

The future in your genes

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A new study has assessed the attitudes of expectant or would be Victorian parents to carrier screening for cystic fibrosis.

Would be parents are opting for cystic fibrosis (CF) carrier screening tests to assess the chances of having a baby suffering with CF, a life-shortening genetic disorder with no cure.

A new study has assessed the attitudes of expectant or would be Victorian parents to <u>carrier screening</u> for CF, and found that most believe the service should be publicly available to all those who wish to access it.

Screening is currently only available in Victoria's private sector via the Victorian Clinical Genetics Services (VCGS) and costs more than \$200 per test.



Dr Liane Ioannou, from Monash University's Department of Medicine, said few women and couples planning a pregnancy are routinely made aware of the availability of carrier screening for CF by their private obstetricians, midwives or general practitioners.

"An alarming fact that many people may not be aware of is that there doesn't have to be a family history for someone to be a carrier of CF. In fact, more than 95 per cent of all carriers don't have a <u>family history</u>," Dr Ioannou said.

"I assessed the attitudes and opinions of people who accepted an offer of screening, declined an offer of screening, and those in the public health care system who were not offered CF carrier screening.

"The general consensus was that carrier screening for CF should be should be made available to all those who wish to access it, and at no charge. These results are in line with recommendations of the Human Genetic Society of Australia, stating all pregnant women and couples planning a pregnancy should be made aware of the availability of carrier screening for CF."

Dr Ioannou said there were barriers explaining why carrier screening for CF was not offered routinely in both the private and <u>public health care</u> system.

"If CF carrier screening was made publicly available, it may help to overcome some of the barriers to access which include a lack of knowledge of the illness among the public and health practitioners as well as funding and affordability," Dr Ioannou said.

CF is the most common life threatening <u>genetic disorder</u> in Australia where a baby is born with the condition every four days. The child suffers serious lung and digestive problems - they don't manufacture a



vital protein.

Provided by Monash University

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