

ALLAN'S OK AND DOING WHAT HE LOVES – TRAVELLING

Since the age of 16, Allan Webb worked continuously all his life until he was diagnosed with multiple myeloma... and he hasn't worked a day since.

His job as a coal miner ended suddenly, in mid-2004, aged 56, when he crushed a vertebra in his back (which still has not healed). He had taken "a bit of a jolt" – nothing of any significance, and that's why his GP decided more tests were needed.

A bone marrow biopsy revealed Allan had myeloma – a disease he had never even heard of.

He started oral chemotherapy treatment - a combination of cyclophosphamide, idarubicin and dexamethasone, as well as drugs to help strengthen his bones – ostelin, caltrate, fosamax and zometa.

Allan can recite the details as he has kept a diary of all his treatment, procedures and medical appointments over the last four years.

"It comes in handy at times," said Allan, who had to give up driving at various times during treatment due to the side-effects of one of the chemo drugs.

"I ran the risk of having a serious road rage attack while on the steroid," explained Allan, who suffered mood swings and his sight was affected.

As his wife, Susan, doesn't drive, the Leukaemia Foundation helped out by picking Allan up from their home at Camden, south-west of Sydney, and taking him to Liverpool Hospital for treatment and back, once a month.

His initial treatment protocol hadn't been as effective as hoped, so at the end 2004 Allan started on thalidomide. But he suffered nerve damage in his feet so this drug was discontinued after a couple of months and he returned to his original protocol.

Around this time, a friend who he had met in hospital and had kept in touch with through a haematology support group, died from myeloma.

"That brought things home a bit as I thought – he had what I've got. It was a bit of a wake-up call," Allan said.

In January 2005, he spent a week in hospital having kidney function tests and he had a fistular implant in July that year so he could receive kidney dialysis, should that be necessary down the track. Since then, thankfully, his kidneys have stabilised, so Allan hasn't needed dialysis.

Allan continued on maintenance treatment – cycles of oral chemo, and tried thalidomide again for a couple of months.



Allan and Susan Webb on Kaula, Hawaii.

Towards the end of 2006 his energy levels had dropped, his tongue was feeling enlarged, and he was diagnosed with amyloidosis*. In November he started treatment with a new drug, Velcade, combined with dexamethasone but his toes and feet became numb and increasingly painful.

It was decided that Allan's only option was a stem cell transplant. His stem cells were harvested in February 2007 and his transplant was in April that year.

"While the stem cell transplant did have the desired result, it was very rough going," said Allan who hasn't received any treatment since, other than injections for a time, to help with red blood cell production, which Susan administered. He takes tablets for fluid and his neuropathy, which has improved, and every couple of months he has a blood test and sees the doctors.

"Things are going pretty good at the moment," said Allan, who lost another two friends to myeloma, in June and December 2007.

"This is one of those diseases where there is no cure. It affects different people in different ways. Some can have smouldering myeloma for 15 years and for others, it can kill you in a year.

"I've had it for four years and I'm doing okay, although it has been very tough at times both physically and emotionally.

"You try doing what you can when you can."

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WHAT IS MYELOMA?

Myeloma (also known as multiple myeloma or plasma cell myeloma) is a cancer of the blood in which malignant plasma cells are overproduced in the bone marrow.

Plasma cells are mature lymphocytes (a type of white blood cell) that help fight infection and disease by producing special proteins known as antibodies or immunoglobulins.

In myeloma, large numbers of abnormal plasma cells, called myeloma cells, multiply without any proper order, forming collections known as tumors that accumulate in different parts of the body, especially in the bone marrow and on the surfaces of different bones in the body.

These tumors secrete chemicals that stimulate other bone marrow cells (osteoclasts) to remove calcium from the bone. As a result bones can become weaker, more brittle and break more. They also collect in the bone marrow preventing it from making normal red cells, white cells and platelets.

Over time, people with myeloma can become anaemic, more susceptible to infections and to bleeding and bruising more easily.

Myeloma cells typically produce an abnormal type of immunoglobulin called paraprotein, or M protein, which can be detected in the blood and urine. Excessive amounts of paraprotein can cause problems in the body, including kidney damage.

Multiple myeloma is the second most commonly diagnosed blood cancer and around 1200 people are newly diagnosed with the cancer each year in Australia. It is expected this will increase as the population ages.

Myeloma is typically diagnosed when the disease is at its most serious.

The risk of developing myeloma increases with age with almost 80% of all new cases diagnosed in people over the age of 60. Myeloma is uncommon in people under 40 and occurs more frequently in men than in women.

The cause of the disease remains unknown and the most common symptom is severe bone pain, usually felt in the back or ribs, and malfunctioning kidneys.

Other symptoms are caused by a lack of normal blood cells and include:

- anaemia, due to a lack of red cells, causing persistent tiredness, dizziness, paleness, or shortness of breath when physically active
- frequent or repeated infections and slow healing, due to a lack of normal white blood cells, especially neutrophils.
- increased or unexplained bleeding or bruising due to a very low platelet count

There is usually no cure for multiple myeloma. Treatment aims to induce periods of remission.

RESEARCHERS OPEN DOOR TO A POTENTIAL MULTIPLE MYELOMA VACCINE

A multiple myeloma vaccine is one step closer following the successful transfer of myeloma-killing immune cells between twins.

Researchers, from the University of Arkansas for Medical Sciences (UAMS) immunised a healthy twin with a cancer protein, known as MAGE-A3, that enabled her immune system to recognise and kill myeloma cells.

The cancer killing antibodies produced by the healthy twin's immune system were then transferred via stem cell

transplant to her twin sister, who had multiple myeloma.

The vaccine treatment, in conjunction with chemotherapy, appeared to wipe out the cancer, with the patient still in remission three years after the transplant.

UAMS is now looking to undertake a larger-scale vaccination trial of multiple myeloma patients.

The study was published in the November/December 2007 issue of the *Journal of Immunotherapy*.

MYELOMA AMONG TOP FIVE CANCERS IN AUSTRALIA

More Australians than ever are developing myeloma and non-Hodgkin lymphoma, according to the Australian Institute of Health and Welfare (AIHW).

In recently released statistics, the AIHW listed the two cancers among the top five cancers which had significantly increased in incidence in the 10 years from 1993 to 2003.

Myeloma incidence had increased by 44 per cent and NHL by 36 per cent.

The AIHW also reported that in the 2004-5 financial year, one in 10 hospital admissions in Australia were cancer related, with cancer now the leading cause of premature death in Australia.

For more information visit: www.aihw.gov.au.

AUSTRALIAN DEVELOPING WORLD-FIRST MYELOMA TEST

Sydney-based haematologist Dr Silvia Ling, under the supervision of Professor Joshua, Associate Professor Ho and Dr Allen, has developed a test to gauge the sensitivity of myelomas to proteasome inhibitors such as Bortezomib.

While myeloma is a notoriously drug-resistant cancer, proteasome inhibitors are a new class of drugs which can be remarkably effective in treating some patients.

Until now, predicting patient response has been impossible because no one precisely understood how or why the drug curbed myeloma. However, Dr Ling believes she has identified why myeloma cells are so sensitive to proteasome inhibitors.

Based on her research findings, Dr Ling has developed a new test, which is being assessed in patient trials. If the trial is successful, the test could provide clinicians with an invaluable tool for developing better patient treatment strategies, according to Dr Ling.

“Our research data highlights the way Bortezomib acts on myeloma cells and can predict those cases that respond,” said Dr Ling.

“Our goal is to improve chemotherapy regimes while reducing unpleasant side effects for patients.

“In addition, through this research pharmaceutical companies could identify new drug targets as well as potential sources of drug resistance.”

The Leukaemia Foundation awarded a three-year, \$40,000 PhD scholarship to Dr Ling, who is undertaking her research at the Centenary Institute of Cancer Medicine and Cell Biology and The University of Sydney.



Dr Silvia Ling

ABOUT PROTEASOME INHIBITORS

In 2003, a new treatment for myeloma was approved in the United States. Bortezomib (also known as Velcade) was the first in a new class of anti-cancer drugs called proteasome inhibitors.

Proteasomes are large protein complexes which exist in all the cells in our body. They digest proteins marked for destruction and are believed to regulate the cell's growth and metabolism by maintaining the correct balance of proteins in the cell.

By blocking the function of proteasomes, it is thought that drugs such as Bortezomib stop cell growth, leading to the death of cancer cells.

WORKING TOWARDS A NATIONAL AUSTRALIAN BLOOD CANCER REGISTRY

Blood cancers, including myeloma, are a significant health concern in Australia and account for 10% of all cancers.

State cancer registries have collected broad incidence and mortality data but the lack of a central repository to consolidate information on treatment patterns and patient outcomes, to optimise clinical decision-making, has been a gap in the management of blood cancers.

To address this unmet need, the idea of developing a national registry was conceived with the goal of providing complete, accurate data on the management trends and outcomes of Australians with blood cancers and related disorders.

Clinical haematologists and consumer organisation representatives formed a project management group and following a research and consultation phase, the first stakeholder meeting, Working Towards An Australian Blood Cancer Registry, was held in Sydney in September 2005.

There was unanimous support for the registry concept by delegates including representatives from consumer organisations, clinicians, researchers, academics, cancer registries government, pathology laboratories, the pharmaceutical industry and software developers.

Since then the Australian Blood Cancer Registry (ABCR) has made inroads into repository development, funding and standards setting and has embarked on various projects such as implementing and piloting data collection via the Lymphoma Wizard Project, communicating the development of the ABCR with key stakeholders while garnering clinical and financial support to bring the vision of the ABCR to fruition.

In November 2007, the ABCR's third annual stakeholder meeting in Sydney was attended by 43 delegates and received unanimous support for the registry's work to date and a strong commitment from stakeholders to continue supporting future initiatives.

Two projects are planned for 2008. In Western Australia, a state-wide data collection will begin on July 1 that will initially focus on lymphoma sub-types, then move on to encompass other forms of blood cancer. In South Australia, a 'RESIST' registry has begun collecting data on CML patients who fail to respond to standard treatments and are being treated with second-generation drugs. The aim of these two projects is to demonstrate the effectiveness of both the Lymphoma Wizard as a data collection tool and improved outcomes for patients through better data collection and analysis.

The ABCR is collecting detailed and accurate information on blood cancers. This information will be used to improve the capacity of clinicians, patients, their families, carers and governments to make informed and timely decisions on the management of blood cancers.

The ABCR will provide clinical haematologists and oncologists with accurate and detailed information to improve survival and treatment outcomes and set standards to achieve best practise in clinical care.

Since January 2007, the Leukaemia Foundation has provided its services as Secretariat for the ABCR. To find out more about this project, visit the website, www.abcr.net.au.

YOUNG RESEARCHER WORKING TO HELP MYELOMA PATIENTS



Researcher, Jennifer Hsu

The Leukaemia Foundation funds a young and talented group of PhD students, medical researchers and Honours students as part of its comprehensive National Research Program. Their work into finding better treatments for blood cancer patients will make a significant impact on the way leukaemias, lymphomas and myeloma are treated both here and overseas.

Researcher, Jennifer Hsu, from the Mater Medical Research Institute, is looking at how immunotherapy can strengthen T-cells so they work to overcome the myeloma cells. Many in the medical profession believe improved treatment for myeloma won't come through better chemotherapy drugs,

but through biological or immune therapy which can be administered combined with chemotherapy. Following are the details of Jennifer's research.

Multiple myeloma is a plasma cell leukaemia that is characterised by painful lesions in the bones that may spread through the lump nodes and into the skin. Despite advances in therapies, such as the use of proteasome inhibitors or stem cell transplantation, multiple myeloma is usually incurable.

One promising therapeutic approach is to eradicate residual disease after chemotherapy and stem cell transplantation by immune therapy targeted against the myeloma cells.

Dendritic cells are specialised white blood cells that initiate and direct immune responses. The Mater Medical Research Institute has developed a new technology to isolate blood dendritic cells and load them with antigens from cancer cells to generate immune responses. This technology is being used to validate which of the potential multiple myeloma antigens induce the most effective immune responses against multiple myeloma, so these antigens may be incorporated into a blood dendritic cell vaccine for multiple myeloma patients.

These studies will discover which multiple myeloma-specific antigens will be most suitable for inclusion in novel immune therapies that will target multiple myeloma.

A clinical trial using blood dendritic cells loaded with peptide antigens identified in this research project is planned to commence in the near future. It is anticipated that this vaccine will stimulate the patients' immune systems to delay or cease progression of multiple myeloma when administered to those with minimal residual disease following autologous stem cell transplantation.

In the future we also plan to expand this treatment to include all patients with minimal residual disease by using antigens that are not restricted to a particular HLA type by using proteins or mRNA that are highly visible target antigens on multiple myeloma cells.

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ALLAN'S OK AND DOING WHAT HE LOVES – TRAVELLING

For Allan and Susan that has meant lots of travelling. Over the last four years they've enjoyed a couple of cruises, to New Zealand, and from Tahiti to Hawaii,

They have driven to Western Australia and caught the Indian Pacific back, have been to Tasmania twice, to Uluru, and flew to Darwin to catch The Ghan to Adelaide.

"The money's running out," said Allan, who was about to leave on another cruise, from Sydney to Perth around the top of Australia, when he spoke to Myeloma News in April.

"I love travelling and I'll drive forever if I have a chance."

Several months after Allan's transplant, when the Webbs were in Perth, Susan broke her ankle.

"Suddenly we had a role reversal and I was the one who had to care for her. I had to get off my bum and strengthen myself up and she needed a rest," Allan said.

"The whole thing has been a terrible strain on Susan. She has handled it very well and her care is probably one of the biggest reasons I am still alive. Friends, family and workmates were also a huge help."

When the Webbs got home from Perth, Allan wasn't able to vacuum or clean the house and the Leukaemia Foundation helped out again by providing the couple with a housekeeper for two hours a week for a month.

"It made a huge difference," Allan said.

** Amyloidosis is the name given to a group of conditions in which an abnormal protein called amyloid builds up in the blood and becomes deposited in different organs and tissues. Amyloid can be produced by abnormal plasma cells (myeloma cells) and deposited anywhere in the body. This is known as primary amyloidosis. The most common organs affected by primary amyloidosis are the heart, kidneys, nervous system and gut. This condition may be treated with chemotherapy and, occasionally, a stem cell transplant. Amyloidosis can be primary (AL amyloidosis) or occasionally secondary to another condition.*

NEW DRUG APPROVED BY TGA

The Therapeutic Goods Administration (TGA) has approved lenalidomide (Revlimid) as a new therapy for multiple myeloma.

The immuno-modulating agent has been shown to be well tolerated and to delay disease progression. Revlimid inhibits proliferation of tumour cells, while enhancing cell-mediated immunity.

Revlimid is indicated for use in combination with dexamethasone in patients with multiple myeloma whose disease has progressed after one therapy.

It has been hailed as a major treatment advance by Australian specialists and described as a life enhancing therapy.

Professor Miles Prince, a myeloma expert and Chair of Clinical Cancer Services at Peter MacCallum Cancer Centre in Melbourne said: "Revlimid is a unique advance over current treatments for multiple myeloma which improves treatment outcomes and is extremely well tolerated, meaning fewer side effects for patients.

"Revlimid is not a chemotherapy drug. It works primarily as an 'immune modulator' inducing myeloma cells to die without the toxic effects patients may experience with chemotherapy."

Through treating the cause of the disease, and not the symptoms, Revlimid has shown dramatic results for people with multiple myeloma, specifically with regards to improvement in overall survival and prolonged time to disease progression.

Professor Prince said results from two large international studies in which Australian patients participated, demonstrated that myeloma patients taking Revlimid lived longer and halted cancer progression for almost a year longer than standard therapy.

"Some patients may have a complete response, meaning that the drug keeps working even after they stop taking it. The earlier Revlimid is introduced into the treatment regimen, we anticipate the better the response will be," he said.

The treatment is taken orally, making it convenient for multiple myeloma patients to take, while minimising the impact of treatment on patient's active lifestyles.

"This new approach means that, unlike chemotherapy treatments, we are not putting patients at risk of infection and their trips to hospital can be minimised.

"This is very important in helping provide quality of life for patients, particularly if they live in regional and remote areas with limited hospital access," said Professor Prince.

TGA approval was based upon the safety and efficacy results of two large, randomized pivotal Phase III special protocol assessment trials. The North American Trial MM-009 and International Trial MM-010 evaluated lenalidomide plus dexamethasone in multiple myeloma patients whose disease had progressed after one therapy.

Lenalidomide also has been approved in the United States by the U.S. Food and Drug Administration (FDA), in the European Union by the EMEA and in Switzerland for multiple myeloma patients who have received at least one prior therapy.

In addition, lenalidomide is approved in the U.S. for treatment of patients with transfusion-dependent anaemia due to low- or intermediate-1-risk myelodysplastic syndromes (MDS) associated with a deletion 5q cytogenetic abnormality with or without additional cytogenetic abnormalities.

Lenalidomide is an IMiD compound, a member of a proprietary group of novel immunomodulatory agents. Lenalidomide and other IMiDs continue to be evaluated in more than 100 clinical trials in a broad range of haematological and oncological conditions. Celgene Australia, manufacturer of the drug, has submitted an application for PBS listing of lenalidomide.

Revlimid is available through a compassionate supply program to all suitable multiple myeloma patients, as well as through a number of clinical trials.



Professor Miles Prince

WONDER DRUG TREATMENT BUYS TIME

Since 2002, Graeme Stuart has lived with a cancer that normally claims patients within three-and-a-half years, but thanks to a new medication he hopes for many more years.

The Hepburn grandfather was one of 200 Australians offered a new treatment for multiple myeloma when six Victorian hospitals were granted limited access to the oral cancer drug, lenalidomide (Revlimid), prior to TGA approval earlier this year.

Tests previously conducted in Australia found treatment with added an average of 14 months to patients' lives.

Professor Miles Prince, who is overseeing Graeme's treatment at the Peter MacCallum Cancer Centre, in Melbourne, said the new drug worked by stimulating the patient's immune system to recognise the cancer, eliminating many of the side-effects of chemotherapy.

"For a disease that has an average survival of only three-and-a-half years, adding an extra 14 months is enormous," said Professor Prince.

International trials are also continuing to see if Revlimid or other similar drugs are effective in treating other cancers.

PRACTICAL ISSUES FOR MYELOMA PATIENTS

By Kim Hobbs Social worker, Westmead Hospital, NSW

People living with myeloma in rural locations have higher levels of unmet supportive care needs than their urban counterparts. Access to resources and organisations, such as the Leukaemia Foundation, to assist with practical needs will help ease the challenges of coping and adjusting to living with the disease.

Income support: If employed at the time of diagnosis, don't resign immediately. Ask your employer about eligibility for entitlements such as sick leave and long service leave. Determine if medical certification is required and begin this process as soon as practical as it may take some time. Seek advice from a union if leave entitlements or rights are unclear. If unemployed or in casual work when diagnosed, or if paid leave expires during the illness, contact Centrelink (ph 13 27 17, www.centrelink.gov.au) for advice on potential support, eg Sickness Allowance or Rent Assistance. Meet with a Centrelink social worker to discuss specific situations. Charitable organisations like the Leukaemia Foundation may provide food vouchers and help with household bills. Most areas have cancer patients' assistance organisations and service clubs that may offer financial support.

Treatment costs: State health departments can offer advice on specific support schemes for travel to urban centres for medical treatment. Your local Medicare office and pharmacist can advise on the 'safety net' threshold to reimburse the cost of pharmaceuticals. Support services may be available for Veterans Affairs cardholders and for indigenous people.

Finances: Check your documents and policies. Make or update wills and consider making an Enduring Power of Attorney, in case it is required. Seek advice about superannuation and insurance entitlements such as lump sum or disability payments. There is comprehensive coverage of these issues on the Brain Tumour Australia **website: www.bta.org.au** or contact the Australian Prudential Governing Authority: **www.apra.gov.au**. Also refer to the next article below.

Back to work: Patients frequently report difficulty in settling back into the workplace. Visit **www.livingcaringworking.com** for information on working and living with a life-threatening illness. For people caring for someone with an illness while



Social worker, Kim Hobbs

still working, visit **www.workingcarers.org.au**.

Children: It can be difficult to share news of a diagnosis with children. However, accurate and timely information reduces their fears and increases their ability to cope. It is better for them to hear distressing news from a parent or caregiver, rather than finding out by chance. Plan family time, even when parents are very ill. The Cancer Council of South Australia has a booklet on this topic that can be downloaded from **www.cancersa.org.au** and more information is available from **www.canteen.org.au** and **www.myparentscancer.com.au**.

A myeloma diagnosis is a life-changing process. Asking for assistance is not a failure to cope, but rather, an important step in empowering people to regain control of their lives. Here is a list that is a good starting point of help and practical advice on living with cancer:

Leukaemia Foundation	Ph: 1800 620 420
The Cancer Council Helpline	Ph: 13 11 20
Centrelink	Ph: 13 27 17
Your local hospital social worker and Community Health centre	

RESOURCES FOR PEOPLE LIVING WITH CHRONIC ILLNESS

Are struggling with the legal aspects or looking for straight-forward practical information about Centrelink, superannuation, insurance, wills, Power of Attorney, or paying your power, telephone and other utility bills?

The Chronic Illness Alliance in Victoria provides good resources and web-based guides on its website, **www.chronicillness.org.au**. On the home page, under the Helpful Resources heading, click on the following:

Workwelfarewills: a practical guide to legal issues around health and life issues. Topics covered include Centrelink entitlements, health privacy, Power of Attorney, guardianship, superannuation, insurance, travel insurance and wills. Some of the information is Victoria-specific.

Utilitease: a guide that assists households with information and resources to help them maintain their gas, water and electricity supplies and access energy concessions, relief grants and other assistance to which they may be entitled.

If you don't have access to the Internet and would like more information about topics covered in either of these guides, contact the Leukaemia Foundation Support Services staff in your state (Freecall 1800 620 420) and ask them to download the specific information you need.

Chronic Illness Alliance
818 Burke Rd, Camberwell, Victoria 3124
Ph: 03 9882 4654

VELCADE® AVAILABLE THROUGH PBS

The door has been opened for yet another weapon in the fight against myeloma following the listing of Velcade on the Pharmaceutical Benefits Scheme. This is fantastic news for people living with myeloma, their families and clinicians who wish to access Velcade for their patients. It enables prescriptions for Velcade to be subsidised by the National Health Scheme. The implications for many

who are candidates for this form of therapy are huge, especially from a financial point of view. Pharmaceutical company, Janssen-Cilag, worked with the Federal government to make the necessary administrative arrangements for the listing on 1 November 2007. Life expectancy for multiple myeloma is three to five years, but clinical trials have shown Velcade can extend that by many months.

A MODEL FOR DEVELOPING CANCER DRUGS

Based on an article in *The Boston Globe* newspaper in May 2007

In 1998, chemist Julian Adams and ProScript Inc. co-founder, Tom Maniatis, had already spent four years pushing the biotech start-up company to develop a promising treatment for cancer, known then as PS-341.

They had overcome internal dissent as well as doctors' fears of toxic side effects. Then the venture capitalist who had been paying the bills died suddenly, and Adams, ProScript's Director of Research, couldn't find anyone else willing to put up the tens of millions of dollars needed to test the drug in people.

Adams was turned down by more than 50 potential backers before ProScript was acquired in 1999 by Millennium Pharmaceuticals Inc., which eventually funded studies of PS-341.

Today, PS-341, now known as Velcade, is recognised as a model for how to develop cancer medicines quickly and cheaply, as Adams and other diehard Velcade champions turned an idea of four Harvard professors into a breakthrough treatment for multiple myeloma in half the average time for drug-testing and federal review.

Since its approval in 2003, Velcade has helped control the rare but deadly blood cancer in more than 50,000 patients and has become an emblematic success story for Boston's biotech community: A drug that emerged from the city's vaunted university labs, then was nurtured along by scientist-entrepreneurs into a successful therapy.

But the drug nearly stalled several times as scientists struggled to get financial support for a new approach to fighting disease and disagreed among themselves about what PS-341 should be used for – some wanted to focus on conditions like arthritis.

The founders and executives at ProScript (and later Millennium) made smart choices that helped them survive, such as enlisting the aid of National Cancer Institute scientists to refine their drug and working closely with academic laboratories and the Food and Drug administration to speed the safety review.

They refused to quit until good fortune and good news – such as the first patient whose cancer went into remission after taking the drug – gave them fresh momentum. Adams and his collaborators believe that dozens of other promising drugs never make it to patients because biotech companies can't hang on long enough.

“Most scientists do not realise how the progress of drug development depends so much on nonscientific issues and random events – and luck,” said Alfred Goldberg, the Harvard Medical School biologist who, with Maniatis and two others, launched the company that would become ProScript in 1993. More than once, Goldberg said, he feared the 38-employee company's work was “headed for obscurity” because of events outside the lab.

Geraldine Ferraro, the Democratic vice presidential candidate in the U.S. in 1984, believes she is alive today in part because Velcade's backers, including the doctors at Dana-Farber Cancer Institute who carried out the human trials, did not give up.

Ferraro already had beaten the odds by living with multiple myeloma for six years, but when she started getting intravenous infusions of Velcade in 2004, the disease went into remission. As a result, she was well enough to receive a stem cell transplant, which sometimes triggers long-term remission. She remains well enough today, nine years after diagnosis, to continue a busy public speaking schedule.

MFA PRESIDENT AWARDED OAM



Myeloma Foundation of Australia (MFA) president, Bob Moran, received the Order of Australia Medal (OAM) in January for his services to community and specifically for his work in establishing the MFA which celebrates its 10th anniversary this year.

Bob was among the three couples, including his MFA co-founder, Brian Rosengarten, patients and carers who got together in 1998 and decided to create a support organisation in Australia dedicated to assisting and representing people affected by myeloma.

He was elected president of the original organisation, then called Myeloma Victoria.

MFA now employs a myeloma support nurse, two days week in Victoria and New South Wales, to answer calls from patients and carers and assist in the education of oncology nurses.

Bob Moran OAM, and his wife, Glenys.

ON-LINE SUPPORT FORUM FOR PATIENTS AND FAMILIES

Talk Blood Cancer* is a moderated on-line information and support forum for patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.

Being diagnosed and treated with a blood cancer like myeloma can be confronting and at times overwhelming. It presents patients and families with many challenges. Being in contact with other people who have experienced or are going through similar, complex feelings associated with the disease is useful.

Talk Blood Cancer is designed to help in understanding and managing the practical and emotional issues that are part of the journey through diagnosis, treatment and recovery.

This safe, supportive, informative environment, moderated by an experienced haematology nurse and allied health professionals from the Leukaemia Foundation, enables people to share ideas, opinions, helpful and practical advice and personal experiences.

Registration is free and participants can remain anonymous. To participate is easy.

1. Visit www.talkbloodcancer.com
2. Click on 'register'
3. Provide a username (for public viewing) and your email address and a password (not public)
4. Take part by posting messages, participating in polls and reading on-line discussions

This service is part of the Foundation's commitment to increasing the delivery and reach of world-class support to patients and families. Talk Blood Cancer is an alternative source of support and information and it is particularly helpful for people who live in regional and rural areas and those who are not able to attend the Foundation's face-to-face support groups.

** Talk Blood Cancer was established with financial assistance from the Australian Government through the Cancer Support Groups Program.*

LIGHT THE NIGHT WALK IN SEPTEMBER

Light the Night is a new fundraising event for the Leukaemia Foundation being held on September 17 in Adelaide and Perth, and September 18 in Brisbane.

Participants pay tribute to patients and families living with leukaemias, lymphomas, myeloma and related blood disorders by lighting a special balloon. Each coloured balloon contains a tiny twinkling light and has a specific meaning. A gold balloon is to REMEMBER a loved one lost, a white balloon is to CELEBRATE being a blood cancer survivor and a blue balloon is to GIVE HOPE and show support.

Before the event, participants will enjoy a family fun atmosphere with entertainment, food and a chance to hear

inspirational stories. After a special balloon lighting ceremony, Light the Night walkers will walk approximately three kilometres together, with balloons lit against the early evening sky, as a beacon of hope for the future.

To register to be part of this Australian first event, visit www.lightthenight.org.au or call 1800 500 088.

Light the Night – Remember. Celebrate. Give Hope.



EDUCATION AND SUPPORT PROGRAM ACTIVITIES

Myeloma Seminar Series	Jul 8/Aug 12	Brisbane, Qld
Carer Coffee Morning	Jun 27/Jul 25	East Melbourne, Vic
General Education/Support Program	June 12	Subiaco, WA
Coffee Morning	June 11	Noarlunga, SA
Caring for the Carer	June 12 / July 3	Sth Brisbane, Qld
Caring for the Carer	June 18	Launceston, Tas
Knowing your disease- Multiple Myeloma	July 11	Sandy Bay, Tas
Carer Coffee Morning	Jul 25/Aug 29	East Melbourne, Vic
Multiple Myeloma	August 1	Townsville, Qld

For more information and a complete list of education and support programs for myeloma 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)

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

Sandy McKiernan 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



This newsletter has been produced with support through an unrestricted educational grant from Celgene.

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

