

Date 8 May 2012
Subject New program helping young people with autoimmune disease improve their quality of life

Autoimmune illnesses are commonly associated with people aged 25 to 40, however young people are being increasingly diagnosed with illnesses such as lupus and scleroderma. Despite the rise of youth diagnosis, health support services and resources are still making the shift to cater for their specific needs.

A new partnership between Newcastle's Autoimmune Resource and Research Centre (ARRC) and nib foundation will provide targeted youth support services and education materials to adolescents with autoimmune illnesses.

Marline Squance, ARRC Executive Officer, said the *Young Autoimmune Person's Education Project* will feature age-appropriate resources that explain the illness, its symptoms and management strategies.

"Autoimmune illnesses often have a significant impact on quality of life and therefore reduce life potential. They are of a complex and multi-faceted nature and are often poorly understood by the wider community and within health professions," Ms Squance said.

"Currently, support for this group of patients is only available once they reach an adult age, leaving many young people to battle their illness on their own," she added.

Aimee Mallalue has experienced the challenges firsthand. Diagnosed with systemic lupus erythematosus two years ago, the 21 year-old was forced to turn to the internet for information about her illness.

"When I was diagnosed my doctor gave me two pieces of paper that had very basic information and that was it. I wasn't satisfied so went home and searched the internet for more information," Mrs Mallalue said.

The Eleebana cafe manager believes that age-specific resources would help young people better understand how to live with their illness.

"For 18 months I was showing symptoms and had absolutely no idea what was wrong with me, which was extremely scary," Mrs Mallalue said.

"If there were more resources available could have gone to a support group or information session. It would have been comforting to know that I was not alone during the process, that there were other people out there that have it and if they are ok then I would be ok," she added.

The program will include printed and online information resources and education workshops that will be developed in consultation with young people to ensure it meets their needs.

nib foundation Chairman, Terry Lawler, said the program will provide self-management strategies for young people with autoimmune illnesses helping to limit the adverse lifestyle effects of their symptoms.

"Our funding will ensure adolescents who suffer from autoimmune illnesses, like Aimee, are given the support, education and self-management strategies they need to manage their symptoms and ultimately improve their quality of life," Mr Lawler said.

Resources will be available from July 2012 at www.autoimmune.org.au

For more information contact:

Marline Squance
Autoimmune Resource and Research Centre
arrc@hnehealth.nsw.gov.au
02 49214095 or 0429637222
autoimmune.org.au

Renea Jaeger
nib foundation
r.jaeger@nib.com.au
02 4914 1739 or 0402 376 835
nibfoundation.com.au