



Story Dr Marline Squance | Autoimmune Resource and Research Centre

Group 2: Dr Marline Squance (EO ARRC), Jan MacGregor (original member), Don Langford, Rita Nicholls (original Member and Warners Bay Lions Member)

A lasting legacy of support comes from humble beginnings and a big vision. A small group of people living lives with the often-debilitating systemic autoimmune illnesses of scleroderma and lupus recognised that the support and information they needed to move forward in their lives were missing.

It seemed that they were left out of the sights of the big organisations and for the most part the medical system, through both delayed diagnosis and ongoing support. That was 27 years ago. Rather than just sitting back and waiting, they decided to work towards building a centre that cared for and supported individuals living with autoimmune illnesses such as theirs. They realised that 'making it happen' needed to come from them.

The goal for the centre was led by Lee Langford and members of the then well-established Scleroderma Association of the Hunter Region. Seed funding was sought and received from a Warners Bay Lions Club grant and support from respected medical specialists, Professor Robert Clancy (Immunologist) and Doctor John Glass (Rheumatologist). The vision was realised in 1989 when the Scleroderma Lupus Resource Centre was born.

The story of the centre has many chapters with twists and turns, however, the centre continues today with new pages still being written, with an ever-growing presence in the Hunter and other regions across Australia. In 1989, the Scleroderma Lupus Resource Centre made an important name change to the Autoimmune Resource and Research Centre (ARRC) and formally became a not-for-profit incorporated charity.

The change was made to better reflect the people and different autoimmune illnesses the centre was supporting.

People living with other autoimmune conditions such as Raynaud's phenomenon, Sjögren's syndrome and fibromyalgia also needed help with day-to-day symptom care. The name change reflected the crossover nature of the autoimmune illnesses and the numerous symptoms experienced. ARRC is unique in catering to a number of autoimmune diseases and their associated symptoms rather than isolating services to a single group. This brings with it many challenges and a high demand on resourcing, however it allows the centre to deliver more comprehensive patient supports.

Throughout its life, the primary mission of the original centre has been retained, that being to provide quality and evidenced-based education for patients and health professionals, coordination of patient care activities and the development of a resource database to help patients better understand and cope with symptoms of these chronic illnesses.

ARRC, as it stands today, holds true with this mission and continues to offer resources and education programs, along with the addition of a research program arm offering access to innovative research projects that can help unravel the mystery of how these illnesses develop and lead to life improvements and reduced disease impact.

Lee Langford and her fellow members' dream for better understanding and support for autoimmune illness may have come from an unmet personal need, however the legacy of their personal tenacity and passion has enabled many thousands of people to receive medical information, education and ongoing support and help over the past years. Lee Langford and her husband Allan are sadly no longer able to see the continuing work of their vision, but their sons, along with original Scleroderma Association members and the original Nurse Practitioner, Sr. Rachel Rossiter, remain involved and active in ARRC activities.

Autoimmune illness affects one in 20 people, with conditions such as lupus affecting one in 1000. The illnesses are not as rare as they were once thought to be, however, still in 2016, 27 years since the centre's beginning, scleroderma, lupus, Raynaud's and Sjögren's do not receive adequate recognition. People living with illnesses experience daily symptoms that can impact heavily on their capacity to study, work and carry out daily activities. Symptoms can range from mild to life-threatening and carry with them a high financial and social burden.

Autoimmune illnesses are chronic in nature; however a lot can be done to ease their health impact. Targeted and supportive self-management, along with ongoing adequate medical care and monitoring can enable people to live fulfilling lives accommodating the illness and its symptoms, lessening life and health impacts and long-term organ damage.

Centres such as ARRC offer the advice needed to help patients live well with illness. ARRC helps people living with illness find the right balance, and encourages them to find a way to 'live a life: not an illness'.

Available chronic disease management programs rarely extend to include these groups of patients, as they don't fit within priority health areas of Government-sponsored programs. Ongoing support is left to the non-government sector, with centres such as ARRC struggling to meet the needs of the growing number of patients seeking help and advice.

To maintain its vision and mission, ARRC is managed under the guidance of Associate Professor Glenn Reeves and Dr Marline Squance, with support from a management advisory committee consisting of medical, community and business representatives.

ARRC is located in the Pathology North building of John Hunter Hospital. The centre is supported through corporate sponsorship, donations and philanthropic grants and does not receive any government funding. The centre is also kindly supported by Pathology North through the provision of space and infrastructure on the Rankin Park campus of John Hunter Hospital.

If you would like to support ARRC and its work, please contact 02 49214095 or email: hnelhd-arrc@health.nsw.gov.au. To access support information or to find out more about ARRC and its services visit: www.autoimmune.org.au.



A Pioneer for Patient Support

Lee Langford (pictured above) had her own lifelong personal battle with a mysterious incurable autoimmune disease, Scleroderma. Her disease remained undiagnosed by a number of doctors for two decades.

Her symptoms began in the winter of 1959 when her hands turned white and became very painful. This led to her first autoimmune disease diagnosis of Raynaud's phenomenon; an interference of the usual blood flow in the extremities.

Ten years later, symptoms became worse, her hands froze and her fingers wouldn't function. She saw a specialist and had a new but now discontinued operation performed to separate the nerves in the neck to help with blood flow.

Despite the operation giving Lee a few years relief from severe Raynaud's symptoms the operation left her with the side effect of making one side of Lee's face drop as if she'd had a stroke. Lee also noticed that new symptoms appeared. The skin on her hands became hardened and scarred preventing movement.

Her hands and fingers also lost sensation. Seeking help again, in 1976 a new physician told her that her file disclosed that in 1969 her doctors had thought she might have had scleroderma and he was now confirming this.

This diagnosis was frightening to receive as the medical understanding of the disease and patient information available was limited. What was available reported that at that time a diagnosis came with a poor prognosis. However with support and management of her symptoms Lee lived with Scleroderma until her passing in 2001.

Lee was a devoted advocate for people living with Scleroderma, Raynaud's and other autoimmune diseases and the Autoimmune Resource and Research Centre is proud to honour Lee and her fellow pioneers by continuing their vision.

Scleroderma is an autoimmune disease that brings about the overproduction of collagen resulting in the hardening and contraction of connective tissue. It affects women 5 times more than men and often in ages of 20 to 40 years. In most cases people will experience skin changes, Raynaud's phenomenon, reflux and dryness of mouth and eyes.

The disease can affect any part of body including the bowel, lungs, heart causing internal organ problems. June 29th is World Scleroderma Day. This day is used to raise awareness of this mysterious disease.

To find out more about Scleroderma www.autoimmune.org.au or www.sclerodermaaustralia.com.au