



Batten Animal Research Network

**BATTEN DISEASE Joint Parent- Supporter- Patient- Funder-
Researcher- Clinician Networking Meeting
Lincoln University, Monday 13 November 2017, starting at 10.00am**

Batten disease, also known as the neuronal ceroid lipofuscinoses (NCLs), is a group of rare devastating inherited neurodegenerative diseases of children which rob them of the ability to see, walk, talk and feed, leading to premature death between infancy and adulthood. Diagnosed patients include Pakeha, Maori, Pacifica and Indian New Zealanders. Presently there are no effective treatments for any forms of Batten disease.

We, BARN (Lincoln) have been successful in treating one form in a sheep model by gene therapy and are excited at the prospect of translating that to children. We will be hosting a one-day Batten disease networking meeting at Lincoln University on Monday 13 November 2017, starting at 10.00am to discuss this and other matters. This is an opportunity to bring the New Zealand Batten disease community together for our mutual benefit and enlightenment, following on from a similar successful meeting two years ago. A number of families and researchers have indicated they will join us along with funders and supporters including Cure Kids, BDSRA, CMRF, LDNZ and BDNZ.

Topics will include:

Successful gene therapies into sheep models

In vivo monitoring of therapies for data collection for translation to humans, including *in vivo* brain imaging, neurological assessments and maze testing

The way forward to translation for therapy for children

What causes neurodegeneration in Batten disease and other therapies

Reaching out to paediatricians and neurologists to raise awareness and improve diagnosis

Family concerns; parental, siblings, the medical system, care and the state

Other Batten disease research in New Zealand

This meeting has been timed as a prelude to the Paediatric Society of New Zealand ASM in Christchurch and we are particularly interested in engaging with paediatricians and neurologists.

Would all interested in attending please contact david.palmer@lincoln.ac.nz indicating their area of interest and if they wish to contribute a presentation. There is no registration *per se*, but there will be a small catering charge. Transport to and from the airport will be arranged. Venue etc will follow when I have a better idea of the numbers.

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