



Unit 7, 16-28 Melverton Drive
Hallam VIC 3803
PO Box 5245, Hallam VIC 3803

Phone: 03 9796 5744
Email: reception@smaaustralia.org.au
ABN 82 885 991 569 A0047660D

MEDIA RELEASE

26 October 2020

For immediate release

Collaborative partnership spearheads move towards unprecedented access to genetic carrier screening

Reproductive carrier screening for three of the world's most common inherited genetic conditions has taken a milestone step towards achieving full public funding in Australia.

The impetus behind this development is a long-term collaborative initiative between SMA Australia, the Fragile X Association and Cystic Fibrosis Community Care. For seven years, this trio of charity organisations has worked cooperatively to advocate for equal access for all Australians to genetic carrier screening for spinal muscular atrophy (SMA), fragile X syndrome (FXS) and cystic fibrosis (CF).

Their collective efforts have now culminated in a recommendation from Medical Services Advisory Committee (MSAC) to Health Minister, Greg Hunt that the triple genetic carrier screening test be listed on the Medicare Benefits Schedule.

The triple genetic screening test has been available in Australia for a number of years and currently incurs a fee of \$385 per person screened.

SMA Australia CEO, Julie Cini says that this development is a game-changer in driving down barriers to accessing crucial genetic screening for these commonly inherited conditions.

“These conditions can affect many children and their impacts are profound. Significant intellectual disability, shorter life expectancy and even life-threatening situations are all hallmarks of these conditions. Naturally, the effects on families are significant, so everyone deserves to get a clear answer about the chance of their children being affected. Access to this information should not be determined by one's ability to afford it.”

Fragile X Association of Australia executive director, Wendy Bruce says that equity of access to genetic screening for all women and couples is the goal underpinning the collaborative initiative.

“The current cost of screening is a barrier for many individuals and couples who have no known family history of SMA, FXS and CF and wish to understand their chance of having a child with one of these conditions. Now we are so close to ensuring that any Aussie who's looking at starting a family or who is newly pregnant can be empowered with the choices that come from being fully informed.

“Great acknowledgement and thanks are due to the Royal College of Pathologists (RCPA) for preparing the comprehensive submission to MSAC. It's this submission that has culminated in the triple genetic carrier screening test taking a big stride forward towards being listed on the Medicare Benefits Schedule.”



Unit 7, 16-28 Melverton Drive
Hallam VIC 3803
PO Box 5245, Hallam VIC 3803

Phone: 03 9796 5744
Email: reception@smaaustralia.org.au
ABN 82 885 991 569 A0047660D

Approximately one in 20 people are carriers of SMA, CF and/or FXS, yet most are not aware of that.

Cystic Fibrosis Community Care chief executive, Karin Knoester says that, despite the relatively high odds of being a carrier, many people are still not aware that genetic carrier screening is an option.

“95% of parents who have a child born with CF were completely unaware of their carrier status and family history. While SMA, FXS and CF are well understood in their respective communities, the general population has low awareness of the conditions and the fact that genetic screening is available. We’re looking to change this.”

Ms Cini says that genetic carrier screening for these conditions should be a standard offering for anyone who is starting a family.

“Our aim is to have these conditions widely understood in the community and for screening to become a typical step in family planning. Having this genetic carrier screening available for parents-to-be at no personal cost will significantly reduce the impact and occurrence of these conditions throughout Australia.”

ENDS:

For more information please contact

Organisation: SMA Australia
Name: Julie Cini
Position: CEO
Phone: (03)9796 5744
Mobile: 0407 091 857
Email: www.juliecini.com.au



Organisation: Cystic Fibrosis Community Care
Name: Karin Knoester
Position: Chief Executive
Phone: 0412 342 813
Email: ceo@CFCC.org.au



Organisation: Fragile X Association of Australia
Name: Wendy Bruce
Position: Executive Director
Phone: 02 9907 2366
Email: wendy@fragilex.org.au

