

KATERINA'S ROLLER COASTER RIDE WITH LYMPHOMA

After having surgery in November 2003 to remove her gall bladder, Katerina Tzikas was diagnosed with an unusual and very aggressive form of sub-cutaneous lymphoma.

"My life was turned upside down," said the social worker, 38, from Melbourne.

"I'd taken a week off for my gall bladder so it was all a bit of a surprise. I went in with one thing and came out with something else."

Four days after the operation, Katerina found a 3cm lump in her groin that had come up overnight,

so she went to accident and emergency: "They thought I had a bowel hernia but found it was a lymph node."

The node was removed and Katerina was told she had peripheral T-cell lymphoma.

"This isn't a good lymphoma, but the good thing was I was only at Stage 1 and it hadn't moved to any other lymph nodes or the bone marrow.

"A lot of the symptoms had been camouflaged by my gall bladder. I'd been feeling quite sick and rundown and always had a cold or felt like I was getting one."

Katerina had three cycles of CHOP* chemotherapy and radiotherapy and was surprised at how well she'd handled the treatment.

"I felt nauseated and lost my hair, but I didn't vomit once."

What she found most confronting, apart from dealing with her mortality, was the loss of her long, wavy hair: "It went down to my bum and was my feature thing."

When her treatment finished, in March 2004, Katerina got on with her life and returned to work for Carers Victoria, in the aged program. Before her diagnosis Katerina had already chosen to work four days a week. "I'd seen the importance of living and decided life was too short to work too much."

She had checks every three months, then every six months and was going to the gym regularly to get fit. Then in May 2006 she found another lump, this time in the lymph node under her right arm.

"In retrospect I'd noticed some of my gym workouts were a bit hard.

"For me the symptoms of my lymphoma have always been very subtle - my lymphoma grows so fast."



Katerina Tzikas at various stages of her battle with lymphoma

Her second diagnosis turned out to be a different T-cell lymphoma – anaplastic large cell lymphoma: "It was more aggressive and in the top half of my body. They (her doctors) were very perplexed about how this could happen and found me a bit intriguing."

Katerina had another four months of a more aggressive chemo but wasn't able to complete the last cycle of her treatment because she had several blood clots and was too unwell.

"It was pretty yucky – more intense. I had to be treated in hospital and had more side-effects."

In early 2007, a new romance blossomed for Katerina, then she relapsed again in February that year. After a bone marrow transplant three months later, using stem cells harvested in 2006, Katerina and her boyfriend moved in together.

"I went home and recovered slowly."

But after the transplant Katerina suffered depression and when she relapsed a third time, in October 2007, she found it hard to accept.

"They said they couldn't do anything more for me and I was told the cancer would take over my body and that in a year or so I'd be dead," explained Katerina.

"I had palliative radiotherapy to control the symptoms but it wasn't treating the lymphoma."

In February last year, after Katerina found another lump in her neck, she was accepted into a clinical trial of a drug called desipeptide.

* CHOP is a combination of cyclophosphamide, doxorubicin, vincristine and prednisone.

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RESEARCHERS REPORT ON LYMPHOMA CAUSES

The world's leading lymphoma researchers, from North America, Europe and Australia shared their latest findings at the seventh annual meeting of InterLymph, in Sydney last year.

The incidence of lymphoma* which has risen dramatically in developed countries during the past 50 years is now the fifth most common cancer in Australia, said the Leukaemia Foundation's General Manager - research advocacy and patient care, Dr Anna Williamson.

"Therefore an international effort to understand the causes is essential if we are to develop better treatments and cures," said Dr Williamson.

"At the symposium, research results from 40 studies were presented, with severe infection and diseases of the immune system appearing to be the most important risk factors for patients developing lymphoma."

Lymphomas, particularly, non-Hodgkin lymphoma (NHL), are known to be caused by inherited immune disorders, immunosuppressive drugs, viruses such as Epstein-Barr virus, many chemicals (such as pesticides, organic solvents, persistent pollutants, hair dyes and chemotherapy), as well as lifestyle factors such as diet.

Researchers at InterLymph reported that specific gene variations could make people more susceptible to these risk factors, while environmental factors could explain incidence

variations between different countries.

Concentrating on the risk of hair dyes, Dr Yawei Zhang from Yale School of Public Health and his research colleagues analysed the personal hair dye use of more than 4500 NHL patients. The team found that women who began colouring their hair before 1980 had a greater risk of developing NHL.

After 1980, many cancer causing hair dye chemicals were changed, however, Dr Zhang found that women who started dyeing their hair after 1980 also had an increased risk of developing follicular lymphoma. Frequency and duration of use as well as permanent, dark colour dyes could place women at greater risk.

An Australian research team reported that people with asthma or hay fever are up to 25% less likely to develop B-cell lymphoma, the most common type of NHL. It was also reported that recreational sun exposure (which stimulates vitamin D production) may reduce NHL risk.

Former Leukaemia Foundation research grant recipients, Associate Professor Andrew Grulich and Dr Claire Vajdic from the University of New South Wales, played a key role in organising the InterLymph symposium. The Foundation was one of the sponsors.

** The incidence of lymphoma worldwide appears to have been levelling out since 2000.*

LYMPHOMA COALITION TO BECOME INCORPORATED NFP

Members of the international Lymphoma Coalition met over three days in San Francisco last December, in conjunction with the annual American Society of Hematology (ASH) meeting.

At the Lymphoma Coalition's annual general meeting, members voted unanimously to incorporate the Coalition. Its status will be changed this year to become an international non-profit organisation, registered in Belgium.

This will give the Coalition more credibility and will help with fundraising, according to the Leukaemia Foundation's General Manager - research advocacy and patient care, Dr Anna Williamson, who was voted in as one of the seven inaugural Board Members at the AGM.

The Lymphoma Coalition was formed in 2001 and has members from 40 countries. In 2008, Venezuela, Slovenia, Denmark and Uruguay joined the organisation.

Coalition members from Australia, Argentina, Bulgaria, France, Germany, Mexico, Slovenia, United Kingdom, Uruguay and the United States attended the 2008 annual meeting in San Francisco.

They took part in a mentoring day that included media and public relations strategies (Blaz Kondza, Slovenian Lymphoma Patients Association) and the young adult experience with lymphoma from diagnosis to long-term survivorship (Jennifer Mills, Lymphoma Research Foundation, USA). There were presentations by two Australians – Dr Anna Williamson, on advocacy and Professor Rob Sanson-Fisher, on psychosocial research.

(See separate story on page 8.)

At a *Partnership for Patients* breakfast briefing, Professor Jesús San Miguel, of the University Hospital in Salamanca (Spain), gave an update on the latest research data being presented at ASH including new drug combinations for non-Hodgkin lymphoma.

An interactive panel discussion on strategic approaches to patient advocacy also involved Dr Williamson along with Anita Waldman (Myeloma Euronet), David Girard (International Myeloma Foundation) and Jan Geissler (CML Advocates).

The Coalition's website, www.lymphomacoalition.org was updated in 2008 and can be uploaded in five languages – English, French, German, Spanish and Italian.



Lymphoma Coalition members at the annual meeting in San Francisco

NATURAL KILLER CELL CONTROL OF LYMPHOMA

The body's front line defence against disease - one type of white blood cells known as Natural Killer cells - is being targeted to develop a new treatment for lymphoma.

Natural Killer cells form an important part of the body's immune system and have the ability to recognise and kill cancerous cells, including lymphomas.

Structures on the outside of Natural Killer cells, known as receptors, are thought to allow the cells to specifically recognise lymphoma.

In 2008, the Leukaemia Foundation awarded a \$10,000 grant to Honours student, Christopher Chan, to investigate how Natural Killer cells detect tumours.

Christopher looked at the role of a newly described receptor, called DNAM-1, on Natural Killer cells. He studied how the receptor contributed to Natural Killer cells recognising and subsequently controlling B-cell and T-cell lymphomas.

"The research progressed well and I found that the DNAM-1 receptor appears to play an important role in the Natural Killer cells' recognition of cancer," said Christopher.

"Ideally, we'll be able to target this receptor to develop treatments which enhance the Natural Killer cells' ability to eliminate lymphomas," he said.

Christopher undertook his Honours project in Professor Mark Smyth's laboratory at the Peter MacCallum Cancer Centre in Melbourne.

He hopes to continue a career in research by undertaking a PhD in cancer immunology.

"I firmly believe that the immune system plays a critical role in controlling the development and progression of cancer," said Christopher.

"Receiving a Leukaemia Foundation research grant confirmed to me the importance of understanding how the immune system can be used to develop treatments for lymphoma."



Christopher Chan - funded by the Leukaemia Foundation to research Natural Killer cells

NEW DRUGS FOR LYMPHOMA

Two new drugs have been approved by the U.S. Food and Drug Administration for treating lymphoma.

Bendamustine hydrochloride (Treanda®, Cephalon, Inc.) has been approved for the treatment of patients with indolent B-cell non-Hodgkin lymphoma (NHL) that progressed during or within six months of treatment with rituximab or a rituximab-containing regimen.

According to Queensland Institute of Medical Research, Clinical Immunohaematology - Laboratory Head, Associate Professor Maher Gandhi, most patients with indolent NHL eventually become resistant to existing treatments such as chemotherapy or monoclonal antibodies.

"New treatment options like bendamustine are needed to improve patient outcome. Trial data indicates that bendamustine injected as a single agent is an effective and well-tolerated chemotherapy that can delay progression of lymphoma," said Dr Gandhi.

"Current trials are assessing the role of the drug combined with more traditional chemotherapies and/or with antibodies such as rituximab."

Also recently approved for patient treatment in the U.S. was Enileukin diftitox (Ontak®, Eisai Medical Research)

for persistent or recurrent CD-25 positive cutaneous T-cell lymphoma (CTCL).

This rare and slow-growing form of lymphoma causes itchy, dry skin patches that can develop into tumours in the skin and other organs.

Enileukin diftitox was produced by genetically fusing a toxin to an immune system protein, called CD25, expressed by the lymphoma cell, enabling the drug to specifically target and destroy the cancerous cells.

"About 60% of patients with CTCL have lymphoma cells which express CD25 and unfortunately only these patients will benefit from the new drug," said Dr Gandhi.

"A Phase III study of patients with advanced CTCL who had failed at least one other treatment, showed promising disease responses with Ontak given as an intravenous injection, including a proportion of subjects who achieved complete remission.

"Such complete remissions would not be expected in an untreated group. However, because Ontak can also affect the normal immune system, further studies are needed to assess the long-term safety and efficacy of the product."

TAKE PART IN THE WORLD'S GREATEST SHAVE 2009

2009 is the 11th anniversary of one of the nation's biggest and most popular fundraising events - the Leukaemia Foundation's World's Greatest Shave. It runs from March 12 - 14, so join the action and shave your head or colour your hair to raise funds to help support the 5000 Australians who will be diagnosed with lymphoma each year. Public shave events, where you can have your head shaved, will be held across the country. Check our website to confirm times and venues. You can organise your own event to coincide with a sundowner at work, a weekend BBQ with family



and friends, or a post-game event at your team's clubhouse.

Will you be brave and shave? For more info or to sign up, go to www.worldsgreatestshave.com or call 1800 500 088 today.

CANCER PATIENTS WANT THE TRUTH AT ALL COSTS

From Canberra Times, 19 November 2008, p3; The Age, 19 November 2008, p12

Some cancer patients have learnt their oncologist did not tell them about a relevant drug because the treatment was too expensive, a study has revealed.

The finding reflects research showing up to 40% of oncologists would hesitate to inform a patient of a drug, which might cost up to \$1000 a week.

University of Sydney Associate Professor of medical oncology Fran Boyle said many oncologists felt it was kinder not to mention expensive drugs not subsidised on the Pharmaceutical Benefits Scheme.

Professor Boyle said some of these drugs might increase the chances of curing a patient or extend their survival.

"Oncologists are in a terrible dilemma," she said. "If they say to the patient, 'Here's an option for your treatment, but the cost is going to be exorbitant' - is that going to add so much to the distress of that patient, when they're already in a vulnerable position?"

Professor Boyle, an oncologist at Mater Hospital in Sydney, spoke to fellow oncologists at a Clinical Oncological Society meeting in Sydney yesterday. She said cancer patients wanted them to be more up front about available drug treatments.

Several participants in the study had found out about a drug after being treated, which they thought would have been useful in their recovery. They described this as a real breach of trust, Professor Boyle said.

"Almost all the women we surveyed, 96%, said they wanted to be informed about high-cost drugs, whether or not they could afford them," she said.

Breast Cancer Network Australia chief executive Lyn Swinburne said the research sent a clear message from women: they wanted to be told the whole story.

"These results provide that knowing a treatment choice is far more important than any potential distress at not being able to afford the treatment," Ms Swinburne said.

The survey, involving almost 50 breast cancer patients across Australia, was conducted by University of Sydney medical student Emily Kaser with Breast Cancer Network Australia.

The Leukaemia Foundation's National Lymphoma Co-ordinator, Tania Cushion, would like to know if people affected by lymphoma would like to know about all possible treatments regardless of their costs. You can contact Tania by email: lymphoma@leukaemia.org.au or phone: 03 9949 5821.

HAVE YOU GOT A STORY TO TELL?

Many people are comforted and encouraged by the positive stories of others who are living with lymphoma. Reading about other people's courageous experiences with the disease can provide real hope, especially to those who feel isolated in some way. In future issues of *Lymphoma News* we would like to share your story about your experience with lymphoma and for the next newsletter, the theme is **the importance of hope**. Here are some topics within this theme:

"I didn't believe in miracles until"

"I shouldn't have survived but"

"They told me I couldn't do it yet"

We urge you to share your story with us to help inspire hope in others – real stories by real people. You can forward your story by email to Tania Cushion: lymphoma@leukaemia.org.au or by post to: Leukaemia Foundation, GPO Box 9954, Melbourne, Vic 3001.

KATERINA'S ROLLER COASTER RIDE

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"It was limited to cutaneous and sub-cutaneous lymphoma patients, had been trialled in the U.S. and had not been long in Australia," she said.

"It's a more targeted chemo. It doesn't blast your system completely. It blocks the lymphoma from progressing and has less noticeable side-effects.

"I didn't lose my hair again which was nice but it was a pretty intense time," said Katerina who split up with her boyfriend in May last year."

She started the six-month trial in April 2008 and when she completed it, she was in remission.

"It's pretty amazing. The lymphoma was spreading through my system and had moved to pretty much all my organs but after two cycles of this new treatment, they couldn't find even a dot of lymphoma. It was a pretty good response.

"I'm still recovering and have to pace myself," said Katerina whose mum, Kalliopi, 63, and dad, Vlasios, 74, were "wonderful parents and dedicated and fantastic carers".

"They would visit me pretty much daily while I was in hospital,

drove me to all my hospital appointments and provided a safe and comfortable space for me in their home."

Katerina is considering going back to work this month – doing two days a week on a project from home.

"I'm feeling like I can make a few plans - getting healthier, going to Greece where my family is from, spending time with my nieces and nephews, enjoying food, outdoor activities and music festivals. And I'd like to fall in love again – be nice to give that another go."

"The Leukaemia Foundation helped me out financially when I has having trouble with some bills. And I joined the lymphoma support group in February 2008 and that's been really good – meeting other people with the same lymphoma. When I couldn't get out, I used the Talk Blood Cancer* website but I like face-to-face contact." - Katerina Tzikas

** The Leukaemia Foundation's online network discussion forum for blood cancer patients, their families and carers - www.talkbloodcancer.com.*

NEW NATIONAL LYMPHOMA CO-ORDINATOR

Not all lymphoma patients are aware that the Leukaemia Foundation's services are available and tailored specifically to them.

The Foundation's education, support, practical assistance and research funding covers all the blood cancers and are for people with lymphoma as well as leukaemia, myeloma and the related blood disorders.

Approximately 5000 people in Australia will be diagnosed with lymphoma this year and the Foundation is working hard to ensure its services are known and available to this patient group.

To help facilitate this, the Foundation has created a new position - National Lymphoma Co-ordinator – and Tania Cushion, a senior member of the Support Services team in Melbourne, takes up this role this month.

Tania is an experienced haematology nurse with a great passion for working with people affected by lymphoma. She will continue to be based in Melbourne and education, support and collaborating with related health organisations are part of her initial focus.

This year more than 50 education and support programs will be provided to lymphoma patients nationally by the Foundation's highly trained support services team.

Multiple health professional education forums will be conducted as part of Leukaemia Foundation's role in commemorating *World Lymphoma Awareness Day* (15 September 2009).

INTRODUCING TANIA CUSHION

The Foundation's National Lymphoma Co-ordinator, Tania Cushion, grew up and did her nurse training in Ballarat before moving to Melbourne as a qualified nurse.

In her graduate year, Tania had the opportunity to work on the haematology ward at the Alfred Hospital and realised she had a passion for this work.

"I knew that in my future somewhere I would do this work again," said Tania.

But first she answered the call to travel and spent two years working, travelling and having a great time in Europe and America. When she returned to Australia she went back to Melbourne and took on a challenge.

"Needing to stimulate my brain again, I enrolled and did my Graduate Diploma in Cancer Nursing which I thoroughly enjoyed," said Tania who also worked casually at different hospitals.

"A job came up at the Royal Melbourne Hospital, at their new bone marrow transplant ward, and I was so excited to think I could get back into the haematology world again. Luckily they employed me and I haven't looked back."

Tania was at the Royal Melbourne for eight years. She worked on the bone marrow transplant ward and the oncology/haematology ward where she became the Associate Nurse Manager of the Day Oncology/Haematology Ward, as well as the Aphaeresis Co-ordinator.

It was in this role that Tania found her interest was stronger in the area of blood cancer compared to the solid tumours: "I was constantly drawn to research, projects and learning treatments for the blood cancers."

To support lymphoma patients who live in regional and remote parts of Australia, a lymphoma telephone discussion forum will be established in 2009. Facilitated by a trained lymphoma nurse, this valuable service will enable lymphoma patients to offer advice and support for each other within a safe environment.

The Foundation is also committed to working collaboratively with the health industry and related organisations to provide the best care and support for patients with lymphoma and their loved ones.

- In a partnership deal with Cancer Australia, the Foundation will increase its funding to lymphoma research to improve patient outcomes;
- The Calvert Jones Foundation has partnered with the Leukaemia Foundation to produce a DVD that will outline treatment options for people with lymphoma and;
- The Foundation has collaborated with the Late Effects Clinic at the Peter MacCallum Cancer Centre to fund a haematology late effects nurse co-ordinator for three years. This clinic supports survivors of lymphoma and other blood cancers who find they are having side-effects from their treatment years after being 'cured'.

For more information on the Leukaemia Foundation's 2009 national lymphoma program, please contact Tania Cushion by email on lymphoma@leukaemia.org.au or call your local support services co-ordinator on 1800 620 420.

Tania then decided to broaden her horizons and in November 2001 she jumped at the chance to work at the Leukaemia Foundation, based in Melbourne.

"I had the privilege to meet and work with a truly inspiring woman, Maria, who is living with lymphoma, and realised there was so much more we could be doing to support this group of people.

"Maria was my catalyst to start up the first disease-specific Lymphoma Support Group, in November 2007. It continues today with a wonderful group of people who inspire me daily to do so much more.

"I am so excited about my new role and helping to facilitate the direction of lymphoma care across Australia, providing the best care and support for people with lymphoma," Tania said.



Tania Cushion and the 'tree of hope' covered in messages of support to patients with lymphoma

PARTNERSHIP WITH CANCER AUSTRALIA

The Priority-driven Collaborative Cancer Research Scheme (PdCCRS) is an Australian government research-funding program to help reduce the impact of cancer in the community and improve outcomes for people affected by cancer.

To support PdCCRS, the Leukaemia Foundation and Cancer Australia will become formal research partners this year, with a focus on lymphoma.

The Foundation has identified lymphoma as a significantly under-funded disease in proportion to its incidence in the Australian community. Cancer Australia agrees and will list lymphoma as a key research priority for the PdCCRS in 2009 and beyond.

This is an excellent outcome for the Foundation and great news for the 5000 Australians diagnosed with lymphoma each year and thousands of others diagnosed in earlier years.

In Australia, lymphomas are the most common form of haematological or blood cancer, they are the fifth most common form of cancer and the sixth most common cause

of cancer death. Their incidence has more than doubled over the past 20 years for no known reason.

The partnership between Cancer Australia and the Leukaemia Foundation will ensure at least one project to the value of \$200,000 per year for three years will be funded for collaborative, outcomes-based research into the agreed research priority - *Innovative approaches to improve outcomes in human lymphoma.*

The call for research applications is now open and closes on March 17. After selection of the best projects, funding will begin in late-2009.

The Foundation's National Manager for Vision, Dr Susan O'Brien said the new partnership was a fantastic opportunity for the Leukaemia Foundation and Cancer Australia.

"This is a significant research initiative which will enable collaboration between Australia's leading lymphoma experts and we believe it will make a major contribution to improving outcomes for lymphoma patients," Dr O'Brien said.

VOLUNTEERING FOR THE FOUNDATION

Hundreds of people around Australia volunteer their time to support the work and services of the Leukaemia Foundation. If you tell us about the great service you've received from one of our dedicated volunteers, we would like the opportunity

to share it with others in our newsletters. Send your story by email to Tania Cushion: lymphoma@leukaemia.org.au or by post to: Leukaemia Foundation, GPO Box 9954, Melbourne, Vic 3001.

TRAVELLING WITH MEDICINES

Restrictions on taking or sending PBS medicine overseas.

Under the Pharmaceutical Benefits Scheme (PBS) the Australian Government subsidises around 2500 prescription medicines. Exporting PBS subsidised medicines to people outside Australia leads to a significant financial loss to both the Australian Government and the community. It is also dangerous for people to take prescription medicine that has not been prescribed for them. The most common illegal export of medicines happens by post or people taking them in their luggage. People caught illegally exporting medicines face two years imprisonment and/or a \$5000 fine. Therefore it is important to read the following information, to ensure you meet all the legal requirements.

PBS subsidised medicines

It is illegal to take or send PBS subsidised medicine out of Australia unless it is for your own personal use or for someone travelling with you, such as a child.

The quantity of PBS medicine that you can take is restricted.

Before travelling you should contact the embassy of the country you are visiting to ensure the medicine is legal there.

You should also carry a letter from your doctor detailing what the medicine is, how much you will be taking and stating that the medicine is for your personal use.

You should leave the medicine in its original packaging so Customs can see who dispensed it, for whom it was dispensed, and the cost. Customs can detain any medicine it suspects is being illegally exported.

Non-PBS Medicines

Medicines that have not been subsidised by the PBS can be taken or sent overseas. However, you should still contact the embassy of the country you are travelling to, to ensure the medicine is legal there.

You should also carry a letter from your pharmacist stating the medicine has not been subsidised. Some overseas countries will require a letter from your doctor for any prescription medicine.

You should leave the medicine in its original packaging so Customs can see who dispensed it, for whom it was dispensed, and the cost.

Reciprocal health care agreements

The Australian Government has signed Reciprocal Health Care Agreements with several countries. This means Australian residents are entitled to assistance with the cost of medical treatment in New Zealand, UK, Ireland, Sweden, Netherlands, Finland, Italy, Malta and Norway. (See the website address below for information on individual countries.)

For more information

Medicare Australia has a 24/7 information line to answer all your queries. They advise getting information from them earlier rather than later as a phone call from the airport can be too late.

Travelling with PBS Medicines enquiry line: 1800 500 147
Translating & Interpreting Service: 13 14 50
www.medicareaustralia.gov.au/public, then Migrants & travellers > Travelling overseas.

SKIN LYMPHOMA - A RARE CHALLENGING CONDITION

Skin lymphoma, also known as cutaneous lymphoma, is a rare blood condition that manifests itself in the skin.

It most commonly presents as an itchy red rash that doesn't disappear or recurs frequently and is often mistaken for eczema according to Odette Blewitt, skin lymphoma nurse consultant at the cutaneous lymphoma clinic at the Peter McCallum Cancer Centre in Melbourne.

The clinic, a collaboration between the Peter MacCallum Cancer Centre and St Vincent's Hospital, is Australia's only truly multi-disciplinary skin lymphoma clinic. More than 400 patients from across Australia are treated at the clinic, headed by haematologist, Professor Miles Prince, dermatologist, Dr Chris McCormack and radiation oncologist, Dr Gail Ryan.

The clinic is internationally recognised and has an active research program.

"This is a very exciting time in the world of skin lymphoma because there are so many new treatments becoming available," said Odette.

Professor Prince is on the Board of Directors of the International Society of Cutaneous Lymphoma and established the NH&MRC guidelines for the management of cutaneous lymphoma.

The success of the Victorian clinic has resulted in development of the Australian Skin Lymphoma Network which has a national strategy developed by haematologists, dermatologists, radiotherapy oncologists, nurses and allied health workers around the country.

Two multi-disciplinary clinics have already been established to treat patients specifically with skin lymphoma - in Perth, with Dr David Joske, and in Adelaide, with Dr Briony Kuss.

The purpose of the Australian Skin Lymphoma Network is to:

- improve the methods and accuracy of diagnosis;
- improve the clinical skills of specialists managing the condition;
- improve the availability of treatments for this condition;
- improve access to patients of specialised nursing care and advice;
- increase the number of clinical trials available to patients.

While the most common types of skin lymphoma are T-cell lymphomas, about a fifth of patients have B-cell lymphomas.

Overall, skin lymphoma represents less than 2% of all lymphomas, with an annual incidence of approximately five new cases per year, per million people. Dermatologists most commonly diagnose people with the disease.

Due to the rarity of the condition, haematologists, oncologists and dermatologists would see a new case every few years.

The disease is complex and requires substantial expertise. There are 30 different subtypes of skin lymphoma which makes an accurate diagnosis challenging. The average time from the appearance of symptoms, to diagnosis, is three years.

The most commonly occurring type of cutaneous lymphoma is mycosis fungoides, followed by lymphomatoid papulosis. Sézary syndrome is rare but is the most aggressive type of skin lymphoma.

There is a range of treatments depending on the type of skin lymphoma, from steroid creams combined with sun treatment, and ultra violet ray treatment, to chemotherapy and/or radiotherapy for visible tumours and nodules. New treatments developed over the last few years include bexarotene, the fusion toxin denileukin diftotox, monoclonal antibodies and the histone deacetylase inhibitors such as vorinostat.

Odette Blewitt can be contacted on Tuesdays and Fridays by calling 03 9656 1111 (pager 7397).

The Leukaemia Foundation supports the ongoing development of the Australian Skin Lymphoma Network by providing secretariat services, banking and grant management, and communication services. Donations to the Australian Skin Lymphoma Network can be made using the Leukaemia Foundation donation slip attached to this issue of *Lymphoma News*.



Skin lymphoma nurse consultant, Odette Blewitt

TOP LYMPHOMA TIPS

People often learn a range of tips as they progress through their treatment for lymphoma. These may be about managing side-effects, how to deal with people, or the hospital system. Often patients say: "I wish I knew that before I started". We would like to share your 'hot tips' for managing life with lymphoma by including a selection of these in future issues of *Lymphoma News*. Here are some examples:

"Washing your mouth out three times a day with a glass of water containing two teaspoons of salt will help cure your

mouth ulcers after treatment and costs much less than the mouthwashes on the market. Just make sure you don't swallow!" (Graham, NSW)

"Try to do a little exercise every day. It feels hard at the time, but will help you to feel less fatigued in the long run. I make sure I walk around the ward a few times every day and I am convinced I feel the better for it." (Joan, WA)

Email your **Top Lymphoma Tips** to Tania Cushion: lymphoma@leukaemia.org.au or post them to: Leukaemia Foundation, GPO Box 9954, Melbourne, Vic 3001.

THE NEEDS OF PATIENTS AND SURVIVORS

Meeting the needs of people receiving treatment for and surviving cancers like lymphoma was addressed at the Lymphoma Coalition's mentoring day by Australian psychosocial researcher, Professor Robert Sanson-Fisher.

The Laureate Professor of Health Behaviour at the University of Newcastle's School of Medicine and Public Health is investigating the unmet needs of patients during treatment and the five survivorship years following treatment. Cancer survivors experience greater levels of anxiety and depression than the general community.

Professor Sanson-Fisher and his colleague, Tara Clinton-Harg, have developed a number of unmet needs questionnaires aimed at finding out what patients are concerned about in the areas of daily living, education, employment, relationships, emotions, their treatment centre, health care providers and treatment, and information.

"We are trying to get people to reach out and tell us about what they feel," Professor Sanson-Fisher said. "People feel things but they don't perceive that other people feel the same. "When you put 500 people together and they all feel or say the same thing – that has power."

Professor Sanson-Fisher and Ms Clinton-McHarg have identified the highest unmet needs of young patients and their parents, and adult cancer survivors and their principal supporters.

For young people the five highest unmet needs are:

- Making plans or thinking about the future
- Coping with changes in appearance
- Talking to people of the same age who have been through a similar experience
- Accepting changes to their future
- Not being able to do the same things as other young people.

For their parents, the highest unmet needs are:

- Worrying about the young person's cancer returning
- Feeling anxious
- Coping with seeing other parents lose their young person
- Feeling helpless
- Accepting changes to their young person's future

The highest unmet needs of adult cancer survivors are:

- Fears about the cancer spreading
- Being told they have cancer
- Feeling tired
- Knowing if the cancer has gone
- Feeling stressed
- Financial assistance and how to obtain it

For the principal support person of adult cancer survivors, the highest unmet needs are:

- Not knowing what lies in the future
- Worrying about the future of the person they are supporting
- Worrying about the person's cancer coming back
- Financial assistance and how to obtain it
- Knowing what information on the Internet to trust
- Feeling stressed

Professor Sanson-Fisher said psychosocial research, while in "its infancy", provides valuable information that can assist patients and their carers. It is an important tool for advocacy and provides credible information to organisations like the Leukaemia Foundation to assist in allocating scarce resources to improve patients' quality of life. The research group at the University of Newcastle welcomes any comments. Please email Rob.Sanson-Fisher@newcastle.edu.au.



Professor Robert Sanson-Fisher at the Lymphoma Coalition's mentoring day

EDUCATION AND SUPPORT PROGRAM ACTIVITIES

Lymphoma lunch	Feb 23	Sydney, NSW
Understanding Lymphoma	Mar 12 – 26	Central Coast, NSW
Lymphoma support meeting	Mar 4 / Apr 1	Melbourne, Vic
Taking Control	Mar 11	Bunbury, WA
Noarlunga coffee morning	Mar 11 / Apr 8	Noarlunga, SA
Taking Control	Mar 19 / Apr 23	Perth, WA
Fertility preservation	Mar 25	Nth Wollongong, NSW
All things transplant	Mar 26	Gippsland, Vic
Carers coffee group	Mar 27 / Apr 24	Adelaide, SA
Transplant education & support meeting	Apr 2	Melbourne, Vic
Post chemotherapy education	Apr 4	Rockdale, NSW
Before & after a stem cell transplant	Apr 22	Adelaide, SA
Understanding Lymphoma	Apr 22	Hobart, Tas

For more information and a complete list of education and support programs for lymphoma patients and families in your state, visit the education and support programs section on www.leukaemia.org.au.

Leukaemia Foundation Support Services
Ph: 1800 620 420 (Freecall)

National Lymphoma Co-ordinator

Tania Cushion Ph: 03 9949 5821

New South Wales / Australian Capital Territory

Ann Schiller Ph: 02 9902 2223

Queensland

Barbara Hartigan Ph: 07 3840 3840

South Australia / Northern Territory

Steve Marshall Ph: 08 8273 3515

Victoria / Tasmania

Samantha Schembri Ph: 03 9949 5824

Western Australia

Katey Stewart Ph: 08 6241 1020

OUR VISION TO CURE AND MISSION TO CARE

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.

The Foundation provides emotional support, accommodation, transportation and practical assistance for patients and their families. It also funds research into cures and better treatments for leukaemias, lymphomas, myeloma and related blood disorders.

The Foundation receives no direct ongoing government funding and relies on the continuous support of individuals and corporate partners to provide its services and to fund its research programs.

To find out more about the work of the Leukaemia Foundation and how we can help, phone 1800 620 420 or visit www.leukaemia.org.au.



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Disclaimer: No person should rely on the contents of this publication without first obtaining advice from their treating specialist.