

Down Syndrome Australia responds to Lateline Story on prenatal testing and support

For Release: 22 November 2016

The story broadcast on Lateline tonight highlights the need for better information and support for families who receive a high probability result of Down syndrome during their pregnancy. It is essential that good information is provided to support informed decision making in regards to testing and responding to the results.

While the study discussed in the broadcast is not scientific or peer-reviewed it provides a description of the experience of a number of women and warrants further investigation. Given the very preliminary nature of the survey and the fact that it was conducted by a private individual we will not comment further on the results.

Down Syndrome Australia is proactively engaged in advocating to government, relevant medical organisations and professional bodies including the Australian Medical Association to promote better information and support for families with regards to prenatal testing. We have developed an evidenced-based submission which will be provided to the Medical Services Advisory Committee as part of their consideration of listing the non-invasive prenatal testing on MBS.

As the only national voice for people with Down syndrome, we will continue to work collaboratively with the sector to achieve better support for families.

There is evidence from a range of sources that suggest that often women are not being provided with adequate information both prior to and after the screening tests are completed. Feedback from the Down syndrome community suggests that in many cases the information provided to families is outdated or focused on a very negative portrayal of what it is like to have a child with Down syndrome.

Some families who choose to continue their pregnancy after a high probability result indicate that they do not feel supported by the medical community and that termination is repeatedly offered despite a clear decision having been made. This is highlighted in the story tonight with one of the families indicating they felt "pressured to terminate".

It is imperative that the medical community provide appropriate counselling and support regardless of the decision to continue or to terminate a pregnancy. It should be acknowledged that many doctors and midwives do support families who have a high probability result for Down syndrome with good information and provide excellent support during the pregnancy.

Down Syndrome Australia recommends that the Government support a national training program for GPs and midwives who are providing pre and post screening counselling to ensure that they are skilled at providing informed consent and appropriate post screening counselling.



More information about the work of Down Syndrome Australia and the contact details for local support and services can be found at www.downsyndrome.org.au.

A fact sheet on prenatal testing can be found here:

http://www.downsyndrome.org.au/documents/DSA_prenatal_resource_201408.pdf

A resource for new parents is available here: <http://www.downsyndrome.org.au/parentresource.html>

For media queries, contact media@downsyndrome.org.au