Senses Foundation (Inc)

The Royal WA Institute for the Blind and the West Australian Deafblind Association

MEDIA RELEASE

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Palmyra parents speak out for Deafblind Awareness Week

Deafblind Awareness Week is held internationally each year to celebrate Helen Keller's birthday on 27 June.

This year, Palmyra couple Nic and Terzita Acquarola are keen to help Senses Foundation raise awareness of this complex and unique disability by talking about their own experiences.

Nic and Terzita's daughter, Alessia, has Pallister Killian Syndrome (PKS) which has resulted in global developmental delay and deafblindness. She is unable to walk or talk and has limited motor skills.

They are convinced that without help from Senses Foundation, they simply would not have been able to cope with the 24-hour demands of caring for their daughter, now four years old.

PKS is a rare sporadic syndrome which is known to affect only 300 children worldwide.

Terzita says she was convinced something was wrong with the baby during her pregnancy, and her fears were confirmed when Alessia was born five weeks early.

"She was full of amniotic fluid and was very blue," Terzita explains.

"They put her on my chest and I knew something was wrong. She simply didn't look like my son, Adam."

While everyone knew something was amiss, obtaining a clear diagnosis for Alessia's condition took 18 months. They were lucky that Nic was a medical scientist and knew which questions to ask.

"So little is known about PKS because it's not a common condition," says Nic.

"There's only one other family in WA that we know of who has a child with PKS, and about 10 in the whole of Australia and New Zealand, so it's still a bit of a mystery."

PKS has some general physical characteristics including a distinctive hair pattern, wide forehead, low set ears, skin pigmentation and low muscle tone.

For the first two years of her life Alessia received a range of services from Princess Margaret Hospital. When these services ceased, Senses Foundation stepped in to provide support under its Early Intervention Program.

Alessia sees Senses' physiotherapist, occupational therapist and speech therapist regularly to assist her physical development.

The Foundation also provides respite care for Alessia, so Terzita can enjoy some precious time to herself or with Nic and their older son, Adam (5).

In addition to the therapeutic services, Senses' staff also provide support for Alessia to attend kindergarten at a local Catholic primary school. They accompany the family to medical appointments to ensure specialists are aware of Alessia's special needs.

Terzita also takes Alessia to the Foundation's Friday morning playgroup which is run by an occupational therapist and Adam is looking forward to attending the Sibling Support Program when he is a little older.

"Without Senses I truly believe our family would have fallen to pieces," Terzita said. "We didn't know where to go or what to do. They have been absolute lifesavers."

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About Senses Foundation

Senses Foundation had its origins 110 years ago as the Royal WA Institute for the Blind, then amalgamated with the WA Deafblind Association in 2001 to become Senses Foundation Inc. The Foundation is a charitable, not for profit organisation providing disability support services to people of all ages throughout Western Australia. Its unique speciality is the provision of services to people who are deafblind.