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PERTH

# Fundraiser for PKS sufferers

## HIGH TEA WITH A DIFFERENCE

DETERMINATION, a handy knowledge of medical science and, most of all, a love for their daughter is driving a couple to raise awareness of a rare disease.

Nic and Terzita Acquarola have been fighting an uphill battle since their daughter Alessia (5) was diagnosed with Pallister Killian Syndrome (PKS) at the age of one, but it is not a fight they are going to give up.

Mr Acquarola, a medical scientist at RPH, said it was a challenge just arriving at a label for the condition his daughter was born with, such is the rarity of the disease.

"It's very stressful when you don't know what you are dealing with — we just knew there was a global delay on her development," he said.



Terzita Acquarola with daughter Alessia, who has a very rare disease, and seven-year-old son Adam. d385158

"Eventually it was a skin biopsy that identified it and from there at least we could move forward."

Despite the daily challenge of caring for Alessia, who will probably have limited movement and speech her entire life, and son Adam (7), Mr and

Mrs Acquarola established The PKS Foundation of Australia to raise awareness of the disease and improve the lives of those with it.

Mr and Mrs Acquarola are the foundation's president and secretary respectively, and also on board are several

## DETAILS

■ PKS is a rare disease that only 200-300 children have worldwide and is caused by the presence of an additional portion of chromosome. In Australia, there are only 15-20 known cases.

■ For more information, visit [pks.org.au](http://pks.org.au)

family members of the few other PKS sufferers.

The foundation will host its inaugural fundraiser, a High Tea with a Difference, on September 30, 3pm-6pm, at Fremantle Town Hall.

Speakers are Daniela and Stefania from *My Kitchen Rules*, with champagne on arrival, a door prize, silent auctions and raffles. For tickets, email [fundraising@pks.org.au](mailto:fundraising@pks.org.au) by September 7.

Businesses are invited to lend their support or donate.