3: A Family Perspective

Maria Heaton
Parent
Member NSW Carers Advisory Council 2015
ACI Intellectual Disability Network, Co-Chair 2011
Board Member, NSW CID 2010
Access Committee Member, City of Botany Bay 2010
Clinical Nurse Consultant, Paediatric Palliative Care 2007
NSW Carer of the Year 2012
My Family

2003

2014
Tiarna

Tristan
Italy vs. Holland
Revealing the diagnosis

Tristan at 4 months

Tiarna at 4 months
Some celebrities who met Tristan

C-3PO actor Anthony Daniels
Fabian & Tristan in the Blackmore's Fun Run across the harbour bridge

Tristan & I share a passion for online games

Tristan loves spending time with Danica
At the footy

Swimming with dolphins

Tristan loves going to Coogee Beach

On the dance floor at a friend’s 21st birthday
Intellectual Ability

Fun in the pool

Music with Fabian

Family cuddles
Special Family Times
Bruno Mars Concert
Tristan’s “Thumbs Up”
Some of Tristan’s Expressions

- Anticipation
- Cranky
- Concentration
- Cheeky
- Mischievous
- Happy
Tristan was a star

Tristan featured in a Steve Waugh Foundation Awareness Campaign for Children with Rare Disease in 2014. You can view it on their website.
Suggestions to build the client clinician relationship

• Acknowledge the individual
• Be responsive
• Listen
• Be honest
• Show you care

CARLY 2004-2013
Final Admission to Hospital
May 11-16th 2014
Tristan days before he died

Tristan’s last visit to Coogee Beach
July 13th 2014
Mental Health Support is more important for people with ID

THE NEXT PLACE

The Invisible String

Patrice Karst
Illustrated by Geoff Stevenson
Tristan
20/09/96 - 18/07/14

Live every moment
love every day
because before you know it
precious time slips away