

# encounter

## Albinism

**Albinism** is a genetic condition characterized by a deficit in melanin and the partial or complete absence of pigment in the skin, hair and eyes.



In New Zealand, it is estimated one person in every 17,000 has some type of albinism. They have inherited genes which do not make the usual amount of a pigment called melanin

which is essential for the full development of the retina. This lack of melanin in the retina is the primary cause of visual impairment in albinism. There are two types of Albinism:

- **oculocutaneous** affecting the eyes, skin and hair
- **ocular** affecting only the eyes

A major issue for people with albinism is avoiding sunburn and skin damage due to fair complexion.

There are currently approximately 115 children in New Zealand known to have albinism and explaining “albinism” to children can be difficult. Every person with albinism is an individual with potential. People with albinism are active in every sector of society, overcoming the challenges of low vision and avoiding sunburn to enjoy life.



## **People with Albinism:**

- live full, active and satisfying lives.
- are individuals who learn and grow.
- contribute successfully in a wide range of vocations.
- are affected by light and the sun's rays.
- are normal people with less pigment in their skin.

## **It's important to remember:**

- Albinism is not a disease.
- Albinism does not affect intelligence.
- Albinism can occur in every ethnic group.
- Albinism is not caused by anyone's action or inaction.
- Albinism does not prevent enjoyment of life.

We are particularly interested in supporting parents and families of children with albinism. All children will thrive in a caring and nurturing environment with the usual flexible, give-and-take of family life along with early childhood education.

**Albinism Trust is a voluntary not-for-profit organisation committed to emphasising positive potential and capabilities of people with albinism. This peer support group was established at Palmerston North on 6 October 2007.**

**Registered Charity CC22352**  
**Write:- C/o 7 Earl Street, Levin 5510**  
**Email:- [albinism@inspire.net.nz](mailto:albinism@inspire.net.nz)**



**People succeed in spite of their Albinism.** An example of this is with our good friend **Professor Paul Delaney** who is a senior lecturer and professor of physics and astronomy at York University in Toronto, Canada. Paul is an Australian who now lives and works in Canada with his wife whom he met while attending university in British Columbia. Despite the challenges arising from his poor eyesight, Paul had always dreamt of becoming an astronomer. While his parents were worried by such a career choice, they were determined to afford him every opportunity to achieve his goals. They convinced teachers to allow him to leave his seat and approach the board to read (and memorize) the lessons, and when it came time to apply to university, ensured he had the confidence and support to leave home and study in Canberra at the Australian National University. Paul studied hard, played cricket, rode bike's on busy roads and even jumped out of a plane or 2 (sky diving) much to his parents consternation. He graduated Bachelor of Science (Honours) in 1978 and promptly journeyed to Canada to continue his studies in astronomy. Following completion of his Master of Science degree (and marriage) in 1980, Paul spent some years working as a nuclear physicist and support astronomer before landing at York University in 1986. He loves to teach and is a regular commentator on astronomy and space science in all types of media. Paul has earned numerous awards. It seems his albinism has not diminished his life's ambitions in the slightest!

**Success begins early in life.** We encourage parents to enable their children with albinism to explore and experience opportunities, in spite of the albinism. We believe it's important to discuss learning options and resources with the **BLENNZ** team during early development. People with albinism make a positive contribution in varying occupations - homemakers, technicians, social workers, engineers, tutors, health workers, academics, secretaries, piano tuners, musicians, broadcasters, audiologists, therapists, counsellors, solicitors, computer programmers, scientists, photographers, farmers, mechanics, administrators, journalists and business executives.



### **Albinism Trust**

- ❖ Shares ideas and information to enable people with albinism to live, learn, work and play.
- ❖ Acts as a resource hub for parents and families of children with albinism.
- ❖ Promotes understanding and positive attitudes about Albinism.
- ❖ Operates the web site [www.aalbinism.nz](http://www.aalbinism.nz) as a public information portal.
- ❖ Runs a monthly SKYPE FORUM for chat, and encouragement of people living with albinism.
- ❖ Provides albinism-specific information to various medical, educational and government agencies.
- ❖ Works in close collaboration with the **Blind Foundation** providing peer support for people with albinism and their families or networks.