

- ▶ AUTOIMMUNE PROJECT . . . 1
- ▶ MEETING REPORT 2
- ▶ WHY I JOINED THE GROUP. 4
- ▶ USEFUL WEB LINKS. 4

Scleroderma

support group

newsletter

Local plan to treat auto-immune diseases

A Wellington immunopathologist has a plan to aid earlier detection and better treatment of autoimmune diseases such as scleroderma.

Dr Richard Steele's ambitious project calls for a combination of detection, treatment and more comprehensive medical training. He's called it the Autoimmune Sera Project.

Dr Steele outlined his plans at May's support group meeting. Dr Steele says there are only 5 immunopathologists in New Zealand and a desperate lack of specialist involvement in autoimmune testing in New Zealand laboratories.

"This leads to a lack of support, education and advice for doctors who treat autoimmune patients," he says.

Dr Steel's project includes establishing a for-profit company that would undertake research and a non-profit foundation that would support patients and grant money for research into autoimmunity.

Dr Steele says he's now raising money to establish the company and employ staff prior to creating the foundation.

See page 2 for project details and a report on Dr Steele's talk.



Winter...

This issue completes our first year as a support group: the newsletter has covered all four seasons. From small beginnings we have stayed small - a reflection of the rarity of scleroderma and the limited numbers of people in the community that it affects.

Nevertheless, with another successful meeting wrapped up we are starting to receive enquires from across New Zealand. Those able to attend our meetings probably represent about half of those on the mailing list.

Autoimmune Sera Project planning

Contd. from page 1.

Commercial potential based on autoimmune sera

There is an international shortage of well-validated autoimmune sera and a plan has been hatched to establish a company to supply sera from Wellington.

This will benefit local sufferers of auto immune diseases, such as scleroderma, because it will increase the training and skills available both to research and treat the disease, Dr Richard Steele says.

Dr Steele told the May support group meeting that most of what is needed to get the company started is already present.



For a start it needs an immunopathologist with an interest in autoimmune serology and that describes him exactly. It also has a resident biotechnology company operating here. As well, diagnostic testing in Wellington would benefit from the improved knowledge and testing for autoimmune antigens.

The company would earn profits from which a proportion would be handed across to a foundation.

The revenue plan is:

Phase 1 Company Building

Build up enough equity to function and employ appropriate staff

Phase 2

- Profits
 - 40% company
 - 60% to a foundation
 - 50% for patient support
 - 50% research grants for research into autoimmunity

The goals are to improve regional diagnostic testing, bolster the local biotech company, Arotech, and raise funds to help sufferers of autoimmune diseases.

The project will also provide a way to pay for advanced research into autoimmune diseases and earlier testing and diagnosis.

Dr Steele says the activity will raise awareness of autoimmune diseases, most of which are rare and not well understood, even by doctors, many of whom receive scant training during their medical college years.

Call for blood donors from autoimmune disease sufferers

The backers of the Autoimmune Sera Project will be seeking donations of blood from sufferers of autoimmune disease to kick-start their research.

They plan to start a website that invites people with autoimmune disease to donate blood samples. Flyers and pamphlets would be distributed to doctors' rooms and support groups (not unlike ours).

The quest for blood from which to make the sera will feed the growing world demand for high quality autoimmune diagnostic kits. These are required by researchers and laboratory testers.

Putting a face to the prime suspect involved in scleroderma

When laboratory diagnostic technicians peer into their instruments looking for signs of autoimmune diseases like scleroderma, they know they've found it when they see what looks like a Hubble telescope shot of a distant galaxy.

The ANA test describes a search for anti-nuclear antibodies. These are the makers found in blood that show the body's producing antibodies directed against its own cells.

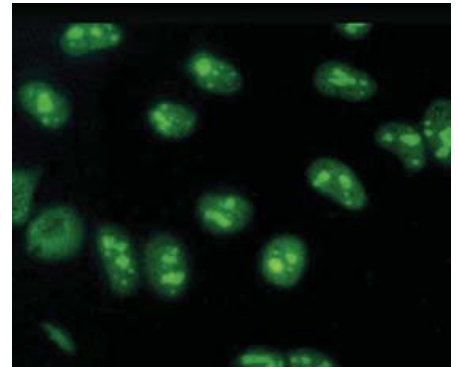
Nearly all those with scleroderma produce these destructive antibodies. In blood test result sheets, the various antibodies that track the intensity of the effect, are reflected in changing levels.

Routinely Tested

Anti-centromere antibodies (CREST)
Anti-Scl70 (topoisomerase 1) antibodies (diffuse scleroderma)
Anti-U1-snRNP antibodies (mixed connective tissue disease)

Sometimes tested

Anti-Pm-Scl antibodies
Anti-histone antibodies



The tell-tale markers that show that the person who provided the blood sample from which this was extracted is producing autoantibodies - immune system proteins that are directed against healthy tissue.

source: Dr Richard Steele.

Our support group: the value of joining

Scleroderma support group member, Valerie Smith tells us why she joined and what she gets out of the regular meetings and contact with fellow sufferers of scleroderma.



When I told a friend about our Support Group, she was shocked.

“You mean, you’ll all sit around and moan about your aches and pains?” I gave up trying to explain; like everybody else, except those afflicted with

scleroderma and our medical experts, they simply do not understand what it is like, and what our group is doing for us all.

“But you look so well,” they say when they see us struggle. Only those close to us see past the façade, which is why our group is so worthwhile. While our medical advisors do their best, this is limited because often there are no answers to our questions. The penalty of our having an extremely rare condition. Before our first meeting, the only others I had met both died; my relief at finding others still getting on with life was enormous.

Sharing helpful tips to overcoming common obstacles, our own newsletter, gaining access to websites from more enlightened countries like Australia, USA and the UK, and just knowing one is with others who understand, are already making our support group valuable. As one living

alone, with no social contacts and few callers since having to drop out of the many community activities with which I was very involved, I find some comfort in knowing I am not really alone. I try to practise the advice from Melissa and Rheumatology on coping with fatigue, frustration, anger, despair and stress, by trying to pace myself.

I listen to beautiful music while writing my book, cuddle my dog, and try not to feel hurt and envious of all those enjoying what was once part of my life: tramping, saving the world, concerts, choir, pet therapy with my dog at a rest home, and continuing study. I am also trying to sum up enough courage to ask for help; failing eyesight means I am not meant to drive, my dog cannot either, and the community spirit of yesterday is truly dead.

I realise how fortunate I am in developing this disease at my vast age, after a lifetime of coping well with severe Raynaud’s, but like you I have no intention of giving up. I have far too much still to do to sit; the “bucket list” still has 8 major goals that I must reach.

So thank you, all those involved in setting up our Support Group. And thank you everybody for just being there.

My sincere best wishes.

Valerie W.Smith



Dr Richard Steele shares information after May's meeting in Lower Hutt.

Morris, an 82 year-old, renowned for his reluctance to spend any money, went to the doctor to get a physical check-up because he hadn't been feeling his best.

A few days later the doctor saw Morris walking down the street with a gorgeous young woman on his arm.

When the doctor next spoke to Morris and said, "You're really doing great, aren't you?"

Morris replied, "Just doing what you said, Doc: 'You're a tight ass. Get a hot mamma and be cheerful.'"

The doctor said, "I didn't say that. I said, 'You've got arthritis and a heart murmur. Be careful.'"

CONTACTS

Newsletter: Barbara Spavin Email Barbara@netco.co.nz

links: www.arthritis.org.nz | www.scleroderma.org

Browsing the web - scleroderma help and information

Tina McLean has dug through the web to find sites of relevance for those with scleroderma. Tina has commented on each for quality of information and ease of use. These links will be put on the the web site for your reference

1. Scleroderma Victoria

www.sclerodermavictoria.com.au/

A nicer, brighter and colourful home page. Easy to read and Navigate around their pages.

The main question "What is Scleroderma? " is short and brief. Clear and easy to understand, but does not go into to much detail. Covers all the basics of the disease. Navigation is easy, and their events page is clearly laid out.

2. Scleroderma Society

www.sclerodermasociety.co.uk

This is UK-based and has been supporting people with Scleroderma for more than 25 years.

Nice home page with clear logo. Navigation is easy, but it does have a lot of information to read on the home page.

Note: Their newsletter is available at :
www.sclerodermasociety.co.uk/newsite/newsletter.php

They also have a useful links page:
www.sclerodermasociety.co.uk/newsite/links.php

3. Scleroderma Foundation (US based)

www.scleroderma.org/

Nice home page with clear logo. Navigation is easy, but does have a lot of information to read on the home page.

Note: News and Events contain their Newsletter, stored chronologically.

The main question "What is Scleroderma ?" is a very short description with few details. Free brochure download:
www.scleroderma.org/medical/download.shtm
which has all useful information about various forms of Scleroderma.

4. Raynaud's & Scleroderma Association (UK)

www.raynauds.org.uk/

Nice clear and easy to read home page.

They have given a brief description of Raynauds and Scleroderma as part of their home page.

Free, downloadable brochures

5. International Scleroderma Network

www.sclero.org/

This site links to Scleroderma websites in all the countries, including New Zealand, which has the Auckland Scleroderma Support group:

6. Auckland Scleroderma Support Group

www.sclero.org/support/groups/new-zealand/a-to-z.html

7. Scleroderma Association of New South Wales

www.sclerodermansw.org/

Their Home page is quite cluttered and not very intuitive. Found I had to read carefully to find the links to their other pages. "What is Scleroderma ?" is pretty informative and easy to read. It explains in everyday language, and drops the jargon.

8. Scleroderma Association of Qld Inc. (Scleroderma Queensland Australia)

www.scleroderma.org.au/

A much better looking Home page, not as cluttered as the previous site. Navigating to their other pages was easy.

The main question "What is Scleroderma ?" A lot more information given than the previous website, a lot more to read and take in, but well written and covers a lot more. Slightly boring page to look at as it had only text, and no pictures.

