

# SCLERODERMA OUTLOOK



NEWSLETTER of SCLERODERMA ASSOCIATION of NSW Inc.

## THE SCLERODERMA ASSOCIATION OF NSW INC.

AUTHORITY No CFN14819

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**Vice-President:** Leslie Samuels  
**Secretary/Public Officer:** Marilyn Singer  
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## CELEBRATION OF WORLD SCLERODERMA DAY

At our meeting on  
Saturday, 27 June, 2015 at 1.30pm  
At City of Sydney RSL  
Afternoon Tea Served  
Guest Speaker  
Come and enjoy this important event.

## SCLERODERMA SUPPORT GROUPS AND NETWORKS

If you live in regional NSW, please contact any of the following members for information, support or just coffee and a chat in your local area!

**Blue Mountains and Mudgee-Blue Mountains and Emu Plains-Les Samuels** (02 4739-2136);  
**Mudgee District-Victoria Barrett** (02 6373-3633).

**Central West Scleroderma Group (Orange) –**  
Jenny 02 6361-4025 or Daphne (02 6342-9267)

**Coffs Harbour – Margaret Hannon** (02 6656-1776)

**Scleroderma Group of the Illawarra –**  
Shelley (02-4229-4307)

**Scleroderma Group of Port Macquarie and Mid-North Coast –**

Jackie (0403 801 923) or [jandtbourne@gmail.com](mailto:jandtbourne@gmail.com)

**Hunter Valley, Central Coast & New England –**  
Autoimmune Resource & Research Centre  
(02 4921 4095) or

**HNELHD- ARRC** [hnehealth.nsw.gov.au](mailto:hnehealth.nsw.gov.au)

**North West Scleroderma Support Group (Tamworth) –**  
Lila Neaves (02 6766-2952)

**Byron Bay/Ballina/Lismore – Dianne Doueihy**  
0414 408 723 or [d7diane@yahoo.com](mailto:d7diane@yahoo.com).

## DATES FOR SUPPORT GROUP MEETINGS 2015

Saturday 28 February	Saturday 27 June
Saturday 21 March	Saturday 25 July
– Seminar	Saturday 22 August
Saturday 28 March	Saturday 26 September
–No meeting	AGM
Saturday 25 April	Saturday 24 October
– No meeting (Anzac Day)	Saturday 28 November
Saturday 23 May	– Christmas Party

The meetings are held at 1.30 p.m.  
City of Sydney RSL Club, 565 George Street, Sydney.



RON DRISCOLL'S  
"My Kinda Country"

## **LETTER FROM THE PRESIDENT**

As we approach winter I hope you are all doing your best to prepare for the cooler weather. Here at Scleroderma NSW we have been very busy since our last newsletter.

Our biennial seminar, held in March, was a great success with many offering their congratulations and thanks to the committee for the day. Please take the time to read Marilyn's full report on the event.

We have also been busy with the launch of our new website (details enclosed).

Following the success of the first national newsletter last August, Scleroderma Australia has decided to produce a permanent quarterly national newsletter commencing immediately. This publication will replace the newsletters for all of the states with the exception of NSW. At our last committee meeting it was decided to retain our individual state newsletter as well as contributing to the national publication. As such you will receive two newsletters each quarter from now on. We welcome your feedback on this decision.

Unfortunately a number of our committee, including myself, have been very unwell lately. As such, manning of the office has been a somewhat difficult task. Please accept our apologies for any inconvenience this may have caused.

Liz Denten  
President

## **MEMORIAL**

### **To a beloved husband and father, JOSEPH HORVAT**

Joseph was first diagnosed with scleroderma in 1996 and with medication still continued to work and live a full and happy life with his family up until the past 6 months where he struggled with his worsening condition, in particular his lungs. Joseph sadly passed away on 1<sup>st</sup> February 2015 and in lieu of flowers asked that friends and relatives contribute towards scleroderma research. As a result a very generous donation was recently made to Scleroderma NSW and sincere thanks goes to the following donors; Susanne Horvat, Anna Horvat, Eva Begovich, Elizabeth Brbot, Nikola and Ivan Brbot, Matilda Kraus and M. Long.

Joseph was a happy and loving husband, of Susanne, and father to their children Emma and Joshua. The Scleroderma Association of NSW Inc. extends their deepest sympathy to the Horvat family.

## **SCLERODERMA NSW NEW LOOK WEBSITE**



We are very pleased to announce the launch of our new website. Designed by NDdesigns and powered by WIX we hope you will find the new site comprehensive and most importantly, easy to use. In addition to the original information we have introduced some new features.

**SUBSCRIBE TO STAY CONNECTED WITH US** located on the homepage, will place your email address on our priority list. You will receive personal notifications of upcoming events and items of interest to scleroderma patients. Please be assured that we will not bombard you with “junk” emails. If at any time you wish to unsubscribe, simply send us an email to this effect and we will remove you from the list. It’s that easy! No strings attached, just the opportunity to stay connected with us.

Our new website will also offer access to invitations and registration forms to events held by Scleroderma NSW. As time goes on we will introduce new features to the website to further enhance your internet experience. Thank you to NDdesigns for their design and technical support and thank you also to those of you who have already subscribed to our mailing list.

### **UPDATE**

#### **RESEARCH PROJECT: PERSPECTIVES & PREFERENCES OF PATIENTS LIVING WITH SYSTEMIC SCLEROSIS (SCLERODERMA)**

Following our announcement in February’s newsletter, Dr Thakkar’s team are now commencing the recruitment of patients into this study. Scleroderma NSW members are invited to participate in this study. Please refer to details below.



#### **Perspectives and preferences of patients living with systemic sclerosis (scleroderma)**

Dear Scleroderma NSW member,

We would like to invite people diagnosed with scleroderma to participate in a study which involves one interview to discuss their experiences and perspectives of living with scleroderma.

If you would like to know more about this project or are interested in participating, please contact: Dr David Sumpton  
email: [sclerodermaproject@gmail.com](mailto:sclerodermaproject@gmail.com) phone: (02) 8738 4088

### **FROM THE EDITOR**

So happy to present our current newsletter for May, 2015. I am sure that you will find the information contained in this edition informative and interesting.

We would love to have some feedback from our readers and members. It would be good to know what topics and areas you might like to see published in your newsletter. As a committee we do our best to source information that will be of interest to our members. We would like to introduce an area in the newsletter where some of your specific questions can be addressed. If you would to see this section added to the newsletter, please send in some questions or suggest the areas you would like covered. You could send your questions to our office or send an email; [scleronsw@aol.com](mailto:scleronsw@aol.com)

As the cold weather approaches, I do hope that you all keep as well and warm as possible.

Marilyn Singer

### **WORLD SCLERODERMA DAY**

World Scleroderma Day, falls on Monday 29 June, 2015. This annual day of recognition and, to honour Scleroderma sufferers, both past and present will again be marked by many different events. Since the creation of this day Scleroderma NSW has hosted an Information table at St. Vincent's Hospital, Darlinghurst. Last year we marked World Scleroderma Day at our regular monthly support meeting in Sydney with a well-attended and enjoyable afternoon tea. This year we hope that you will support this event once again by joining the committee and other members to mark this important day. Please come and share the company of 'fellow travellers', catch up, socialise and be informed by our guest speaker.

<http://worldsclerodermaday.org>

### **KRISTIN ATKINSON'S STORY**

Pelting towards the try-line, Kristin Atkinson heard something she wasn't used to. With the loud breath of an opposing team member on her shoulder, the representative touch football player knew something was seriously wrong. What started as a rash on her hands and face had developed over a few months into an exhausting, painful condition that mystified her doctors and saw her try a series of fruitless alternative therapies.

"It was a social game and I was breaking away for a try and the fact that they were able to catch me was a real shock," Kristin says.

"I had always been very fit but by that point I couldn't even finish a training session. I just knew something was not right. It was going to be bad."

Sure enough, nine months after those first spots appeared, came a devastating diagnosis. At 32 Kristin had scleroderma, a rare and often fatal disease in which the body's immune system creates an excess of collagen.

"It was like my body was breaking down," she explains.

"With the condition your skin gets incredibly tight and you get really stiff. It's like you have concrete poured into your body and the joints ache. It's very painful and when you knock into something, it's like a knife is cutting into you."

Kristin was devastated. Already no stranger to hospitals, with her husband Adam having been diagnosed with cystic fibrosis as a child, she had always assumed she may need to become the main breadwinner within the family so that he could concentrate on his health. (Adam is currently on the lung transplant waiting list at St Vincent's Hospital and continues to work full time).

Although there is no cure for scleroderma, a trial at St Vincent's Hospital led by Dr John Moore since 2001 has had marked success in halting the progress of the condition, through an autologous stem cell transplant.

Dr Moore, a clinical haematologist, has performed 14 of the transplants whilst around the world 200 of the procedures have been performed.

"The patients have to be young and like Kristin they have tried and failed every treatment available. Like any transplant, it is also a risky procedure, so the patients need to weigh that up as well," Dr Moore said.

"We collect their blood and stem cells and transplant them back after a course of chemotherapy. The theory is it suppresses the immune attack on their skin to such an extent that the skin eventually starts to repair."

The procedure has worked with every one of Dr Moore's patients.

"This is unlikely to be a cure, but it has halted the progress. For three of our patients the disease has come back and sadly two of those patients have died of their disease.

"But for the others, several of them were on disability pensions and have now gone back to work or are studying and we think it's very successful."

Dr Moore's trial is awaiting review with the medical journal Bone Marrow Transplantation, but he said, "It's likely this will become standard treatment for this condition and if that's the case it will be the first time that something has been shown to be effective in treating this devastating illness."

For Kristin, there is no question that her transplant in 2004 saved her life.

"A lot has changed for me, my hands are permanently clawed and I can't play sport anymore. But I am back now at work as a HR operations project manager in a business and technology solutions company, and I consider myself incredibly fortunate to be in remission," she says.

"My illness is in the background for us. Now it's time to focus on getting a lung transplant for Adam." *Kristen Atkinson. Printed with permission from St. Vincent's Publications.*

### **BONE MARROW TRANSPLANT CELEBRATES 35 YEARS**

On 31 October 1975 St Vincent's Hospital performed Australia's first bone marrow transplant (BMT). The patient, a 31 year old mother of two with Acute Myeloblastic Leukaemia, knew that transplantation in terminal leukaemia could achieve a 10 to 15 percent chance of long term survival. Almost 35 years on, St Vincent's Hospital continues to be a pioneering Australian BMT facility.

Unfortunately, the patient passed away 18 days later of disseminated fungal infection and her medical records include entries by several prominent current and former names from the Darlinghurst campus - Tony Dodds, John Casey, Ron Benson, Richard Lee, Brett Courtenay, Sam Breit and Alan Concannon.

In 1974 a cell separator unit was installed at the Department of Haematology, as founded by Dr James Biggs in 1970. The first unit of its kind to be installed at an Australian teaching hospital, the unit was to be used for therapeutic leucapheresis and plasmapheresis. In 1975 Dr Len Johnson, an Australian who had been working in Seattle, supplied the department with a set of Thomas needles, specifically designed for donor bone marrow aspiration. The infrastructure for BMT was now in place at St Vincent's Hospital.

The first successful allogenic transplant was performed on a patient with Severe Aplastic Anaemia (SAA) in 1976 - the patient remains alive and well today. This success stimulated Dr Biggs' resolve to set up a dedicated BMT program. He succeeded in establishing the program over the coming years, however it was not without intense lobbying of private sources for the funds.



Between 1975 and 1980 some 18 allogenic transplants were performed - nine on patients with acute leukaemia and nine on patients with SAA. Of the leukaemia patients, all in relapse with terminal disease, one survived four years and another two years, both eventually dying of chronic graft versus host disease. The remaining seven patients died soon after transplantation, but of those with SAA four survived long term.

Until well into the 1980s St Vincent's remained the only hospital in NSW to transplant adult patients and additional patients were referred to the hospital from across Australia and South East Asia. Activity increased during the 1980s in terms of both patient numbers and research.

In 1979 the department performed the first autologous transplant, in 1983 Australia's first matched unrelated donor (MUD) transplant and in 1996 the first allogenic peripheral blood stem cell transplant. Since 1975 the department has performed over 1,200 transplants and remains at the forefront of clinical care and laboratory research.

Today, the department hosts the NSW BMT Network, the Australasian Bone Marrow Transplant Registry (ABMTRR) and the Haematology Research Unit. Established in 1992 the ABMTRR collects data on transplant activity and outcomes in Australia and New Zealand. The department has strong links within the Arrow Bone Marrow Transplant Foundation, the foundation funds research into leukaemia and other blood diseases and provides patient support services including accommodation, financial assistance and patient information books.

The department is preparing for the move to The Kinghorn Cancer Centre, which will facilitate the expansion and improvement of outpatient and stem cell laboratory services.

*Over four years have now passed since this article was written, but the success of this programme continues. Printed with permission from St. Vincent's Publications.*

## **SEMINAR REPORT: SCLERODERMA ASSOCIATION OF NSW Inc.**

After many months of hard work and careful preparation the Scleroderma Association of NSW held a very successful and informative Seminar on Saturday, 21 March, 2015. It has been a long standing tradition to mark Scleroderma Awareness Month, which is held in March, with a major event. We hold a Seminar biennially and a social event the intervening year. These events are always welcome additions to our Scleroderma year of service to our members.

This Seminar was no different, it was well supported by our members as an important way of keeping up to date with the latest medical research. The day also offers opportunity to catch up with friends or meet new people, all with a common cause – to discover, understand and be supported on our Scleroderma journey. This year we were fortunate to have as our guest speakers, Dr Vivek Thakkar; Rheumatologist. Dr Thakkar is currently receiving a grant from the Scleroderma Association of NSW to fund a Patient centred research programme. Dr Benjamin Ng; Lung and Sleep Specialist. Dr Ng spoke on the lung disorders which most affect Scleroderma sufferers. Prof. Glenn Reeves; Immunologist. Prof. Reeves spoke on his research into Autoimmune Diseases. Prof. Reeves is always a welcome speaker at our events, as he has the gift of presenting his knowledge with both humour and the common touch. This year Prof. Reeves delivered the Inaugural Yvonne Turner Memorial Presentation. Yvonne Turner, who passed away last year, was a loyal and active member of our association for many years. Mr Colin Turner, Yvonne's husband, generously initiated this memorial to his wife. It was a fitting tribute that Prof. Reeves should be the first presenter, as he was one of Yvonne's medical team.

Mr Gerry Freer, widower of our esteemed late committee member, Alison Freer, addressed

our Seminar on the 'Role of the Carer'. Gerry, with his background as an English Head Teacher, was both inspiring and practical in his approach to this role. He brought a tear to many an eye.

Ms Debbie Blanchfield, Clinical Nurse Consultant – Wound Care Illawarra; was our final speaker for the day. What Debbie does not know about wound care is not worth knowing. Her expertise in this area was greeted enthusiastically by our attendees.

We have had very positive 'feedback' from our members who attended our Seminar. Our members and guests found it a wonderfully informative day, with a chance to catch up over a beautiful lunch served by the Bowler's Club of NSW. Our committee worked tirelessly to present this seminar to our valued members. Special mention must go to our

President, Liz Denten and Clara Dias, our office administrator, who sourced the great bags and contents for the Seminar. Thanks also to all the committee, who helped to make the Seminar a success; Yvonne Witts, Jenny White, Les Samuels, Dayle Shafer and Marilyn Singer.

We welcomed, as our guests, the President of Scleroderma Australia, Robyn Sims; and Dr Helen Englert, a supporter of our association over many years.

Look forward to seeing even more members and guests at our next seminar.

*Marilyn Singer – Secretary Scleroderma Association of New South Wales. Inc.*

### 2015 Scleroderma Assoc. of N.S.W. Inc - Survey Results

**Question 1:** With regards to the speakers today; I found the presentation informative.

**Dr. Vivek Thakkar:**

Strongly agree 95%	Slightly agree 3%	Slightly disagree 0	Strongly disagree 0	Did not answer 2%
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**Dr. Benjamin Ng:**

56%	38%	3%	0	3%
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**Prof Glenn Reeves:**

92%	8%	0	0	0
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**Ms D Blanchfield:**

51%	21%	0	0	28
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**Mr. G Freer:**

62%	15%	3%	0%	20%
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**Question 2:** The venue was easy to access & suitable for the event.

79%	18%	3%	0	0
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**Question 3:** The selection of food offered was suitable to my dietary requirements.

69%	15%	8%	5%	3%
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**Question 4:** Overall I found the seminar to be very informative and an enjoyable day.

Strongly Agree: 90%	Slightly Agree: 10%
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**Question 5:** Based on today's experience, I would attend other seminars held by Scleroderma NSW.

Yes: 95%	No: 0%	Not sure: 5%
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**Question 6:** My Age Group.

Under 25: 0%	26-40: 18%	41-50: 3%	51-60: 28%	61-70: 33%	Over 70: 18%
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## **Back to Basics**

Scleroderma is an uncommon disease that results in hard, thickened areas of skin and sometimes problems with internal organs and blood vessels. There's no cure, but most people can lead a full, productive life.

Scleroderma is an autoimmune condition, which means the body attacks its own tissues. In the case of scleroderma, the connective tissue underneath the skin and surrounding internal organs and vessels is affected. This causes scarring and thickening of the tissue in these areas.

Depending on the type of disease, the skin may be affected by a few thickened oval patches that can occur anywhere on the body, or there may be lines of thickened skin across the face, scalp, fore arms or legs.

Other possible symptoms of scleroderma depend on which internal organs, if any, are affected.

The symptoms of scleroderma can usually be controlled by a range of different treatments. For milder forms of the disease, treatment may not even be needed. But of course this must be discussed with your health care professional.

## **Causes of scleroderma**

Normally, the body's immune system fights off any bacteria or viruses that infect the body by releasing white blood cells into the blood to isolate and destroy the germs. The immune system responds like this to anything in the body it doesn't recognise, and settles down when the infection has been cleared.

It is thought scleroderma occurs because part of the immune system has become overactive and out of control. This leads to cells in the connective tissue producing too much collagen, causing fibrosis (scarring and thickening) of the tissue.

It's not clear why this happens to people with scleroderma. Genes are thought to be involved, although scleroderma is not regarded as an inherited disease and cannot be passed on to relatives. There are many similar diseases, such as rheumatoid arthritis and lupus, which are caused by the immune system. These are collectively known as autoimmune diseases.

## **How scleroderma is treated**

The aim of treatment is to relieve symptoms, prevent the disease getting worse, detect and treat any complications (such as pulmonary hypertension) and minimise disability through occupational therapy and physiotherapy. Different medicines may be needed, such as: medication to improve circulation immune suppressants such as cyclophosphamide and methotrexate may be taken to suppress the immune system and slow the disease's progression high doses of corticosteroids may lessen or slow down damage to the skin and organs different medicines may be needed to control the various symptoms (such as heartburn, constipation and high blood pressure)

*Reprinted with permission from Scleroderma Foundation USA.*

## **Managing a Chronic Illness**

While there is no proven cure for scleroderma, much can be done to prevent, minimize or alleviate its effects and symptoms. Scleroderma symptoms vary greatly from individual to individual; the manner in which each person responds to treatment also varies greatly; and there are many treatment options. It is important that a physician experienced in scleroderma management works out an individually tailored program to meet the specific needs of a person with this disease. Close cooperation with the physician will help him or her develop such a program.

## **The emotional aspects of scleroderma**

A common reaction to being told that one has a disease such as scleroderma is “Why me?” It is unknown why some people develop the disease and others do not. One does not bring scleroderma upon himself or herself; therefore, one shouldn’t feel guilty or responsible for the illness.

A person newly diagnosed with scleroderma may feel alone and uncertain about where to turn for help. He or she may experience a number of other feelings and emotional reactions from time to time, including initial shock or disbelief, fear, anger, denial, self-blame, guilt, grief, sadness or depression. Family members may have similar feelings.

Feelings in themselves are neither good nor bad. One simply has them. Sharing them with family and friends or with others who have had similar experiences can help. Professional counselling also can help people with scleroderma and their family members who are having difficulty coping with their feelings.

We try to use the term “person with scleroderma” instead of “scleroderma patient.” The person with scleroderma may be a “patient” in the physician’s office, hospital or clinic, but he or she is much more than

that. Thinking of oneself as a total person with a full life to lead may help to keep scleroderma in perspective and enable one to maintain a positive but realistic attitude.

## **Building a health and support network**

Participating actively in one’s own health care is of prime importance to the person with scleroderma. It is equally important to cooperate and communicate effectively with the physician who is managing the disease. While these two—the person with scleroderma and the physician—are the focal point of the management “team,” many other people and resources also form a health and support network.

Family and friends can provide emotional support for the person with scleroderma, encourage him/her to follow the recommended treatment program, and assist in carrying out activities that he/she finds difficult.

The health team begins with the physician, but can include many other health professionals such as medical specialists, nurses, physical and occupational therapists, and psychologists or others trained in counselling.

Joining a scleroderma support group, such as one affiliated with the Scleroderma Foundation, enables the person with scleroderma to meet and exchange information with others who have similar problems, as well as to learn more about scleroderma.

*Your Scleroderma Association of New South Wales subscribes to publications from Scleroderma Foundation USA. Scleroderma Association of NSW holds regular support group meetings – see front page for details.*

## **Practical Tips**

There also are a number of general common-sense measures that a person with scleroderma can take to enhance his/her well-being. These measures include:

Avoid over-fatigue by taking it easy and getting sufficient rest. Knowing your own limits does not indicate you are lazy.

Learn to control and minimize stress.

Eat well-balanced meals and maintaining a sensible weight.

Practice good hygiene habits, especially of the skin, teeth, gums and feet (including the wearing of cushioned and well-fitted shoes).

Avoid smoking. The health risks of smoking are well known but frequently ignored. It is particularly dangerous to persons with scleroderma because it can have effects on blood circulation and lung function.

*Scleroderma Foundation USA – Spring Edition 2015.*

## **MEMBERS REQUESTS**

From time to time we receive requests from our members for information on specific aspects of Scleroderma and associated conditions. Recently a member requested information on the effect of Scleroderma on the feet.

## **SCLERODERMA & THE FEET**

The feet can be affected by Scleroderma in a number of ways.

### **Circulation**

We usually associate Raynaud's phenomenon with the hands as this is where we notice it the most, however the feet can also be affected in the same way. We may not notice the colour changes though as our feet are usually covered up, especially in cold weather.

## **Nails**

Some patients experience a change in the bones at the ends of the toes. This can have an effect on nail growth causing ingrown toenails, which are both painful and prone to infection.

## **Skin**

Tightening of the skin on the feet can cause dryness and irritation. As with other parts of the body, calcinosis may also occur on the feet. Some people with Scleroderma also experience general pain in the soles of the feet when walking. This may be due to changes in the fatty tissue which normally protects the ball of the foot.

## **Looking after your Feet**

If you experience dryness or itchiness make sure you moisturise your feet regularly. Find a moisturiser that suits your skin, preferably a simple one free from perfume. Choose comfortable footwear that does not rub and provides adequate support. Be careful not to confuse tightness with support. If shoes are too tight they will restrict the circulation. For some people, the use of insoles may be of assistance, whilst others may require orthotics. Take care when cutting your toenails. They should be cut in a straight line.

If you are unable to adequately reach your feet and care for them yourself, seeking the help of a podiatrist may be advisable. As a specialist in feet, the podiatrist will be able to treat any issues you may have including the maintenance of ingrown toenails. They will also be able to advise you on care and treatments specific to your individual needs. Please speak to your GP who will be able to provide you with a referral to a podiatrist.

Liz Denten. Major References: RSA, *Footcare (in Raynauds and Scleroderma) An Information Leaflet*, Scleroderma Society, *The Foot in Systemic Sclerosis (Systemic Scleroderma)*

SCLERODERMA NSW WOULD LIKE TO THANK THE FOLLOWING  
DONORS FOR THEIR GENEROSITY IN CONTRIBUTING TOWARDS  
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Golden, Elaine	Milat, Robyn	Witts, Yvonne
Halverson, Julie	Miller, Robyn	
Harburg, Phyllis	O'Leary, Daniel	
	Pitkin, Jean	

Please remember that Scleroderma NSW, Inc. in no way endorses any of the medications or treatments reported in this newsletter. The information is intended only to keep you informed. We strongly advise that you consult your doctor regarding any medication or treatment which may interest you.