Professor in bid to explain ageing illness

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It's terrifying. Dozens of children whose tissue is ageing at such a rapid rate that they need a bone marrow transplant.

They are afflicted with one of several hereditary conditions grouped under a complicated heading - short telomere syndrome.

It's so rare that even some of Australia's best doctors are unable to explain what's going on.

But that's about to change, thanks to the caring efforts of Professor Roger Reddel, who has spent much of his career investigating the role of telomeres in cancer.

Although the syndrome is not linked to cancer, he has brought some of the world's top experts to Sydney to inform doctors and to discuss the best ways to help patients and their families.

"Many doctors are not aware of the condition, which is understandable because it is rare and the telomere connection was only discovered about 15 years ago," he says.

"We are bringing in the overseas experts to first of all increase awareness among Australian doctors.

"We also must consider the best approach to looking after these people and for doing the best possible research so that one day the condition can be treated much more effectively."

Prof Reddel is regarded as the go-to person for information about the syndrome and has been instrumental in setting up a local blood test.

"Just getting an accurate diagnosis and knowing which members of a family are at risk is a major step forward for the families," says Prof Reddel, director of the Children's Medical Research Institute in Sydney.

He explains that telomeres are tips at the end of each of the 46 human chromosomes.
They can allow cancer cells to grow out of control if they are too long and cause premature ageing if they are too short.
"Our cells can divide a certain number of times and have to stop when the telomeres get too short.
"Individual organs age very rapidly, although the child may not look like they are ageing, apart perhaps from signs like a grey forelock.
"It can be a very nasty condition," says Prof Reddel, who asked a family with the syndrome what they would like done for them.
"One of the things they wanted was for their own doctors to be updated by the best experts in the world on international best practice."
There might not be a cure, he says. But at least families will know their loved one is getting the best possible treatment.