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## **FASD CARERS CARRY HEAVY LIFE-TIME BURDEN**

**20 November 2012:** In an Australian first, researchers have reached out to families and carers affected by Fetal Alcohol Spectrum Disorders (FASD) to identify gaps in existing services.

The research found that FASD carers are often stigmatised, find it hard to obtain a diagnosis and to access appropriate health services.

The study, to be presented this week at the *Australasian Professional Society on Alcohol and Other Drugs (APSAD) Conference* in Melbourne, examined health, education and social issues around caring for children living with FASD in Australia.

Caused by exposure to alcohol during pregnancy, FASD is the most common, preventable cause of disabilities and brain damage in children.

Funded by the Foundation for Alcohol Research and Education (FARE), 26 women and four men from throughout Australia including foster, biological, adoptive parents, and guardians, took part in the study between October 2011 and March 2012.

Dr Courtney Breen of the National Drug and Alcohol Centre (NDARC) says parents and carers of people with FASD spoke with great candour about the strains and challenges they endure in caring and advocating for their children.

“For the first time in Australia we have reached out to parents and carers of people with FASD to ask them what they need to help them manage with what is a life-long and often severe disability. What we have found is that in most cases carers are carrying the burden without adequate support or assistance,” Dr Breen said.

FASD was described by carers as an ‘invisible’ or ‘silent’ disability with little recognition of the burden associated with the disorder.

*“This isn’t like any other disability in Australia. If it is a common disability, then there are services and support; if it is a rare disability, there is compassion and support; with FASD there are no services, no compassion and no support.”* Carer of an adult living with FASD.

The study highlighted the lack of knowledge about FASD among health practitioners, in the education system and criminal justice system. It also found that carers are often labelled as bad parents by services that expect them to try harder, believing the issues with the child are a result of poor parenting rather than the child having FASD.

Speaking of the stigma associated with FASD, carers spoke openly and honestly.

*“We have to prevent it, absolutely 100 per cent we have to prevent it but we also have to accept that it happens, and it’s happened and there should be no shame and blame for anybody. What needs to happen is that the people who have acquired it need to get the best support and assistance they can.” Carer of child living with FASD.*

In September FARE released the *Australian FASD Action Plan 2013-16*, a fully costed \$37 million solution to address the extensive gaps in prevention, intervention and management of FASD in Australia, and the House of Representatives Committee Inquiry into FASD will soon hand down its recommendations to government.

FARE Policy and Research Manager, Ms Caterina Giorgi, said the new research adds further momentum and a compelling personal dimension to calls to effectively address FASD in Australia.

“There is no doubt that parents and carers of people with FASD are doing it tough. Governments can no longer ignore the needs of carers of people with FASD and must act now to improve the services to families affected by FASD, to increase community awareness of FASD, to inform women about the effects of alcohol use in pregnancy and to increase awareness and training of health, justice and educational professionals,” Ms Giorgi said.

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“Culture of Change” is the overriding title of this year’s [APSAD 2012 Scientific Conference](#). The program will include keynote presentations on emerging issues and developments in the treatment of alcohol and other drug related problems.

**Dr Courtney Breen and Caterina Giorgi are available for interview.**

**Media Contact: Joanna Allebone 0402 265 145**

**Foundation for Alcohol Research and Education (FARE)** FARE is an independent, charitable organisation working to prevent the harmful use of alcohol in Australia. Since 2001, FARE has invested over \$115 million in research and community projects to minimise the impact of alcohol misuse on Australians. Through its national grants program and commissioned research, FARE has established itself as a leading voice on alcohol and other drugs issues. FARE works with community groups, all levels of government, police, emergency workers, research institutions and the private sector to address alcohol-related problems. For further information visit FARE’s website: [www.fare.org.au](http://www.fare.org.au)