

Disorder unites families

By MANIKA DADSON

HAVING children can create bonds between strangers, and for one group, the bond is extra special.

Fifteen families from across Australia met at Archers Manor, Newnham, yesterday for the annual gathering for people affected by Cornelia de Lange Syndrome, a rare genetic disorder that affects about one in 30,000 children.

Many individuals with CdLS look similar, with typical facial features including thin eyebrows that meet in the middle, long eyelashes, a short upturned nose, and thin downturned lips.

Cornelia de Lange Syndrome Association Australasia president Jenny Rollo said about 200 Australians were diagnosed with CdLS, but little was known about it.

"We're hoping that we might be able to find other families who may be looking for other people like their child," Ms Rollo said.

It is unclear exactly what causes CdLS, but researches have identified four genes responsible for it.

Ms Rollo said when her son David was born 31 years ago there were no support networks and not much knowledge about the syndrome.

Launceston mother Sharyn Burston realised her daughter had the syn-



At the Cornelia de Lange Syndrome gathering are (back) Peter Crawford, Phyl Crawford, Connor Wood, 10, Sean Wood, David Rollo, Jenny Rollo, Nada Gillete, Sharyn Burston, Colin Burston, Rose Humphrey and David Humphrey, (front) Isla Steed, 3, Kylie Steed, Corey Wood, 10, Lynne Wood, Paula Kot, Addi Micigolski, Kate Burston and Laura Humphrey, 17.

Picture: MARK JESSER

drome after Ms Rollo shared her story with a national magazine.

"(Reading that story) was our lifeline," Mrs Burston said.

"The medical journal had one paragraph (about the syndrome) with the most severe case you could think of and that's all they read out to us."

The case was that the child would only live a few years, however, nowadays many people diagnosed live to at least 50 and some reach their 70s.

Mrs Burston said she was grateful to have a national support network.

"To actually get a friendship group together like

this is really important. It's how we learn," she said.

"I remember once when Kate (our daughter) was little, we were all sitting in a group and she was picking her fingernails and I said 'does anyone else's child pick their fingernails?' and around the group, they were all picking.

"I was like 'OK we're not the only ones'."

Ms Rollo said the group held a national gathering in different cities across the country each year.

For more information about Cornelia de Lange Syndrome can contact Jenny at jennyrollo@bigpond.com or visit the CdLS Australia Facebook page.

272 victims identified

THE HAGUE — Medical experts have now identified 272 of the 298 people aboard the Malaysia Airlines flight MH17 shot down in Ukraine in July, the Dutch justice ministry says. Ten more people were identified in the past week, of whom seven held Dutch nationality, the ministry said, adding that their relatives would be informed. It did not reveal the nationalities of the three others.

Bacall's art for sale

NEW YORK — The art collection of late Hollywood legend Lauren Bacall, which includes work by some of the greatest artists of the 20th century and is worth an estimated \$US3 million (\$3.25 million), will go on sale in New York next year. Auction house Bonhams said that many of the lots in the 700-piece collection graced the Los Angeles home she shared with first husband Humphrey Bogart.

Budovsky extradited

NEW YORK — Authorities say a man accused of being behind one of the world's biggest money-laundering businesses has been extradited from Spain to the US to face charges. Manhattan prosecutors say Arthur Budovsky arrived in New York on Friday. The 40-year-old Costa Rican citizen founded currency transfer and payment processing company Liberty Reserve.