

## RON'S NOT OFFICIALLY ON ANY TREATMENT FOR MDS

**Ron Saunders was 84 when he began having a raft of tests after his GP was concerned his fatigue and pallor were due to something other than his age.**

"I was getting wearier and paler and I just thought I was getting old and tired," said the retired Churches of Christ minister who was sent off to two major Adelaide hospitals for investigation four years ago.

"I had every blood test you can think of. It was a long and tedious process," said Ron.

"They stood me in front of everything you can stand in from of and lay me down on everything you could lie on.

"Then someone thought to take a hip bone marrow biopsy and that picked up MDS. I'd never head of it.

"It's a rare form and I didn't understand it all and still don't, but it's very interesting and complicated stuff.

"My health was pretty good at first, but I gradually gave up everything I was doing and I hired a gardener," said Ron, an avid gardener who enjoyed tending to the garden on their large house block.

He became a full-time carer looking after his aged and ailing wife, Alice, but 12 months after Ron's diagnosis, Alice's health deteriorated.

"When she got a terrible virus and went into a coma, we were told she'd have to go into a nursing home.

"I've still got my cognitive processes and it was a shock having to sell our house, give away most of our goods and chattels and move into a nursing home. We're a married couple, but they don't believe in double rooms."

Ron initially began treatment with erthropietin, which he described as the "race horse drug".

"It creates red blood cells and I really believe it did me good," said Ron who received this treatment for 12 months.

"But evidently it was fiendishly expensive and at my third six-monthly appointment, the prescription was stopped and I haven't officially been on anything since.

"They said they'd give me a bone marrow transplant if I was younger but at 88, it's not a risk to be taken."

However, Ron has a pharmaceutical friend who prescribed a range of vitamin and mineral supplements which he has been taking for three years now and he swears by them.

"There are about 10 of them, all in little jars and they are

all numbered for the day of the month," said Ron.

"My health is poorly and sometimes when I get up each morning I feel as if a truck has run over me. I take my vitamins after breakfast and they give me a bump and make me feel ok.

"But I am definitely getting weaker and sometimes I feel woozy, as if I'm drunk. I've never been a drinker or a smoker.

"I don't walk much but I'm still allowed to drive a car and I go to the bank and to the shops and I've got a couple of cataracts so I haven't been reading for a while.

"I tend to lie down and sleep more and do fewer activities. I have a snooze after breakfast and can sleep very easily. I'm catching up for all the sleep I missed out on when I was working," he said.

Ron receives a regular blood transfusion once a month and his blood is checked every six months.

The Leukaemia Foundation helps Ron with transport. Volunteer drivers pick him up and drop him home for his six-monthly visits to the oncology department at the Royal Adelaide Hospital.



Ron Saunders with his wife, Alice

# MANAGING AND SUPPORT FOR IRON OVERLOAD

**Iron overload is a term that describes an unavoidable problem that develops over time due to an excess of iron from red blood cells.**

This excess iron is delivered after multiple blood transfusions and is more than your system can handle.

Moderate levels of iron are necessary for a person's well-being and you receive all the iron your body needs through your diet.

Too much iron, if left untreated, can lead to serious health problems such as heart disease and diabetes. While you may not feel sick, the excess iron begins to build up in key parts of the body, especially the heart, liver and pancreas.

If you have received more than 20 transfused units of blood (about 10 transfusions) in your lifetime, you may be at risk of iron overload. A simple blood test measures iron levels (serum ferritin).

Iron overload cannot be resolved by your body as it has no natural way to remove excess iron so treatment is required to keep you healthy.

Your doctor may prescribe a medicine, called an iron

chelator, which is the primary treatment for reducing the iron excess that builds up as a result of multiple blood transfusions.

You can take an active role in your treatment, and help your doctor better manage your therapy, by noting the total amount of blood transfusions you have received and telling your doctor about any side-effects.

Iron overload happens over time, so you may not feel it right away. Therefore it is important to take your iron chelation treatment correctly even if you feel healthy.

To provide you and your healthcare team with additional support, Novartis has established the Exjade Patient Support Program. This is a complimentary service and all patients who have been prescribed Exjade by their doctor are welcome to enrol in the program. By registering, you will receive 12 phone calls a year from a haematology nurse to discuss any issues, concerns or side-effects experienced in their treatment.

To join the support program, call 1800 465 597 or fill out and return the enrolment form that is included in boxes of Exjade medicine.

## IS IT SAFE TO EXERCISE WHEN DIAGNOSED WITH MDS?



*by Karen Anderson, exercise physiologist from Body Maintenance*

**Exercise physiologists can help people with MDS to become functionally fit. Research shows that exercise is beneficial and starting a physical activity program when you are first diagnosed will help you through your treatment phase.**

### Exercise can:

- reduce fatigue
- increase the quality of your sleep
- reduce risk of developing secondary cardiovascular complications
- increase your self-esteem and independence
- regain your independence
- reduce the length of your hospital stay
- help walking, standing and general daily household tasks
- give you something fun to do with your carer
- build your muscle strength
- reduce the side-effects of your medication.

Fatigue is a more common problem experienced by people with cancer than pain and nausea. Despite the common saying: "I feel too tired to exercise", you need to exercise through the fatigue barrier. The way to do this is to start slowly and increase the quantity of exercise gradually so you reduce your level of fatigue rather than increasing it. Exercise may be the last thing you feel like doing when you have no energy and feel sick, but it does not have to be a 10 km run. There are several simple ways to increase your fitness and there will be days when you won't feel like doing anything, and that is absolutely okay.

### Special considerations before you exercise

An important consideration is for the activity to improve your functional fitness and daily living activities. Loss of leg strength is the most common problem for people who are sedentary for periods of time. This can affect standing, sitting, walking, the ability to carry out household chores and most importantly, your balance. It is recommended that you get out of bed and do a few simple exercises to prevent loss in leg strength.

- Do not exercise in the heat, use an air-conditioned room
- Do not exercise if you have a high fever
- Choose exercises that you can do at home or in hospital. Start doing a few exercises a day which will only take a few minutes and slowly build up as you become stronger
- Avoid direct sunlight
- Avoid busy gyms and swimming pools (a low neutrophil count means high risk of infection)
- Use good equipment (a low platelet count increases your risk of bruising and bleeding)
- A low haemoglobin reduces oxygen delivery
- Increased pain
- Breathlessness
- Severe nausea or dizziness

### Medicare rebates

Medicare rebates are available for people with chronic conditions. This entitles you to rebates for special allied health services like exercise physiologists, physiotherapists, dieticians, podiatrists and psychologists. Your doctor is eligible to allocate five visits to one service or a combination of different allied health professionals.

### How to access an exercise physiologist

You can locate an exercise physiologist in your area by visiting the website of the Australian Association for Exercise and Sport Science (AAESS) on [www.aaess.com.au](http://www.aaess.com.au).

# AUSTRALIAN RESEARCHERS FIND EVIDENCE FOR NEW MDS GENE

**Researchers from St Vincent's Hospital Melbourne have found evidence for a new cancer gene involved in the development of myelodysplastic syndromes (MDS).**

The Leukaemia Foundation has awarded a \$100,000 Grant-in-Aid to researchers Dr Ruth MacKinnon, Associate Professor Lynda Campbell and Professor Harshal Nandurkar to identify the gene.

The team's research is focused on chromosome 20, which is known to contain a region of DNA critical to MDS development in about five per cent of patients with MDS, and two per cent of acute myeloid leukaemia patients (AML).

In these patients, part of chromosome 20 has been deleted, including a tumour suppressor gene.

It was reasoned that the loss of the tumour suppressor gene allowed the cancerous cells to multiply leading to MDS, according to Dr MacKinnon.

"However, we've found evidence that a second oncogene, or cancer gene, is activated by the DNA damage," she said.

"Although we are looking for a leukaemia gene, the chromosome abnormality on its own is more typical of MDS and is therefore one of the earliest gene errors in AML which has developed from this type of MDS.

"We're the first group to propose this new model of AML development and it could be an important breakthrough, particularly for MDS patients, because identifying the gene opens up the potential for developing new, targeted treatments."

The researchers began their investigations in 2002. Using cells from 44 MDS and AML patients, they have identified a cluster of 16 genes of interest on chromosome 20.

This year, Dr MacKinnon and her team hope to gather evidence to support one of the candidate genes in the cluster.

"With the Leukaemia Foundation grant, we've been able to use more precise gene mapping technology and this appears to provide even better evidence supporting our hypothesis.

"In addition, some other early studies on the genes have been showing promising results and we are seeing a difference between cancerous and normal cells."

This project is also funded by the James and Vera Lawson Trust (managed by ANZ Trustees), the Harold and Cora Brennen Benevolent Trust (managed by Equity Trustees Ltd) and the Cancer Council.

# DAMAGED BONE MARROW STEM CELLS MAY LEAD TO MDS

**Western Australian researchers believe alterations to a rare sub-population of bone marrow stem cells could be the underlying cause of myelodysplastic syndromes (MDS).**

The researchers from Royal Perth Hospital and Curtin University of Technology reason that mesenchymal stromal cells (MSC) may play an important role in these syndromes through their impact on the body's immune system.

The Leukaemia Foundation has contributed to the team's research efforts by awarding the 2008 Dominic Di Giacomo Honours Scholarship to Curtin University student, Lawrence Jyh Yeu Liew.

Lawrence will examine MSC cells from the bone marrow of 10 MDS patients to discover if the cells have been altered and are affecting the body's immune system by interacting inappropriately with white blood cells.

"Most patients with myelodysplastic syndromes respond to treatment with immuno-suppressant drugs, which appears to indicate that the immune system is playing a role in MDS," Lawrence said.

"There is also recent evidence that the mesenchymal stromal cells from patients with MDS and blood cancers have been altered.

"If we can prove our theory by showing that in MDS patients the MSC are damaged and playing havoc with the immune system, it may lead to new treatments being developed for these syndromes, including using donor MSC transplantation."

Internationally, Lawrence's research project is one of the

first to investigate the role of MSC in the development of MDS. To date, he has isolated and cultured MSC in the laboratory from three MDS patients.

Lawrence said he was inspired to undertake the project by his interest in haematology and the loss of relatives from cancer: "This is a challenging project and I hope our team comes out with a better treatment or even a better diagnostic protocol for MDS patients."

Lawrence's research at the Royal Perth Hospital is supervised by medical scientist, Dr Marian Sturm, and Curtin University's Dr Anna Cook. He hopes to further his studies by undertaking a PhD.

## WHAT ARE MESENCHYMAL STROMAL CELLS?

**Mesenchymal stromal cells (MSC) are a form of stem or 'mother' cell found in the bone marrow and blood. The cells can be difficult to distinguish and their full function is still being determined.**

**Present in small numbers only, MSC have the ability to differentiate or 'turn into' a range of cell types, including cartilage, bone and muscle.**

**This allows them to help repair injured tissues. MSC also appear to play a role in the immune response and have been shown to have a localised ability to suppress immune cells.**

# ABOUT THE AUSTRALIAN BLOOD CANCER REGISTRY

## The establishment of Australia's first national blood cancer registry is continuing to gain momentum.

The Australian Blood Cancer Registry (ABCR) project was initiated in 2005, with funding from Roche Products and the support of representatives from clinicians, researchers and patient support organisations, as well as registries, government and pharmaceutical organisations.

When fully established, the ABCR will collect detailed and accurate information on blood cancers to form a central database; providing essential information for research and improved treatment outcomes. Australian cancer registries currently only collect diagnosis and death data which means we lack information about the effectiveness of treatments for blood cancers in the Australian population.

Steady progress has been made towards creating the national registry, according to ABCR Co-Chairman, Dr David Joske: "I'm excited and energised by the possibilities that are opening up to realise this complex, massive, and potentially rewarding project, both for the haematological clinical community and our patients."

"This year, we expect to get some runs on the board to prove the value of blood cancer databases and to help make our case for wider rollout of the registries in Australia and New Zealand with stable long-term funding," he said.

Dr Joske's primary focus for the ABCR in 2008 has been to help establish a blood cancer registry in Western Australia<sup>1</sup>. At the time of print, the registry was scheduled to begin collecting new cases of acute leukaemia in WA, with other blood cancers to be added sequentially.



At the last ABCR Stakeholder Meeting, back row from left, Steve McKechnie, Campbell Tiley, Peter Brown, Michael Legg, Sarah Swain. Front row, Suha Patel, Anna Williamson, Susan O'Brien and David Joske

"The WA registry will provide the ABCR with invaluable information on the software, processes, database infrastructure and expertise required to expand the registry nationally," said Dr Joske.

The ABCR is working with several other projects which will support the national registry, including improved pathology reporting, and lobbying the Federal Government for support and funding. The Lymphoma Wizard – software developed to help haematologists better diagnose and manage the disease – is also being deployed.

The Leukaemia Foundation supports the establishment the ABCR by providing administrative services as the organisation's Secretariat. For more information, contact Dr Anna Williamson on 07 3866 4060 or visit [www.abcr.net.au](http://www.abcr.net.au).

<sup>1</sup> The Western Australian Blood Cancer Registry is a joint initiative between the ABCR, the WA Haematology Collaborative Network, and the Western Australian Institute for Medical Research.

## EDUCATION AND SUPPORT PROGRAM ACTIVITIES

Understanding MDS	Nov 4	Melbourne, Vic
Understanding MDS	Nov 5	Orange, NSW
Understanding MDS	Nov 10	Dubbo, NSW
Understanding MDS	Nov 11	Bathurst, NSW
MDS information evening	Nov 12	Hunter, NSW
Understanding MDS seminar series	Nov 13	Brisbane, Qld
MDS - disease & management	Nov 18	Rooty Hill, NSW
Transplant support meeting	Dec 4	Melbourne, Vic

For more information and a complete list of education and support programs for MDS patients and families in your state, visit the education and support programs section on [www.leukaemia.org.au](http://www.leukaemia.org.au).

## LEUKAEMIA FOUNDATION SUPPORT SERVICES

(Freecall) Ph: 1800 620 420

### 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.

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

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](http://www.leukaemia.org.au).

