Cancer was the furtherest thing from her mind when Anne-Marie Brandon of Chinchilla was suffering from a series of annoying skin complaints.

“I have never had good skin, but for the past 10 years I had battled increasingly worsening skin issues - rashes, acne and dry, itchy skin - and had tried many different creams and treatments,” Anne-Marie said.

“I came to accept that I was just afflicted with bad skin, but things kept getting worse and in early 2010 I developed an extremely itchy scalp. I literally became itchy from head to toe.”

Anne-Marie became determined to find answers when a large, extremely itchy lump developed on her scalp and she began to lose large patches of hair. Months of frustration followed.

“I visited my GP many times and, despite his best efforts, a diagnosis proved elusive and I tried a myriad of creams and antibiotics,” she said.

“The pathology report from a biopsy of the lump caused my GP concern and he organised an appointment with a dermatologist in Brisbane who, suspecting lymphoma, arranged further tests.”

On the day Anne-Marie and her husband William arrived in Brisbane she was diagnosed with cutaneous T-cell lymphoma (CTCL), a rare form of non-Hodgkin lymphoma which primarily affects the skin and can cause patches, plaques and tumours.

“I was immediately seen by a haematologist and by the end of the day we understood that I had cancer,” she said.

“I was told I had a tumour on my scalp that was going to require radiation as soon as possible and that although it was not likely I would ever be cured, the disease can be managed and most people with CTCL die with it, not from it.”

Reeling from the shock of the diagnosis, Anne-Marie and William’s primary focus became their three beautiful children Isaac (14), Sophie (10) and Isobel (9).

“After I was diagnosed we decided we wanted to keep the kids’ lives as normal as possible and be completely honest with them about what was happening with me,” Anne-Marie said.

“For the first six months following my diagnosis we managed with the support of our family and friends to juggle the demands of family life, work and cancer.”

During six weeks of radiation Anne-Marie stayed with friends in Toowoomba where she worked and had her treatment, and travelled home on weekends.

continued on page 2
From the editor

With the first quarter of 2012 already over, we would like to sincerely thank those who supported the Foundation’s World’s Greatest Shave again this year. It was a fantastic success and funds raised will allow us to continue to support patients and their families living with these challenging diseases. It is exciting to see the finishing touches going on at our brand new ESA Village at the Boggo Road precinct in Brisbane as well as the new apartments being added to our Townsville village. Patients and families will be moving in over the next few weeks.

This edition we have decided to feature an often misdiagnosed disease, cutaneous lymphoma. I was fortunate to attend the Skin Lymphoma Conference last October in Melbourne. The event enabled patients with this rare form of lymphoma to share their experiences, gain further knowledge of this disease and its treatments, and to ask questions of experts in the field. Guest speakers shared their knowledge and experiences with attendees. The second day of the conference enabled doctors and medical professionals to discuss developments and different approaches in diagnostics and treatment, and to present case studies.

I hope you enjoy Anne-Marie Brandon’s story on the front page who kindly offered to share her own personal experience with cutaneous lymphoma.

Please mark 15 September in your diary for World Lymphoma Awareness Day which will be held at our brand new ESA Village. Stay tuned for more information and take care!

Nicole Douglas | Support Services Coordinator
Leukaemia Foundation of Queensland

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Reality hits home
continued from page 1

“It was hard being away from my family but the tumour on my scalp was successfully treated and I thought this meant the hardest part was over,” she said.

“I then started treatment that could be self-administered at home - initially Interferon injections and then an oral treatment. Unfortunately the disease was resistant to both of these.”

In April 2011 Anne-Marie received the news she had dreaded. She needed to go to Brisbane for what she thought would be a few months of treatment to get the disease under control.

“We contacted the Leukaemia Foundation of Queensland to discuss our options and were amazed when we were told they could provide accommodation for the duration of the treatment. I was fortunate that my mum was able to come to Brisbane as my carer so William could continue working and the kids could continue their schooling,” she said.

“We were so grateful to have somewhere to stay where we received great support and that was so comfortable and free of charge. I am not sure how we would have afforded the treatment without this assistance.

“What I thought would be a few months in Brisbane ended up being 10 months.”

Treatment included eight rounds of chemotherapy and two stem cell transplants using her own stem cells, the first in October 2011 and the second in January 2012.

According to Anne-Marie, her time in hospital having treatment was very confronting.

“I had to accept that I had cancer and that my life and my family’s was going to change, a reality I struggled to cope with,” she said.

“Up until going to Brisbane for treatment I was still working and looking after the family, so I felt very lost with a lack of purpose and control. I used to be a bit of a control freak and the fact that I was no longer the carer, but the one being cared for was challenging to accept.”

“As time progressed and with the help of the amazing staff at the hospital I came to see that I needed to accept that I didn’t have control over what was happening and I needed to live in, and focus on, the moment and on getting better.”

Anne-Marie said it has been a difficult journey but there had been many positives as well.

“My relationship with my parents and siblings has strengthened and I have had the opportunity to spend more time with them as they visited me in Brisbane during treatment;” Anne-Marie said.

“Even though I was the one diagnosed with cancer, it has affected the whole family and everyone is involved in my fight to bring the disease under control.

“At this time I don’t know how long my CTCL will be controlled for, but I figure no one knows what the future holds. At the moment I am enjoying being back home in Chinchilla with my husband and children and I feel confident that I am going to be able to manage the challenges ahead with the support of my family and friends.”
Lymphoma is the most common blood cancer, and is generally broken down into two different subtypes: Hodgkin lymphoma and non-Hodgkin lymphoma. Lymphoma occurs when lymphocytes, a type of white blood cell, grow abnormally. The body has two main types of lymphocytes that can develop into lymphomas: B-lymphocytes (b-cells) and T-lymphocytes (T-cells). Cancerous lymphocytes can travel to many parts of the body including the lymph nodes, spleen, bone marrow, blood or other organs, and can accumulate to form tumours.

T-cell lymphomas occur when T-lymphocyte cells become cancerous. One of the most common forms of T-cell lymphoma is cutaneous T-cell lymphoma (CTCL), a general term for T-cell lymphomas that involve the skin. CTCL can also involve the blood, the lymph nodes and other internal organs.

Types of cutaneous T-Cell lymphoma

The two most common types of CTCL are mycosis fungoides and Sezary syndrome

Mycosis fungoides is the most common type of CTCL. The disease does not look the same for all patients and may present itself as patches, plaques or tumours. Patches are usually flat, possibly scaly and look like a rash. Patches are often mistaken for eczema, psoriasis or non-specific dermatitis. Plaques are thicker, raised lesions. Tumours are raised bumps, which may or may not ulcerate. A common characteristic is itching, although some patients do not experience itching. It is possible to have one or all three types of lesions. The disease course for mycosis fungoides is based upon the stage at diagnosis. Most patients with early stage CTCL have slow-growing disease that often does not progress to higher stages. However, some will progress rapidly.

Most patients experience skin symptoms without serious complications. However, approximately 10% who experience progressive disease with lymph node and or internal involvement develop serious complications. Many patients live normal lives and some remain in remission for long periods. Mycosis fungoides is difficult to diagnose as the symptoms and skin biopsy findings are similar to those of other skin conditions. A medical history, physical exam and skin biopsy are essential for diagnosis. A physician will examine lymph nodes, order various blood tests and may conduct other screening tests such as a chest x-ray or CT scan.

Sezary syndrome is an advanced, variant form of mycosis fungoides, which distinguishes itself by the presence of malignant lymphocytes in the blood. It is usually characterised by extensive thin, red, itchy rashes covering over 80% of the body. In certain cases, patches and tumours appear. These symptoms may be accompanied by changes in the nails, hair or eyelids or the presence of enlarged lymph nodes. Many of the same procedures used to diagnose and stage other types of cutaneous T-cell lymphomas are used in Sezary syndrome, including a physical exam and history, blood tests, a skin and/or lymph node biopsy for examination under the microscope and a series of imaging tests such as CT, MRI and/or PET scans to determine if the cancer has spread to lymph nodes or other organs. A bone marrow biopsy may be done, but is usually not necessary to complete staging.

Treatment options

Selecting a treatment for a patient depends on the symptoms, the patient’s general health and stage of disease. For mycosis fungoides, treatment is either directed at the skin or the entire body (systemic). Because Sezary syndrome is chronic and systemic (affecting the entire body), it is usually not treated with skin-directed therapies alone. Treatments may be prescribed alone or in combination to achieve the best long-term benefit.

Though this article focuses on mycosis fungoides and Sezary syndrome, it is important to note that there are also other forms of cutaneous T-cell lymphoma such as cutaneous anaplastic large-cell lymphoma, adult T-cell leukaemia/lymphoma, peripheral T-cell lymphoma and lymphomatoid granulomatosis. Cutaneous lymphomas can also present as either T-cell or B-cell lymphomas. Cutaneous B-cell lymphomas however, are much rarer, representing about 20% of all cutaneous lymphoma cases. There are a variety of treatment options available to patients in Australia, including skin-directed therapies and systemic therapies. It is important to discuss these options with your doctor, as not all therapies may be appropriate for your particular situation.

For further information

Peter MacCallum Cancer centre
www.petermac.org.au
Cutaneous Lymphoma Foundation
www.clfoundation.org
Lymphoma Research Foundation
www.lymphoma.org
The role of autologous stem cell transplant

As an advanced practice nurse in an inpatient haematology / transplant unit Diana Moore works closely with people requiring a stem cell transplant. Here she provides an overview of the transplant process.

Being diagnosed with a condition such as lymphoma can be a stressful and life-changing event no matter how old you are. When your doctor also explains that you need a transplant using your own stem cells to complete your treatment the emotions you experience can be numerous - ranging from excitement that the treatment is nearing a conclusion, to fear of what the transplant involves.

First, who needs a stem cell transplant? Once a person with myeloma has reached the plateau phase and the myeloma protein has dropped to its lowest level, the next step involves the collection of enough stem cells for two to three transplants. For a person with lymphoma the particular features of your lymphoma will guide the doctor in deciding whether stem cell transplant becomes part of your treatment. Lymphoma encompasses a diverse group of malignancies with differing behaviours and responses to treatment. Transplant is usually for those whose disease is high-risk or has relapsed and remains sensitive to chemotherapy.

The first step of the transplant process is to assess a person’s suitability to collect stem cells by completing blood tests to check liver and kidney function and past exposure to viruses. After a discussion with your doctor you are then scheduled for your collections with the apheresis unit at your hospital. Collections of stem cells may be done in one of three ways. The most common is a single day of chemotherapy using the drug cyclophosphamide, or having your normal chemotherapy treatment, then - on completion of the chemotherapy-commencing daily injections of Granulocyte - colony stimulating factor (G-CSF) until you have completed your collections. Finally, some people may have completed treatment and the thought of further chemotherapy daunts them. They may choose to attempt collection of their stem cells using G-CSF with collections starting from day five onwards.

Most people usually need two to three days of collections to obtain enough stem cells for transplant. This can be an emotionally challenging time, as some people may place a lot of importance on the transplant as part of their treatment. While most people will be successful in stem cells being collected, others may experience difficulty due to previous treatment for their disease, infection at the time of collection, or the inability to mobilise stem cells into their peripheral blood. When this occurs some people may need several attempts to collect enough stem cells.

While you may want to step ahead and find out about the transplant process your doctor and nurses will be cautious in giving you further information until the stem cells have been collected. Once this has occurred you can then start discussing what the transplant involves. Once again you will be scheduled for your transplant as this is considered elective treatment and involves a lot of coordination between departments. Firstly you will have several tests organised over a couple of days to assess your health (such as heart and lung function, dental check-up and blood tests). If you do not already have a central line in place a booking will be made immediately prior to admission or the day of admission to hospital for your transplant.

The actual transplant usually involves one day of chemotherapy for myeloma and for those with lymphoma the chemotherapy is usually over several days with the stem cells being reinfused 24 to 48 hours later. While the treatment may seem vastly different both protocols can be very debilitating with physical symptoms. The main aim of transplant is to induce bone marrow suppression and rescue is achieved with the reinfused stem cells engrafting and replenishing the blood within 10 to 14 days. While infection and the risk of bleeding is a major issue at this time the supportive care you receive such as antibiotics and blood product support can minimise complications.

The other significant side effects experienced relate to the impact of the chemotherapy drugs on the gastrointestinal system. Nausea and vomiting can be acute on the days of chemotherapy only or can be protracted lasting up to seven to 10 days. Be assured that your nurses will do everything possible to minimise this symptom with regular antiemetics. Trying your usual remedies for nausea and vomiting can sometimes also help. For those with prolonged nausea and vomiting they may also experience anorexia where even the smell or thought of food can produce overwhelming symptoms. You will be monitored closely by your healthcare team and additional nutritional support will be offered.

The other debilitating symptom is inflammation of the gastrointestinal tract (GIT) called mucositis. This can occur anywhere along the GIT with the most
common being the mouth, throat and small or large bowel. This may result in difficulty swallowing food and fluids or produce significant diarrhoea for several days. You will be monitored closely for symptoms and your healthcare team will implement strategies as symptoms arise. One strategy that is implemented from the beginning is using mouthwashes and keeping the mouth clean and the lips moist. The symptoms of diarrhoea may be mild, requiring you to alter your diet and take antidiarrhoeals, or can be more severe where you are asked to stop eating and drinking until the symptoms settle. Again you will be monitored closely and additional nutritional support offered if required through your central line.

Another symptom may include a level of fatigue/lethargy that starts when the chemotherapy is completed and can last until you are at home. It is important to continue to do small amounts of exercise such as walking. In fact exercise and activity during treatment can improve your outcomes by reducing feelings of nausea and lethargy, reducing feelings of anxiety or depression and improve your appetite. Be aware that you might not be able to exercise at the same level every day, but try to do a gentle walk or some simple stretching exercises even if you are not feeling well.

Mentally it can be challenging to maintain a sense of control when faced with the prospect of requiring treatment that may keep you in hospital for up to four to six weeks if the symptoms are severe. Equally challenging is discovering it may take a further four to six weeks at home before you start to see improvements. An important person in the transplant process is your carer who will track your appointments, support you emotionally and physically and be your advocate when you are too unwell. Other ways of coping are to keep a journal where you can write how you are feeling and what you did each day. This allows you to see how you are progressing. The journal is the place where you can also write questions down for the doctor. Don’t be afraid to ask for help if you need it and assess how you are feeling at regular intervals throughout your treatment. This will hopefully identify what things are getting you down before they escalate to a crisis level. The Leukaemia Foundation has trained support people available to help you, and speaking with your nurses can also help.

It is usually around day 100 (three months) that people say they start to feel well again without symptoms of the transplant getting them down. This is when you can start looking ahead and get back to socialising with your family, friends and work colleagues. At times you may feel a burden and will not be able to contribute the way you would like. Basically it is finding that balance in enjoying the simple pleasures such as food and exercising without feeling exhausted and making sure you have plenty of rest! It is important to regain a sense of the new you and find meaning in the things that you can still do.

Join the Leukaemia Foundation’s telephone discussion forums

Each month we hold a telephone discussion forum to connect people with all types of lymphomas right across Australia.

It can be hard for people who aren’t living with lymphoma to understand what it’s like. And if you live in a regional area you might not have the opportunity to meet other people with lymphoma very often.

Telephone forums can be accessed from the comfort of your own home. Each discussion is facilitated by a trained Leukaemia Foundation health professional.

The call is free if you live in the country, or the cost of a local call when phoning from a city location.

**Dates for 2012 telephone discussion forums**

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<th>Date</th>
<th>Time</th>
<th>Topic</th>
<th>Facilitator</th>
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<tr>
<td>26 April</td>
<td>1.00pm – 2.00pm</td>
<td>Open session</td>
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<tr>
<td>28 June</td>
<td>1.00pm – 2.00pm</td>
<td>Anne Criner (Nutritionist)</td>
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<tr>
<td>30 August</td>
<td>1.00pm – 2.00pm</td>
<td>Dr Cecily Forsyth, haematologist</td>
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<tr>
<td>25 October</td>
<td>1.00pm – 2.00pm</td>
<td>Louise Nelson, Psycho-oncologist</td>
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<tr>
<td>29 November</td>
<td>1.00pm – 2.00pm</td>
<td>Open session</td>
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All forums are held from 1.00pm – 2.00pm EST – Sydney (that’s 12.00pm – 1pm Queensland time!)

To register, please call 1800 620 420

A place for patients

The Leukaemia Foundation of Queensland has made life a little more comfortable for haematology and oncology patients at the Royal Brisbane and Women’s Hospital. The Foundation contributed almost $5,000 to the renovation of a former procedures room into a patient interview lounge in Ward 6AS. Families of patients also use it to stay overnight in times of crisis to be close to their loved ones.

Pictured in the new room are: Nursing Unit Manager, Eileen Fennelly; Nursing Director Cancer Care, Alanna Geary; Acting Nursing Unit Manager, Samantha Cunningham; Executive Director of Cancer Care Services, Dr Roger Allison; and Leukaemia Foundation of Queensland President, Beverley Mirolo OAM.
Exploring how young cancer survivors find meaning and identity after treatment

Understanding how young cancer survivors create a sense of identity and meaning in life in adulthood is the aim of a unique three-year study being undertaken by a Leukaemia Foundation PhD scholarship recipient.

The study by Danielle Tindle (pictured), a researcher at the Queensland University of Technology (QUT), will involve participants from Australia, England and the United States. The project focuses on cancer survivors who were diagnosed between the ages of 15 and 29.

A special thanks goes to the many Queenslanders who put themselves forward to be involved in this ground breaking research.

Danielle, who is a lymphoma survivor herself, says her study aims to help address “critical gaps in knowledge about this growing cancer survivor population and how to best provide age-appropriate services”.

“This research is unique in that it will explore issues associated with finding meaning in life, how this is influenced by the cancer experience, and what this means for quality of life for these young people in adulthood,” said Danielle.

Care of young people with cancer has recently become an area of international focus within the multi-disciplinary oncology profession, primarily during the treatment phase.

“There has recently been greater recognition of the importance of supportive care services for adolescents and young adults, especially during their treatment experience,” said Danielle.

“However, little is known about the effects of cancer and treatment on a young person’s life beyond the initial treatment phase.

“Furthermore, the broader research on cancer survivorship focuses predominantly on health needs and/or post-treatment effects alone.”

The Australian Institute of Health and Welfare (AIHW) recently reported there had been considerable improvements in the diagnosis and treatment of common cancers in young adults over the past few decades, resulting in an increase in the number of them surviving their disease and a steadying of cancer incidence in Australia.

Leukaemias and lymphomas are among the top five cancers experienced by the adolescent and the young adult age group.

The findings from Danielle’s research will help ensure that future developments in supportive care services for young adult cancer survivors reflect a broader understanding of the life experiences of this group.

The Leukaemia Foundation has committed $40,000 a year over three years to support the project.

“It is hoped that the future outcomes of this research will greatly contribute to improving the lives of young people who have survived cancer around the world,” said Danielle.

As a passionate advocate for delivering quality, individualised care for patients and their families, Danielle is involved with a variety of national and international committees and organisations such as Cancer Voices in Australia, the UK’s Teenage Cancer Trust and the US-based Livestrong. She also holds postgraduate qualifications in teenage and young adult cancer care, a Bachelor of Arts (majoring in Philosophy), and a Masters of International Relations.

Danielle is employed by Queensland Health as the Senior Project Officer for Adolescent and Young Adult Cancer Services based at the Royal Children’s Hospital, Brisbane.
New research developments in Waldenstrom’s Macroglobulinaemia (WM)

At the annual American Society of Haematology (ASH) meeting held on 12 December 2011, Dr Steven Treon presented the latest findings on Waldenstrom’s macroglobulinaemia (WM) identified by researchers at the Dana-Farber Cancer Institute in America.

Research lead by Dr Treon and Zachary Hunter and partially funded by the International Waldenstrom’s Macroglobulinemia Foundation (IWMF), found that within a small cohort of Waldenstrom’s patients whose DNA was sequenced using whole genome sequencing, 90% of those individuals expressed the same single gene mutation.

Significantly, this mutation was found in the WM cells, but not in the patient’s normal cells, and was not found in patients with IgM-MGUS or myeloma.

The discovery will potentially lead not only to the earlier differentiation of WM patients from other types of lymphoma and myeloma, but also opens up options for new, effective treatments that may be able to directly target WM cells.

The mutation produces an abnormal protein which activates the NF-kB pathway, essential for the growth and survival of WM cells. As stated in a Dana-Farber press release: “Drugs that block the abnormal protein or other proteins in the NF-kB pathway could, theoretically, short-circuit the disease process in many patients. Some of these drugs already exist, having been developed for other conditions. Dr. Treon and his colleagues are currently working to develop others and are testing them in experimental models.”

Though research is a slow methodical process, this is certainly an exciting new development which may come to shape diagnostic and treatment options in Waldenstrom’s Macroglobulinaemia in the years to come.

For further information on this study visit the International Waldenstrom’s Macroglobulinaemia Foundation website www.iwmf.com and check “News and Events”.

Allise joins north Qld team

Welcome to Allise Beldan, the Leukaemia Foundation’s new support service coordinator for north Queensland.

Allise has experience in haematology/oncology nursing and clinical research.

Based at Freemasons Village in Townsville, Allise looks after patients and families in the Townsville / Thuringowa and surrounding areas as well as travelling bimonthly to Cairns and Mackay and twice a year to Mount Isa.
Queensland Support Services team

Director of Support Services
Barbara Hartigan

Support Services Coordinators
Sheila Deuchars
Scott Martin
Maryanne Skarparis
Nicole Douglas
Kate Arkadieff
Michele Leis
Allise Beldan (Townsville)

Grief Support Services Manager
Shirley Cunningham

Support Services Administration Officer
Marian Marshall

Contact us

Brisbane
Support and information: 07 3055 8233
Accommodation booking and enquiries: 07 3055 8200

Townsville
Support, accommodation and information:
07 4727 8000

Freecall
1800 620 420
lfq@leukaemia.org.au
www.leukaemia.org.au

Support seminars delayed due to building projects

Support seminars and programs will not be held in Brisbane in the first half of 2012 due to the construction of the new ESA Village. Dates for seminars to be held later in the year will be advertised in upcoming editions of Lymphoma News.

Could you leave a gift in your will?

Once you’ve remembered your loved ones you can help the Leukaemia Foundation give hope to patients in the future by leaving a gift in your will.

Every gift large or small really counts.

To find out how to leave a special gift to the Leukaemia Foundation of Queensland contact Hedley Lockyer on free call 1800 620 420 or visit www.leukaemia.org.au.

“I am a leukaemia survivor, a dedicated husband and a father of three. A gift in your will, can ensure more patients in the future survive...like I have” - Brendan Wesley.

Our Vision to Cure and Mission to Care.

The Leukaemia Foundation of Queensland is a not-for-profit organisation focused on the care and support of patients and their families living with leukaemias, lymphomas, myeloma and related blood disorders.

The Foundation does this by providing emotional support, accommodation, transportation and practical assistance for patients and their families. The Leukaemia Foundation also funds research into cures and better treatments for blood cancers.

The Leukaemia Foundation receives no direct ongoing government funding and relies on the continuous support of individuals and corporate partners to expand its services.

To find out more about the work of the Leukaemia Foundation of Queensland and how you can help, phone 1800 620 420 or visit the Foundation’s website at www.leukaemia.org.au.

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