

opendoor

spring
2011

the newsletter of the Lynda Jackson Macmillan Centre

LJMC achieves Information Standard certification

With its reputation for the production of high quality patient information, the LJMC was keen to be one of the first organisations to achieve certification to the new Information Standard. This was successfully accomplished by the Information team within just six months.

Around 50,000 organisations produce health or social care information in the UK. The quality of this information varies greatly and a study by the Department of Health¹ identified that 75% of people find it hard to work out whether information is trustworthy or not. The Internet has served to increase confusion with vast quantities of information available and no way of guaranteeing its quality.

The Information Standard (IS) is an independent certification scheme that helps the public identify reliable and trustworthy sources of health and social care information. Central to the scheme, which is supported by the Department of Health, is a set of criteria that define good quality information and the methods needed to produce it.

... independent certification scheme...

The LJMC has always prided itself on the quality of its publications, winning several commendations in the BMA

Patient Information Awards over the years. It was a natural step to apply for this quality mark that will give patients confidence in our publications.

... quality mark will give patients confidence...

To achieve the standard, the LJMC had to show that our processes and systems are robust enough to create information that is accurate, impartial, evidence-based, accessible and well written.

Macmillan Patient Information Lead, Sarah James, took on responsibility for heading up the certification project. Having run the quality system in the Mount Vernon Cancer Centre in the past, she was the perfect person to get everything shipshape for our assessment.

... 12-Point Plan defines the steps...

For many years, the Information team has used its 12-Point Plan that defines the steps used to create our publications, from an initial request to final delivery. This provided a great starting point as the nuts and bolts of

Look out for the Information Standard quality mark on all patient literature



Members of the LJMC Information team celebrate news of certification

the publication process already existed so Sarah was able to focus on the strategic issues and policies that were required by the IS.

The actual assessment took place over two days in January when an assessor from G4S, the certification body, visited the LJMC. As well as interviewing members of the LJMC Information team, he met with senior managers and clinicians in the Cancer Centre who are integral to the production of information as authors and stakeholders.

... continually able to improve what we do...

The assessor will visit the LJMC each year to check that we are adhering to

continued on page 2...





Lynda Jackson Macmillan Centre

... supporting people affected by cancer...

Mount Vernon Cancer Centre
Northwood, Middlesex HA6 2RN

Telephone Helpline: 01923 844014

Website: www.ljmc.org

Moor Park 10k: www.moorpark10k.org.uk

Webshop: www.buy.at/ljmc

Online Fundraising: www.justgiving.com

Registered Charity No: 1053338

The LJMC is part of the
Mount Vernon Cancer Centre
(East & North Hertfordshire NHS Trust)

Drop-in Advice and Information

Telephone Helpline

Monday – Friday

9.30am – 1.00pm + 2.00pm – 4.30pm

Complementary Therapies Counselling

Available by appointment to patients
under the care of an oncologist at
Mount Vernon Hospital

Benefits Advice

Drop-in service during opening hours

Relaxation Classes

Monday: 2.30 – 4.00pm

Tuesday: 10.00 – 11.30am

Thursday: 11.00 – 12.30am

No need to book

Look Good...Feel Better™

Skin care and make-up sessions
for ladies

Support Groups

Contact the Helpline for details of local
support groups

Staff at the LJMC are always delighted to give
talks about the work of the centre and also
cancer-related issues.

If your company, school or other organisation
would be interested in an LJMC speaker,
please contact Buzz Coster (01923 844107) or
buzz.coster@nhs.net.

OPEN DOOR is sent to friends and supporters
of the Lynda Jackson Macmillan Centre who are
on our mailing list. If you wish your name to be
removed from future mailings, please contact
Buzz Coster.

We would like to reassure you that our mailing
list remains confidential and will not be sold
to or used by any organisation other than the
Lynda Jackson Macmillan Centre.

Information Standard certification

... continued from page 1

our procedures and Sarah has also
set up a programme of audits that will
highlight any issues that may arise.

It is this system of both internal and
external verification that will ensure
that we are continually able to improve
what we do and how we do it.

... we involve users...

One of the requirements of the IS is
that we involve service users so
members of our patient panel have
been busy reading leaflets and
commenting on their readability

and content. This feedback has been
invaluable and we are very grateful
to them for the time they give to this
important aspect of our work.

*... media campaign will
highlight quality mark...*

Achieving certification to the IS
is a demonstration of the LJMC's
commitment to the provision of good
quality information for the patients and
carers at Mount Vernon Cancer Centre.

We know that if people do not have
good information, they will not be able

to look after themselves effectively,
navigate the health system or make
appropriate decisions about their own
or their family's health.

A forthcoming media campaign, 'I'm
Informed', will be highlighting the IS
quality mark and you can expect to
see it on more health information
publications as more health and
social care organisations apply for
certification.

Meanwhile, congratulations to Sarah
and the members of the Information
team for this tremendous success.

Teresa's presentation judged the best at BPOS conference



Teresa Young's presentation at the 2010 annual conference of the British Psychosocial Oncology Society (BPOS) was judged the best of the bunch.

Battling snow, delays and even a fire at the station, Teresa and the other delegates made their way to Chester for the conference at the beginning of December.

The theme for the conference was 'Cancer and relationships with others', highlighting the impact of cancer on patients and their partners in their daily lives, relationships and key roles.

Teresa's presentation provided an insight into the development of the spiritual wellbeing measure for palliative care patients, a Quality of Life questionnaire which is now in its final phase of testing.

The conference committee judged Teresa's presentation to be the best, presenting her with the Walker Trophy, a silver quaich, making her the latest in a long line of prestigious winners.

Moor Park 10k reaches its tenth anniversary

Plans are starting to fall into place for this year's Moor Park 10k and Junior Fun Runs which will take place at Merchant Taylors' School on **Sunday 25th September 2011**.

We're delighted that Stewarts Law LLP has agreed to continue their generous support of our largest annual fundraising event which raised more than £46,000 in 2010 – a record amount.



This year, we are celebrating the tenth anniversary of this popular annual road race. From a field of 250 runners in 2002, we welcomed more than 1,100 runners of all ages and abilities last year. What makes it extra special is that many of the runners come back each year to take part, beat their personal best times and, of course, support the LJMC.

As always, there is a lot to be done to organise and promote this event and we welcome any support and help you might wish to give.

We particularly welcome people to help promote the event in schools. If you are able to 'champion' the event at a local school, please get in touch with the Race Director, John Hambleton (07779 458285). We can supply you with leaflets, entry forms and other material.

We also welcome sponsors for the individual trophies. If you or your company would like to find out more, please contact John Hambleton.

Sponsors' names are listed in our promotional material and also engraved on the trophies. Sponsorship starts from £100.

Offers of help with our fundraising activities will be welcomed by our Community Fundraiser, Sue Hordyj (01923 844589).



Sunday 25th September

(entry opens in May)

Further information from:

07779 458285

www.moorpark10k.org.uk

Volunteers flock to the LJMC

New projects and new services led to a recruitment drive for volunteers with an overwhelming response beyond our wildest dreams.

With the new iPoint information service and other information projects starting, it was clear that more volunteers were needed.

A couple of open days were planned and the local press were contacted.

The story hit the front page and, before we knew it, the telephone was ringing off the hook with dozens of people enquiring about the available opportunities.

More than 80 people came along to the open days with many others coming later as word spread.

We were absolutely delighted with this response from some truly wonderful and amazing people.

It took a while to interview everyone and identify where we might best utilise their skills but we have gradually worked through the long list and the first volunteers have now started.



Special Lingerie Evening

The next **Special Lingerie Evening** at **John Lewis, Watford** will be held on **Thursday 12th May 2011**.

We always look forward to these events which are organised by the Lingerie department for ladies who have had breast surgery. The highlight of the evening is always the fashion show by members of the Trojans Breast Cancer Support Group.

There is a nominal charge of £2 for tickets which are available from the LJMC. Please call the Helpline (01923 844014) to book.

Get fitted, get rewarded

Marks & Spencer is retraining their bra fitters and inviting ladies who have special bra fitting requirements following surgery to help with this training programme. As a 'thank you', ladies will be given a £10 voucher to spend on lingerie.

The training is taking place in specific stores on 24th March and 28th July. The nearest store to the LJMC is London Colney. Please call the store (01727 828418) to find out more.

Focus on... Support Groups

Over the last few years, the number of local support groups has grown considerably with new groups starting all the time as more people find benefit from this method of self-help. Self-help and support groups aim to help people through some of the difficulties that accompany a diagnosis of cancer, giving back a sense of control.

Cancer can be a lonely business and support groups can help reduce the sense of isolation, offering a safe haven where people can talk openly and express feelings and emotions to someone who has had a similar experience.

The relief at finding there are others in the same position was highlighted when OpenDoor talked with Cherry Mackie, the support group co-ordinator at the LJMC.

... cancer can be a lonely business...

Some years ago, Cherry was running a meeting of a local group. About 20 members had arrived and Cherry was busy serving refreshments, preparing for the evening to come amid the hubbub of general chatter.

Out of the corner of her eye, she noticed a lady open the door and start to enter. The lady paused, took in the scene, turned round and left.

Cherry slipped out after her and enquired as to whether she could help.

"I'm looking for the support group meeting," said the woman. "You've found it," replied Cherry. Tears welled up in the lady's eyes as she said, "I didn't know there were so many others in the same position as me."

What happens at support groups?

There are two main types of group:

Professionally led groups: This type of group is usually co-ordinated by a professional such as a specialist nurse.

Self-help groups: This type of group is usually run by its members although it may receive regular support and input from health professionals.

Winnie Nugent is the Urology Clinical Nurse Specialist (CNS) at Mount Vernon Cancer Centre (MVCC). One of the support groups she runs at MVCC, together with Cherry, is for men who have experience of prostate cancer.

She explained that it is typical that a group led by a health professional focuses on clinical issues so Winnie and Cherry organise the monthly programme of speakers to include health professionals working in all the different treatment areas.

These include oncologists, radiographers, dieticians and other allied professionals.

... something for everyone...

They balance the programme with some regular subjects as well as new topics so that there is something for everyone, regardless of how long they have been a member.

On talking with members, it was clear that they appreciate this approach. "Even if you've heard a speaker before, there's always something new to be gained from what they say," explained one man who has been coming along for several years.

After the talk and time for questions, tea is served and members can stay and chat. This is when much of the 'support' happens. A conversation about the speaker leads naturally into further discussion and questions. One man who has already had a particular treatment may share his experiences with another about to start the same regime.

... reassurance from speaking with someone who's 'been there'...

Winnie encourages this sharing of knowledge and experience. Indeed, when she sees patients in clinics, she actively encourages them to come along to the group as she knows the best way for them to get answers to their questions is to speak to someone who has had first hand experience.

This can be particularly beneficial to patients faced with different treatment options where she needs to remain objective.

The support group also helps Winnie in her role as a CNS as both have the same aims – to support people affected by cancer. For all her years of experience working with cancer patients, there is a different reassurance to be gained from speaking with someone who's 'been there'.

The Trojans Breast Cancer Support Group was started eleven years ago by one of the Breast Care Nurses. Ann Phillpot joined the group and, when changing work patterns necessitated a change of leadership, found herself 'volunteered' as the group's new Chairman.

... new members are welcomed and introduced...

Meetings start with a cup of tea and time for chat. Ann and Trojans Secretary, Wendy, keep an eye on the door for new members who are quickly welcomed and introduced.

Wendy organises the programme of speakers for the group who tend to be from less clinical backgrounds. They've had speakers on fashion and clothing, complementary therapies and even a laughter therapist, as well as from wig manufacturers and specialist lingerie suppliers.

After the speaker has finished, there's further time for an informal chat. Ann



laughs when she says she often finds herself having to throw the last people out, rather like pub closing time. Clearly it's a very successful and lively group.

Although the group has occasional input from health professionals, it is run by the members for the members.

...mutual support...

As a former nurse as well as Chairman, Ann often finds people asking her questions about medical matters. "It's a fine line between sharing your own experience and giving advice," she cautions. Another valuable role that support groups play is to signpost people to sources of further information and Ann is quick to highlight the many reliable websites and leaflets available. Ann finds running the group extremely rewarding personally. "It's good to be able to give," she said. As well as having strong support from her husband, Ann receives support from members of Trojans too. "It's a question of mutual support – it's not a one-way process," she stresses.

When's the best time to join a support group?

One of the many benefits of support groups is that they welcome people at all stages of their cancer journey, from the newly diagnosed to patients who have long since ended treatment.

It is the nature of the 'shared experience' that provides such immense strength to support groups, no matter when that experience was gained.

Many patients find that they can only begin to talk about their cancer after active treatment has finished. However, they may find it difficult to talk to friends and family who may believe that, now they are well, they can put things behind them. To find a safe and confidential place in which to open up and express their feelings can be a huge relief.



What else do support groups offer?

Most support groups offer regular meetings, usually monthly. Outside of these they may also offer other services such as complementary therapies, counselling and bereavement support, a telephone helpline, practical help and home visits.

How much does it cost?

Some support groups charge a modest membership fee and/or an attendance fee. Others may only charge for refreshments. Charges usually depend on whether or not the group has to pay to hire the meeting venue.

What other support is there?

New Perspectives is a self-management course run by Macmillan Cancer Support. Participants meet weekly for six weeks to learn new skills and techniques to help manage their diagnosis.

The course is designed to help people with cancer to regain their confidence and enjoy a better quality of life.

A similar course for patients from the South Asian community is also being run at the LJMC.

Please contact the LJMC Helpline (01923 844014) for further information including details of the next courses that will be run at the LJMC.

The LJMC holds a list of support groups in our catchment area so please get in touch with the LJMC Helpline (01923 844014) or download a copy from our website: www.ljmc.org

Personal reflections

When James* was diagnosed with prostate cancer in 2007, the very word 'cancer' filled him with fear and dread. He was concerned for his family and for what the next few months would hold for them all. He had more questions than answers and anxiety that dominated every waking moment. What would treatment be like? What would the side-effects be?

James had been given a leaflet about the Prostate Cancer Support Group by the nurse at his clinic appointment and, on the basis that a problem shared is a problem halved, decided to go along to the next meeting.

When he met other men who had already trodden the path on which he was about to embark, he was able to share his problems and fears. He found answers to his questions from people who really knew and he started treatment feeling much better prepared for what lay ahead.

He did admit that he felt a bit lost at the first meeting of the group but soon felt comfortable and it wasn't long before he was offering support to new members who were themselves about to start treatment.

Like James, Andrew* was also frightened by his diagnosis. Andrew's wife had picked up a leaflet about the support group and passed it to him. "One of the best things she ever did," he declared.

Andrew particularly appreciated being able to ask questions in a frank and open way without the need for euphemisms. Prostate cancer affects many personal areas of a man's life and it has been really helpful to be able to talk about these issues.

If they could summarise the support group in one word, it would be 'optimism'. David and Andrew describe the group as happy; they have a good laugh – so often the best medicine.

Thank you so much...

Fundraising activities November 2010 – February 2011

- Despite the snow at the beginning of December, Middlesex County Automobile Club's annual Rockingham Stages was able to go ahead, raising £1,000. Rob Brook's fundraising of £100 was matched by his employer, Cadbury UK.
- Sheila King sold handmade cards to raise £20
- Staff at the Harrow office of Blaser Mills Solicitors raised £80 through a range of fundraising events over the last year.
- As President of the Inner Wheel Club of Greenford, Julie Hendry chose the LJMC as her special charity. She organised a quiz night to raise £310.
- Pilates instructor, Mary Clarke-Mills, took a LJMC collecting tin to her classes with pupils donating £30.
- Pauline Hurst and staff at Manor Farm Library organised a jazz concert to raise £350.
- Staff at the Concorde Club Admin Office sold doughnuts to raise £20.
- Staff at Print.Uk.Com held a charity collection to raise more than £250.
- Steve Young took part in the New York Marathon, completing the hilly course in a personal best of 5 hours 4 minutes. He thoroughly enjoyed the atmosphere which was helped by knowing that he had raised £250 for the LJMC.

Organisations who have supported the LJMC include:

- B'nai B'rith (Jerusalem Lodge)
- Oceanteam Logistics Ltd
- Hillingdon branch of the British Sugarcraft Guild
- Donald Forrester Trust

Congratulations to...

- Elise Toshman and Jeff Carson celebrated their 80th birthdays and asked for donations to the LJMC instead of gifts.

In loving memory

Thank you to the families who asked for donations to be made to the LJMC in lieu of flowers in memory of:

- Mike Burgess
- Malcolm McKaig



Splashing out

Following the hugely successful sponsored swim organised by Lesley Ferguson and friends last year, another marathon swim is planned for 2011.

If you are interested in taking part, please call
LJMC Community Fundraiser,
Sue Hordyj
(01923 844589).



Cat Creed, together with friends and family undertook a 50-mile cycle ride round the Milton Keynes area in memory of her mother, Isabel. From the money raised they were able to make a donation of £340 to the centre.

Counter collections

Thank you to the patrons and customers of the following venues that display our collecting tins:

- Costa Coffee, Mount Vernon Treatment Centre
- Misty Moon, Northwood
- The Partridge, Watford
- The Western Club, Acton
- Old Northwood, Northwood Hills
- William Hill, Rickmansworth
- Café Loco, Moor Park
- Ducks Hill Garden Centre, Ruislip
- Food Fayre, Ruislip
- Dick Whittington, Watford
- Adams Opticians, South Oxhey
- Bouticare, Ruislip
- Ye Olde Greene Manne, Northwood
- The White Bear, Rickmansworth
- NatWest, Northwood

If you are able to find a good home for one of the LJMC collecting tins in your local shops, pubs or clubs, please get in touch with Sue Hordyj (01923 844589).

Shopping online?

Don't forget to shop via our webshop:

www.buy.at/ljmc

and help raise money for the LJMC at the same time.



Staff at NATO Headquarters in Northwood continue to support the LJMC throughout the year with various fundraising activities. LJMC Marketing Manager, Buzz Coster, was presented with a cheque for £1,500 by Commander-in-Chief Fleet of the Royal Navy, Admiral Sir Trevor Soar KCB OBE.

Christmas at the LJMC

Christmas was certainly the season of goodwill last year. Many of our supporters used the festive season as an opportunity to support the LJMC including:

- Lyn Metcalfe made a donation instead of sending Christmas cards to her friends at St Mary's Church, South Ruislip
- Maureen Connelly and her colleagues at British Airways donated money to the LJMC instead of giving Christmas cards to each other
- Alison Leah and members of her family made their own Christmas cards and hand delivered as many as they could, donating the money they would otherwise have spent to the LJMC
- Each year, the Vafiadis family decorates their house with Christmas lights. Sadly, Androulla Vafiadis died in 2010 but her husband, Seth, and daughter, Sophia, were determined to go ahead with the Christmas decorations in her memory. They raised £220 for the LJMC.
- Staff at the Pinn Medical Centre raised £53 instead of sending Christmas cards to each other.
- Mrs S Creedon made a donation instead of buying Christmas cards.
- Once again, staff at Rooks Heath College for Business & Enterprise put a poster up in the Staff Room which staff signed with Christmas greetings to each other, raising £145.
- John and Frances Denton took a stall at their local Christmas Fayre and raised £25 for the LJMC.
- Girls at St Helen's School in Northwood ran a LJMC stall at their Christmas Fair to raise £75.
- We are immensely grateful to members of Ruislip-Northwood Rotary Club who braved the freezing conditions at a bucket collection in Ruislip in December to raise more than £950.

The Appeals team approaches Christmas with trepidation as the LJMC selection of Christmas cards goes on sale.

Will anyone like the designs they chose?
Will anyone buy them?

In 2010 they need not have worried as they experienced their best ever sales figures and ran out of nearly all the stock, raising £8,000 in the process.

If you bought our cards, thank you for your support! We're sorry if we'd already sold out of your choice of cards when you placed your order.

Despite the fact that British Summer Time is imminent, the team is already hard at work choosing a completely new selection for 2011.

Special thanks to the wonderful team of supporters who sold our Christmas cards both here at Mount Vernon and also through other outlets, contributing to this fantastic, record-breaking total.



We were delighted to have the opportunity to provide a gift wrapping service in the Harlequin Centre, Watford just before Christmas. This was a very enjoyable, fun event which was also very profitable raising more than £560. Thank you to everyone who helped.

If you would like to organise or help with a fundraising event for the LJMC, please get in touch with our Community Fundraiser

Sue Hordyj
01923 844589

Sue particularly welcomes offers of help with the tin collection in June and also at the Stewarts Law Moor Park 10k in September (see page 3)

Raffles galore

Our Christmas raffle – **Tickets & Treats** – was a huge success and raised more than £3,500. Thank you so much for your generous support of this event.

Thank you also to the donors of the wonderful prizes:

- Atelier Hairdressers, Northwood
- The Barn Hotel, Ruislip
- Blackhorse Restaurant, Shefford
- The Bricklayer's Arms, Flaunden
- Marks & Spencer
- Presence, Watford
- Snow Centre, Hemel Hempstead
- and other anonymous supporters

Tickets have now gone out for our annual

Easter Egg Draw which will take place on Monday 18th April.

If you haven't received yours or you would like more, please don't hesitate to get in touch with Sue Hordyj (01923 844589).

Sue also welcomes donations of Easter eggs and other seasonal goodies as prizes. Please get in touch!



Tin collections

Thank you to everyone who helped at our tin collection at Tesco, Pinner. Despite the freezing cold, we raised £250.

We'll be holding another tin collection at

Tesco, Rickmansworth
on 23rd June 2011

If you can spare an hour to help (it'll be warmer in June!), please call
Sue Hordyj
(01923 844589).

Information service goes mobile

In the last issue of OpenDoor we reported that the LJMC had been awarded Beacon status for the implementation of the new Patient Information Prescription service (IPS). We're delighted to report on progress...

As a Beacon site, we are blazing the trail, testing and trialling the system so that we can share our experience with others.

We have been delighted to receive the support of Jenny Freeman who has been seconded by the National Cancer Action Team to work as a facilitator, helping us set up new projects and providing a link with other Beacon sites.

Jenny brings huge experience to the LJMC having worked in project management within the NHS for a number of years, including implementing change within cancer services. She is with us for six months so we are making the most of her expertise!

The early days of implementing the IPS have been challenging and rewarding in equal measure as the Information team identified the tasks that lay ahead.

The IPS provides a simple and quick way to provide information for patients and carers using an online system that collates good quality, nationally available information into a personalised pack.

The original idea was that a healthcare professional in the clinic could use a

checklist to identify suitable publications for patients. The patients would bring the list to the LJMC where the publications would be printed out for them.

Seeking to 'go the extra mile', Macmillan Patient Information Lead, Theresa Sullivan who is heading up the project, believed that it would be more helpful to take the system to the patients, rather than expecting them to come to the LJMC.

We have therefore identified an area in the Outpatients department in the Cancer Centre where we are setting up 'iPoint' – a mobile information service where patients can stop as they leave the clinic to pick up the leaflets they need.

Initial trials of the service have been conducted with great success for all – patients, carers and healthcare professionals – and the service will launch properly in April.



NCAT facilitator,
Jenny Freeman

Renewal of funding for Art Psychotherapy

We were delighted to hear from the Trustees of the Corinne Burton Memorial Trust that they are extending their funding of our Art Psychotherapist post for a further year.

This is welcome news as demand for the service has grown significantly since Shona Elrick joined the LJMC team in January 2010.

Shona's diary is now fully booked as word of the service has spread and patients have become aware of this supportive therapy.

As well as seeing patients on a one-to-one basis, Shona also runs a weekly open group that patients can come to as often as they wish and this has become extremely popular.

"I was quite nervous that first session – however I found using the chalks really relaxing and was quite surprised to find that I had filled the whole paper. It gave me confidence."



Donation form

I would like to make a donation to the Lynda Jackson Macmillan Centre

I enclose a cheque for £ made payable to 'Lynda Jackson Macmillan Centre'

Name:

Home Address:

Telephone:

giftaid it

I am a UK taxpayer and wish this donation (and any others I may subsequently make*) to be treated as a Gift Aid donation, increasing this donation by 25% [To qualify for Gift Aid, what you pay in income tax or capital gains tax must at least equal the amount we will claim in the tax year] *delete if applicable

Signature: Date:

Lynda Jackson Macmillan Centre, Mount Vernon Hospital, Northwood, Middlesex HA6 2RN

Registered charity no. 1053338

Office use:

Spr11 TQ: