more control. The more you feel in control of

your life, the more empowered you are, the better you feel and the less frightening the future looks. From this perspective you can begin to look at your life and your future in a more positive way.

Having and surviving cancer is life changing. You may think I'm way off line to suggest that it could ever be a positive occurrence, but it's down to your attitude and outlook on life. This can be a turning point for you; you could chose to let it define you, you could brush it aside, or you could turn it into a positive, life enhancing experience. It's not what happens to you in life that counts; it's how you deal with it and how you perceive it that makes all the difference.

Thomas Crum, an American author and speaker on amongst other things stress and conflict management, put it much more eloquently when he said, "Instead of seeing the rug being pulled from under us we can learn to dance on a shifting carpet". So are you going to trip and stumble, or are you going to pirouette through life?

Claire Flint works with people who have survived cancer who are now ready to move forward. She helps them to take control and make the most of life. Contact her on 0115 8776461, email claire@whatifcoaching.com or visit www.whatifcoaching.com.

Support Groups

Here are details of two groups which some of you may find of interest. My thanks go to Mollie Calladine, Audrey and Roger Phillips and their friends Bill and Evelyn Lankester for the following information.

I would like information about support groups to be a regular item in the newsletter so if you are a member of a group please let me know the details.

Nottinghamshire Ovarian Cancer Group

Type of group: Ovarian cancer only

When meet: A Tuesday evening, every 2 months, from 7 pm to 9 pm

Where meet: Reception area of The Seven Mile Beefeater Pub, on the A60, between Mansfield and Nottingham

Contact: Mollie Calladine, Ovacom Member (contact via the Ovacom office)

Other info: Very informal, local gynaecological Oncology Nurse attends when she can and is happy to answer questions

Living with Cancer Group

Type of Group: All Cancers

Meetings: 1st Thursday in the month at Lymbourne and Aroot Social Hall, Sidmouth at 7.30pm

Last Wednesday in the month at Keel House, Sidmouth, at 2.30pm

Contact: Bill and Evelyn Lankester (via the Ovacom office)

Other info: The group has being in existence for four years and has approximately 70 members aged between 23 and 85 years. Everyone is welcome. In addition to the regular meetings where they sometimes have speakers they also organise regular social events. Living with Cancer Group also has a quarterly newsletter.

Thanks to our fund-raisers

collection at local superstore raises £663!

Thanks to P. Cox who recently donated an amazing £663 which her family and friends collected in their local supermarket. How and why did they do it?

"I recently collected on behalf of Ovacome, as I myself was diagnosed with ovarian cancer in July 2003. It gives me great pleasure to enclose a cheque for £663. This amount was collected at my local ASDA store plus a couple of small businesses.

"I got together with a few members of my family and some friends and we 'sold' the teal ribbons over two days in ASDA's foyer. I found it an exhausting but rewarding experience. I met so many people who had lost family and friends to ovarian cancer and I felt humbled by their generosity. I would like to say thank you to the people of Thurrock for their enormous generosity.

"Since my diagnosis and I have had two chemo courses and I just felt that I had to bring this silent killer to people's attention."

debbie raises £2,400 in Ovarian Cancer Awareness Month

During March, ovarian cancer awareness month, Ovacome member Debbie Kuca raised an amazing £2,400.

Debbie, who was diagnosed with ovarian cancer in January 2004, achieved this fantastic amount by organising a toddler lunch, and a table top sale and raffle. She also took to the streets with a collecting tin. Lloyds Bank matched £400 of the money raised, as her sister-in-law works there.

Debbie would like all Ovacome members to know that Lloyds Bank will match fundraising up to £400 if an employee of Lloyds Bank is involved in the fundraising! So if you are thinking of fundraising for Ovacome check out if any of your friends work for Lloyds Bank and get them involved too!

louis' breakfast run raises over £3,000

Louis Castellani took part in the Adidas Breakfast Run on Sunday 20th March in Kingston-upon-Thames, Surrey. He completed the 8.2 mile event in memory of his mother, Judith. When he sent in his sponsorship money Louis wrote the following:

"My mother Judith, was diagnosed with ovarian cancer 3 years ago in Lyon, France, where she lived and where she received excellent treatment. I originally wanted to take part in the race to raise money for Ovacome and to generate whatever awareness of ovarian cancer that I could in the process. My mother was in fact the very first person to offer to sponsor me, just a week before she

suddenly and unexpectedly lost her fight in December 2004. She was 53. I therefore also ran the race in her memory on behalf of her family and friends.

"My mother had incredible faith and capacity to love. She often declared that in her opinion the best cocktail for trying to beat cancer is one-third god, one third medical treatment and one-third having the love of her family behind her. She said that cocktail gave her the strength and motivation not just to fight her own corner but also the strength to help women who found it more difficult to cope with the consequences of having cancer.

"She would often stay behind after

her chemotherapy sessions to help women who were not coping. She would worry much more for those women than she would for herself. Those of us who watched her live this way, from her family, to the local baker, to her surgeon, found her strength awe-inspiring and at times simply bewildering. So it is understandable and only fitting that her family and friends wanted to recognise the work that Ovacome does for women who need not just medical treatment but also support."

"Please keep up all your excellent work. Kind regards."

Louis Castellani
Surrey

snowdrop walk 2005 raises £205

My Mum found great comfort and support through Ovacome during her illness and expressed a desire to fundraise for them, but sadly she became too ill.

Her favourite flowers were snowdrops and since her death in March 2002, the snowdrop has become the logo for our fundraising group - 'The Snowdrop Trust, Fundraising In Memory of Therese Seed.'

On 20th February, my family and friends took part in the Snowdrop Walk at Lytham Hall. Everyone who took part donated what they could afford and in total we raised £205 for Ovacome.

The Snowdrop Trust raises money for various cancer charities and we have decided to give the annual snowdrop walk donations to Ovacome each year.

Not only was the snowdrop my Mum's favourite flower but it is also a hint of Spring and brighter days ahead.

It is almost impossible to imagine a brighter future when



surrounded by the darkness of cancer, but she always believed that there would be brighter days ahead.

My Mum's life was extraordinary, like her. She gave so much to so many in her 56 years and will always be remembered.

Katy Seed

The Snowdrop Trust

ladybirds ball raises over £1,000

On 16th October 2004, The Ladybirds held a black-tie ball in aid of your charity, Ovacome. The total raised was over £1000.

The Ladybirds are a group of girls who organise a couple of parties a year, principally to raise money for charity, but also to have fun! We have been in existence for over 15 years, with invited members that retire when they wish (usually after getting married / having babies!) We are currently a group of eight, with varied backgrounds – a Therapeutic Radiographer, two nannies, two teachers, a farmer, a farm business consultant and a financial controller! The very fact that we are a group of girls was



behind our decision to support Ovacome. Fortunately, we have all been lucky enough not to be directly affected by ovarian cancer, but we felt nonetheless that it is an incredibly good cause.

The venue, a local golf club, was booked well in advance, and was

able to seat 100 for a three-course meal. We contacted local businesses for donations for raffle prizes, which were all very generous, with prizes including wine, a voucher for some local meat, meal vouchers and a waistcoat provided by Puffa. We decorated the venue using a mixture of your Ovacome balloons, and white balloons, inflated with helium. We also attached the 'business card' Ovacome information to the balloon ribbons, to provide the tables with facts about the charity. The evening was very successful, with an excellent disco and practically a dry bar by the end of the night! We were all thrilled to be able to send the cheque for £1300 to your charity at the end of 2004.

ovacome member fiona jackson raises over £130 at her local one-stop shop

Our thanks again to Fiona Jackson, pictured on the right with her friend Jill Long. Fiona continues to raise awareness of ovarian cancer both in her local area and nationally by writing to the Secretary of State for Health.



£2000 raised in marathon

Paul Welch, Operations Director, Central London raised £2,000 for the Ovacome charity by taking part in the London Flora Marathon this year.

Completing the marathon in 3 hours, 39 minutes and 55 seconds Paul said: "I'd like to thank Ray and everyone at Prospects for their support and the company's contribution to my fund-raising effort. Running the marathon for Ovacome gave me a great sense of achievement whilst being lots of fun too".

Louise Bayne, Director of Ovacome said: "I'd like to thank Paul and Prospects very much for raising this great amount for Ovacome and to congratulate him on his excellent time".

Pictured here is Ray Auvray, Prospects Chief Executive and Paul Welch presenting Prospects contribution to Louise Bayne, Director of Ovacome.



future fundraising events and ideas

Hydro Active Women's Challenge

Sunday 4th September

As mentioned in the Spring issue of the newsletter, the Hydro Active Women's Challenge (formerly the Flora Light) is taking place on Sunday 4th September in Hyde Park, London, Birmingham city centre and for the first time Liverpool city centre.

At the last count we had 15 members, family and friends taking part in the London event. If you or anyone you know is taking part in any of the three events please let the office know.

Three members of Ovacome's office staff are taking part in the London event – Louise, Teresa and Jayne. If you also running in London let us know as we hope to meet up with everyone before and after the run.

Christmas 2005

I know it is only the summer but if you are thinking of starting to prepare for Christmas look no further than the Funding Direct/Webb Ivory catalogue which is available from the Ovacome office. The catalogue includes cards, wrapping paper, calendars, decorations, tableware, toys and gifts for children and adults. Up to 25% of every order from the catalogue is donated to Ovacome.

Charity Direct Flowers

If you are thinking of sending flowers to a loved one or friend look no further than Charity Flowers Direct.

By choosing Charity Flowers Direct you will be doing more than sending beautiful flowers – you will also be helping Ovacome as 15% of the order is forwarded to Ovacome.

You can view the flowers on the website: www.charityflowers.co.uk or ring for a brochure if you have not got access to a computer.

You can order flowers and/or chocolates by:

- Calling 0870 5300 600 from the UK
- Calling +44 (0)1282 704068 from Overseas
- E-mailing help@charityflowers.co.uk
- By post from Charity Flowers Direct, PO Box 555, Guernsey, Channel Islands GY1 6JA

When making you order do not forget to include the Ovacome code – OVA.

London Marathon 2006

Please note our five 'golden bond' places for London Marathon 2006 have been taken. But it is still worth letting us know if you or someone else you know would like to run for

Ovacome as we can put you or them on the reserve list. We ask all potential Ovacome 'golden bond' runners to apply for their own place in the first instance. In the past, some people who have a 'golden place' have been successful in obtaining an individual place so people on the reserve list have taken their 'golden bond' place.

our london marathon success - ovacome's 2005 triumphant marathon runners

Congratulations and many, many thanks to everyone who ran the London Marathon for Ovacome this year.

Our golden bond runners Isla, John, Mark, Paul and Sara raised over £15,000.

Paul Welch who completed the Marathon in 3 hours, 39 minutes and 55 seconds is pictured on the previous page.

In addition, our other Ovacome runners – Sue Dale, Susan and Lawrence Taylor, Helen Marshall, and Richard Hull raised over £3,000. Thank you to you all.



John Wheatley and his wife Corinna



Sara Khan

the cooper family

Thanks to the Cooper Family - running in memory of Maureen Cooper and raising money for Ovacome

Maureen's daughter Karen explains: "Maureen Cooper passed away in August 2004 after a very short illness. At the time of her death, she was Lady Captain of Welton Manor Golf Club. In memory of Mum, the present Lady Captain chose Ovacome as her fundraising charity during her term of office.

"The family supports her fundraising and has raised, so far, £1,633.50 from the sale of ribbons and from sponsorship of runners. My husband Tim Wilkinson (4 hours 5 minutes) and Luke Rodwell who ran for my brother Russell Cooper, who had developed glandular fever, ran in the London Marathon and five members of our family ran in the Lincoln 10k road race.

"Our family will continue to support Ovacome in memory of a loving wife, mum and grandma. Keep up the good work."



Sue Dale looking as fresh as a daisy after running 26.2 miles!



Susan and Lawrence Taylor before the race. They ran together and raised £500.

success in paris

Congratulations and many thanks to Judith Eccles who is pictured here looking great at the 30km mark of the Paris Marathon, which took place on 10th April.



and thanks to ...

Denise McIntyre who ran in the Race for Life event in Manchester and raised £400 for Ovacome and also to Martin Ashing who ran in the Edinburgh Marathon.

Thanks also to the "Quinn runners" (I spotted you on the Just Giving website) – Pam, Jo, Sue, Margaret, Caroline, Paul, Ian, Mel and Iain who ran in the British 10K on 3rd July in London and raised £500. (More about Ovacome's British 10K success in the Autumn wsletter.)



Lincoln 10K runners from left to right – Amy Willoughby (grand-daughter), Debra Willoughby (daughter), Tim Wilkinson (son-in-law), Neil Cooper (son) and Steve Mable (son-in-law)

ovacome .. at Christmas

Ovacome is delighted to present our 2005 Christmas cards, available to order from the Ovacome office from late September onwards. These high-quality cards are sold in packs of ten of one design. Clearly printed inside each card is that it is sold in aid of Ovacome.

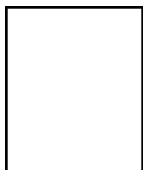
Christmas cards are an excellent way of raising awareness of Ovacome: just imagine the nationwide publicity if every member just purchased one pack! You could also sell packs of cards at your place of work, to family and friends or even arrange a Christmas card sale and coffee morning.

In addition to this year's designs, we also have stocks of last year's cards. Please note that the old Ovacome logo is printed on these cards. These cards are available at reduced prices while stocks last:



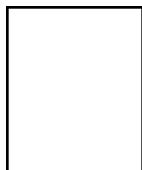
1

Angels
was £3.25 now
£1.00 per pack
of 10 cards



2

Kings
was £3.50 now
£1.75 per pack
of 10 cards



3

Geese
was £4.50 now
£2.25 per pack
of 10 cards



4

Trees
was £4.25 now
£2.00 per pack
of 10 cards

Christmas card order form

Please return this form, with a cheque or postal order made payable to Ovacome, to **Ovacome (Cards), Elizabeth Garrett Anderson Hospital, Huntley Street, London WC1 6DH**

I wish to order the following 2005 Christmas cards:

- _____ packs of Design A at £3.25 per pack
- _____ packs of Design B at £3.25 per pack
- _____ packs of Design C at £4.25 per pack
- _____ packs of Design D at £3.50 per pack

I wish to order the following OLD STOCK cards:

- _____ packs of Design 1 at £1.00 per pack
- _____ packs of Design 2 at £1.75 per pack
- _____ packs of Design 3 at £2.25 per pack
- _____ packs of Design 4 at £2.00 per pack

For all orders up to and including £20.00 please add £2.50 for postage and packing. For orders over £20.00 please add £1.50

I enclose a cheque/postal order for £ _____ made payable to Ovacome

PLEASE PRINT CAREFULLY

NAME

ADDRESS

.....

..... POSTCODE

Contact Telephone Number
(in case of order query)



Nativity Play 98 x 130 mm

A



Christmas Tree 98 x 130 mm

B



Peace, Hope, Joy 159 x 159 mm

C



Santa's Arrival 121 x 121 mm

D

From our postbag

Sara celebrates 5 years since her diagnosis

It took a year from the time that I first noticed a new ache in my back to my arrival on the operating table and my diagnosis ... I have ovarian cancer and it and it has spread. It was January 4th 2000 and I was 36 years old. Not the best start to the new millennium.

I had just split with my husband, my house sale had fallen through and I had just managed to rent a house, miles out of town with my three children and three dogs, a few days before Christmas.

I had six weeks off after surgery before starting chemotherapy (Taxol and Carboplatin). It did not really hit me for a few weeks just how ill I was until I read a copy of your newsletter. Then I realised that this was real and this was happening to me, and my children. I could feel myself plunging into depression and for a short while felt as if I would be overwhelmed by it but there is always that spark inside of us that rescues us in times of need. My inner light was to be my guide.

I found the easiest way to deal with it was just one day at a time. The love and compassion shown to me by friends, family and even strangers was phenomenal. I have many friends who were Reiki healers and I was sent regular healing by them. People who I had not heard from in months would send a letter, just chatting about their day. My house looked like a huge flower shop!

I moved into my own place in the middle of treatment. The children were happier in town with their friends and my daughter successfully completed her GCSEs.

I went back to work after a year that in hindsight was too soon. There is definitely a fine balance between getting back to normal and being compassionate to yourself. I eventually gave up worked and lived my dreams by moving to Finland last year, to my grandparents' old place in the forest by a lake. I am now a Reiki teacher and practitioner.

It was always very important to me, particularly at the beginning, to hear success stories. Now 5 years later I am still fit, healthy and cancer free and I wanted to share my good news with everybody.

Brightest blessings to you all.

Sara xxx

Finland



Sally 'lets off steam'

As a regular reader of the Ovacome newsletter I just felt I had to write in response to a letter you featured in the Spring issue from Dawn Melrose. Dawn is the daughter of a victim of ovarian cancer, as am I. I am very pleased to hear that she is being regularly screened because of the hereditary link.

For the last ten years I have been regularly screened, although sometimes I have 'slipped through the net' and missed about two years while trying to get back on the screening programme. It also took a while to convince the powers that be that a CA125 test is a valuable tool for the detection of ovarian cancer together with an ultrasound scan. In February, I attended my regular check up at the hospital to discuss my results and was told that I would not be able to carry on being screened unless I can prove there is a 'risk.' I have now completed a genealogical questionnaire that has now been sent to the Genealogy Department at Oxford Hospital.

I find it quite staggering that with a history like mine that there is any

doubt. My mother and cousin on my mother's side died of ovarian cancer, my sister has successfully recovered from womb cancer, my cousin on my mother's side is being treated for bowel cancer, my aunt (on my mother's side) died of spine cancer. In addition, my uncle (brother to my mother) died many years ago with some form of cancer but at that time cancer was referred to a 'C' and not discussed.

I now have to wait in excess of SIX months before I am referred to Oxford for an appointment. Only then will I find out if screening can continue, i.e. how high is the risk. It seems where you live is very relevant to what is available to you from the NHS. Ironically, I have private medical insurance through the company I work for. On enquiring, they are not prepared to cover me for screening, simply for treatment if and when it should be necessary!

I do hope that some time in the future screening for this disease becomes available nationwide, as is the case currently with mammograms. In the meantime, I will carry on fighting for the right to protect myself against this invasive disease.

Thank for allowing me the time to let of 'steam.' May I congratulate you all on the work you do at Ovacome and the enormous help it must give to thousands of women, their families and friends. Long may it continue!

Sally Brown

Wiltshire

sources of information

Listed below you will find various sources of information from Ovacome and from CancerBACUP. These are free to women with ovarian cancer and their families and friends.

If you would like to have copies of any of these items please indicate your requirements below. There is a form on the back page which you should use for your name, address and contact details. Then simply send the whole of this page to us at the office.

Ovacome Fact Sheets

We continue to have our own fact sheets on subject areas that are particular to ovarian cancer. Although

most of the information in the Ovacome fact sheets remains current we have decided that the time has come for them to be re-written.

Updated versions of these fact sheets will be available in May/June 2005.

CancerBACUP Fact Sheets

You will notice that the fact sheets that particularly concentrate on the different chemotherapy and other treatments are, in fact, from CancerBACUP. Given the speed at which treatments can change and as new treatments are becoming available all the time we at Ovacome

thought it best to have this arrangement with CancerBACUP so that we could keep our members as up to date as possible. Other CancerBACUP fact sheets cover subject areas that are common to all cancers. Our thanks go to CancerBACUP for this invaluable resource.

We hope that this new arrangement with CancerBACUP will provide our members with more of the information they may require.

Ovacome Fact Sheets

Quantity
Req'd

No.11	Sources of information and support
No.12	Ovarian cancer and your sexuality
No.13	The role of radiotherapy in ovarian cancer
No.14	The staging of ovarian cancer
No.15	Is there a link between ovarian cancer and talcum powder?
No.18	Screening for ovarian cancer
No.19	Fertility issues for women with ovarian cancer
No.20	Nutritional advice
No.23	Fibre restriction for bowel obstruction
No. 5	An overview of ovarian cancer
No. 26	Treatment-induced menopause: facing the issues

Ovacome details: a credit sized card containing Ovacome's contact details and the aims of the charity

Ovacome posters, A4 size

Ovacome posters, A5 size

Ovarian cancer ribbons: teal ribbons for use when fundraising

Ovacome Video – What to expect – Please tick if you wish to borrow a copy. We ask that videos be returned within one month. If you wish to keep the video, please send £5.00 to cover the costs of producing further copies for future requests.

CancerBACUP Fact Sheets

Quantity
Req'd

Single Chemotherapies

Carboplatin
Cisplatin
Cyclophosphamide
Docetaxel
Epirubicin
Etoposide
Gemcitabine
Liposomal doxorubicin (Caelyx)
Paclitaxel
Topotecan
Treosulfan

Combination therapies

Paclitaxel and carboplatin
Hormonal Therapies
Tamoxifen (as used in breast cancer)
Other Treatments
Erythropoietin (Eprex)
Steroids
Thalidomide

Other useful fact sheets

Avoiding infection when you have reduced immunity
Controlling nausea and vomiting
Cancer in the family
Cancer and fertility
Financial issues
Management of ascites
Management of pleural effusion
Peripheral neuropathy



justgiving.com – charity made easy

Ovacome would like to introduce those members who have computer access and on are online to justgiving.com, a website that, in their words, “has put the fun back into fundraising and aims to change the way people give to charity.”

Justgiving enables donors to give to charity quickly, tax-efficiently and easily and it also enables anyone to raise money for their favourite cause with minimum hassle.

The website is very user-friendly and Ovacome has recently become a receiving charity. Just Giving opens Ovacome up to receiving credit card donations, which some members have asked for in the past. It also opens fundraising to friends and family abroad who may like to donate.

How you can use Justgiving

If you wish to donate: Justgiving has the facility to accept one-off or regular donation

If you wish to sponsor someone involved in a fundraising event: Individual Ovacome fundraisers have set up their

own fundraising pages and you can sponsor them directly through the website.

If you are planning a fundraising event: You can set up your own fundraising page

Why not sponsor one of our current fundraisers on our justgiving.com web page?

At the time of going to press, Richard Satchell and Hannah Young, who ran in the British 10k on 3rd July, and Simon Cook who ran the San Francisco Marathon on 31st July, are still hoping for more sponsors and donations after the event!

And Wendy Walker is running in her first event, the Great North Run, on 18th September, Katherine Price is writing a book and Claire Pattie is walking up Mount Killimanjaro around 16th October.

Order Form: Sources of Information

Name
Address
.....
..... Postcode
Tel (Home) (Work)
Please return this form to: Ovacome, EGA Hospital, Huntley Street, London WC1E 6DH

Registered Charity Number
1058026

To register as a member of Ovacome please send your details to the following address or call the telephone number below

© 2005 Ovacome

Elizabeth Garrett Anderson
Hospital, Huntley Street,
London WC1E 6DH

Support line 020 7380 9589
Admin line 020 7380 9877
e-mail ovacome@ovacome.org.uk
www.ovacome.org.uk

Ovacome is a voluntary organisation and relies on donations

The information gathered in this newsletter is from many sources and is provided for guidance only. Ovacome has made every effort to ensure that it is accurate but can make no undertakings as to its accuracy or completeness. All medical information should be used in conjunction with advice from medical professionals

gift aid declaration

If you are a taxpayer and wish to donate to Ovacome please complete this form as we can reclaim basic rate income tax paid on your donation

Title: Forename(s) Surname
Address
..... Postcode

I want Ovacome to treat as Gift Aid Donations:

- the enclosed donation of £
- the donation(s) of £ which I made on ... / ... / ...
- all donations I make from the date of this declaration until I notify you otherwise

Signature Date

.. it with us