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Scleroderma

New Zealand support group

newsletter

Spring Issue 2013

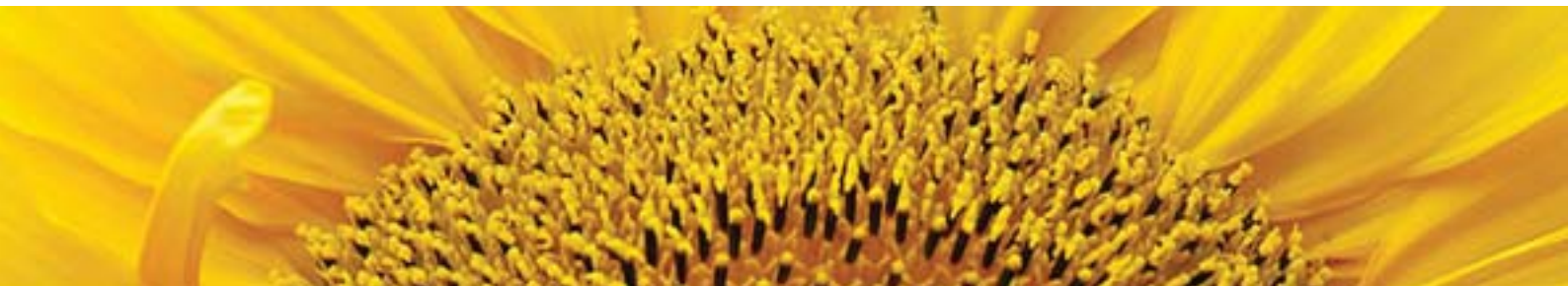
From the sounds of the birds chattering, the sights of blossom breaking out and the happy chatter at our last meeting, I'd say that spring has sprung again, right on cue.

Raynauds may begin to be held slightly more at bay as the weather warms and coughs and colds that bedevil someone who has to put up with scleroderma may recede for the warm months.

Since our last newsletter, we have celebrated World Scleroderma day and later in these pages there are some images and a short report on our response. The day, remember, is celebrated in memory of Paul Klee, a noted Swiss painter who contracted scleroderma and died from its complications in 1940, and in honour of all those who have no choice but to fight the disease daily - that's us!

In the US, where everything seems bigger, the annual scleroderma convention held in August attracted more than 515 conference attendees, speakers, volunteers, exhibitors and sponsors. Atlanta houses the headquarters of Coca Cola and CNN and is a typical high-rise American city. Next year, they'll all gather in Anaheim, California. They have extensive cover of the event on their facebook pages.

So, to Spring and warmer days!



Autoimmune support group starts

My name is Natalie Willis, I am a 47 year old New Zealander, living in Auckland, who was diagnosed with Autoimmune Hepatitis 4 years ago.

It came completely out of the blue, I had been healthy and active for many years, I was only 43 yrs old, and we had no family history of an Autoimmune disorder. In September 2009 I became very unwell (over the weekend) and was admitted directly from my GP's office to Auckland City Hospital's Liver Transplant Unit, whilst they tried to diagnose my condition.

There, they tested me for Hepatitis A, B, C, D, and even Hepatitis E (those are viral hepatitis strains), but after extensive blood work, which was sent to Australia, I was finally diagnosed with Autoimmune Hepatitis. The months following, the inflammation was controlled (with terribly high doses of Prednisone) and the disorder was managed with an Immuno Suppressant (Azathioprine), which I will stay on for life.

The adjustment for me was not hard, and I changed my diet immediately. I now eat a 'liver friendly' diet of no dairy or meat.

The hardest challenge, was by far, the lack of support and compassion from the medical community. With the privacy protocols surrounding patient information being the way they are, my specialist (and unfortunately I have never seen the same specialist twice) couldn't help with any form of social contact with others with the disorder, and subsequently, right from the start I felt alone and isolated.

"I was finally diagnosed with Autoimmune Hepatitis"

In 2011, I posted a message on the www.grownups.co.nz website and through that met another Auckland women with the same disorder, and ever since we have

enjoyed a growing friendship.

Some time ago we chatted about reaching out to others with AIH (Autoimmune Hepatitis) and decided to build a website to promote a 'wider sense of community', regardless of location, and so I set about learning how to do this.

Initially I built a website called Autoimmune Hepatitis NZ, which was similar to the one we have today, but over time I felt that whilst there was no specific support for New Zealanders with AIH, I didn't feel comfortable only offering support for our specific disorder.



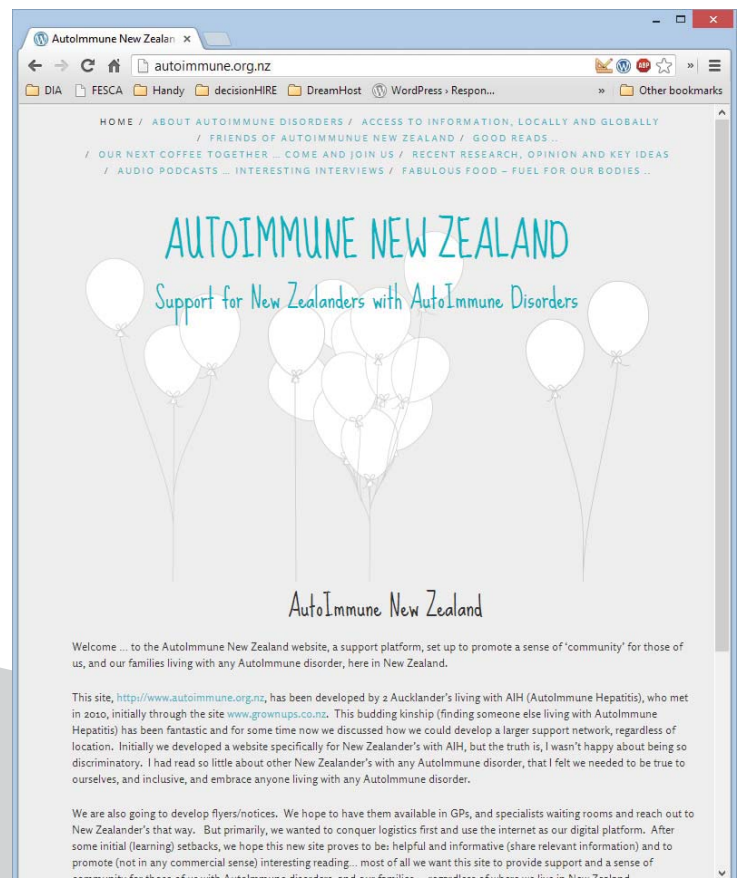
In March of this year I re-developed the site (purchasing a new domain name and adjusting the focus and content of the site) and now feel much more comfortable by being 'inclusive' and 'open' to all New Zealanders with any Autoimmune disorder.

www.autoimmune.org.nz

Maintaining the sites content, marketing the site and building the community is where I see an (exciting) future for Autoimmune NZ.. I appreciate your community support and always welcome feedback (e: info@autoimmune.org.nz) ...

Kind regards,

Natalie Willis

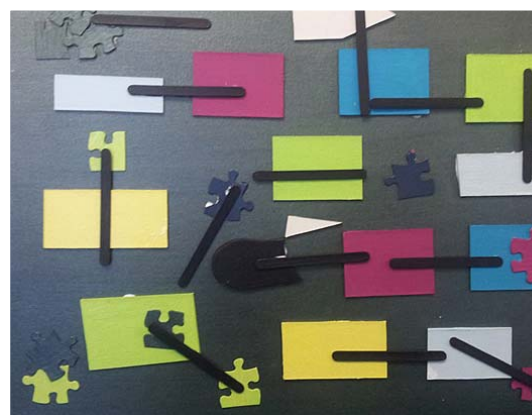


World Scleroderma Day Celebrated

Colourful contribution from the support group

World Scleroderma Day was marked by many groups, including ours, either on or close to the June 29 day. The occasion recalls the life of Swiss artist, Paul Klee who died from the effects of Scleroderma in 1940. It was with an artistic theme that Adrienne set out to help us celebrate the day and add a bit of colour to the proceedings. The results speak for themselves.

See more pictures on the website: www.scleroderma.org.nz/about/gallery/



From the Auckland Scleroderma group's latest newsletter

Noticeboard



Well July brought us some sad news our dear friend

Bev Wetzel passed away, Bev had a lovely service at the Weymouth School Hall and it was really nice that nearly all of our SD members attended this service. Bev will be missed in our SD family always so

bright & positive, Bev had a great passion for life, teaching, ceramics, children, family ... Bev had a great ability to bring people together and make them feel so welcome, And Bev had a great following on Face book, Bev is very much missed on our FB pages.

Bev has left behind Mark Wetzel and their 2 children Nikita & Cameron, A great family unit that looked after each other, As a group our thoughts are with Bev's family and our support & friendship will always be there for the Wetzel's.

Pernicious anemia?
[More information here](#)

Next Meeting

16 November 2013

New meeting Rooms

Don't forget: we have new meeting rooms.

See below for directions!

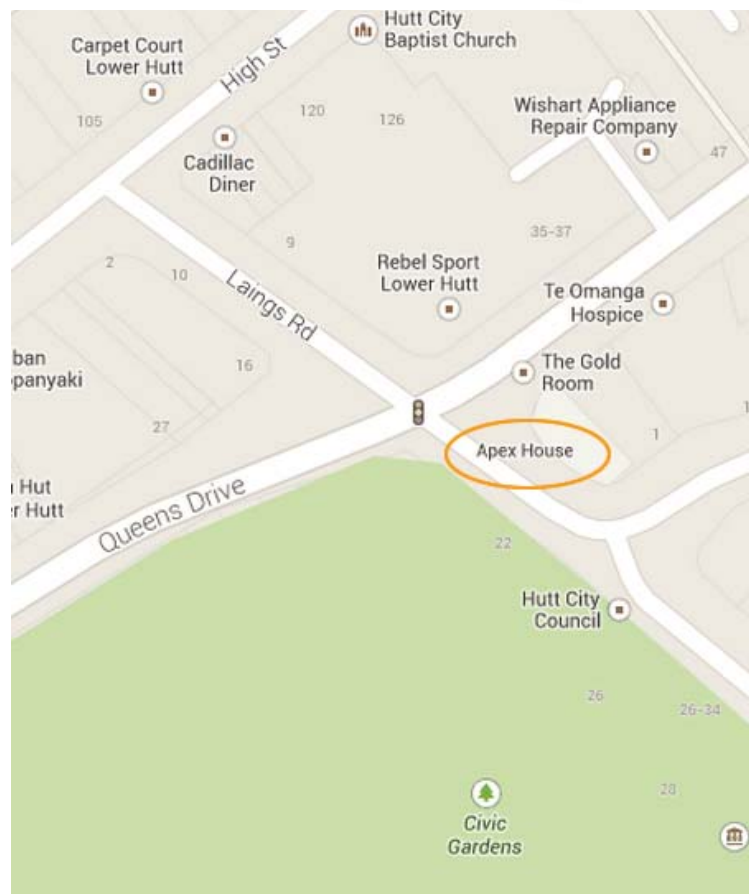
New meeting rooms

The next time we meet, in November, will be at new premises in Lower Hutt.

The new rooms are at Apex House, corner of Laings Road and Queens Drive.



Apex House is just down the road from the Lower Hutt Town Hall and across the corner from Rebel Sports.





Three August birthday girls were present at the last meeting. Linda Bell, who had travelled down from Hamilton was joined by Tina and Val, who both live locally. We cut a cake in their honour and have diared the occasion for next August.



From the seen recently on Facebook department: Our volunteer cheerleaders from the Great Hill community are all ready for the Oldtime Baseball Game happening Wednesday, August 21 at St. Peter's Field in Cambridge, MA. They have their cheer rehearsed and are ready to rev up the crowd for a great game. Who knew baseball had cheerleaders?

CONTACTS

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Links: www.arthritis.org.nz | www.scleroderma.org.nz | www.sjogrensnewzealand.co.nz