prepair™ genetic carrier screening | 3

MEDICARE #

VCGS leaders in genetic health

1. PATIENT DETAILS

LAST NAME: GIVEN NAME: SEX: DOB: LABORATORY REF

ADDRESS: POSTCODE: MOBILE:

2. TEST REQUESTED

☐ prepair 3 (CF, FXS, SMA)

☐ BLOOD

4mL EDTA blood

Scan QR below for 4Cyte Pathology collections sites.

3. CLINICAL INFORMATION

It is recommended that samples be taken pre-pregnancy or before 12 weeks gestation.

☐ NOT-PREGNANT ☐ UNSURE

☐ PREGNANT TESTING

GESTATION (weeks): ..... EDD: .....

DONOR: ☐ Egg ☐ Sperm ☐ Embryo ☐ Self Determined

4. IS THERE A FAMILY HISTORY OF CF, FXS OR SMA?

Biological Female Partner ☐ YES ☐ NO

Biological Male Partner ☐ YES ☐ NO

If yes, provide details on gene/variant, familial relationship:

5. REPRODUCTIVE PARTNER DETAILS (if partner testing required)

LAST NAME:

GIVEN NAME:

SEX DOB MOBILE

6. PATIENT CONSENT, SIGNATURE & EMAIL

By signing this form, I request that VCGS perform the prepair genetic carrier screen. I have read the patient consent included on the back of this form.

The risks & limitations of this test have been adequately explained to me.

SIGNATURE: DATE:

EMAIL:

In some cases, Medicare rebates may apply for testing.

MEDICARE AGREEMENT:

Section 20A of the Health Insurance Act 1973) I offer to assign my right to benefits to the approved pathology practitioner who will render the requested pathology service(s) and any eligible pathologist determinable service(s) established as necessary by the practitioner.

SIGNATURE: DATE:

REQUESTING PRACTITIONER

PROVIDER #

ADDRESS:

SIGNATURE: DATE:

COPY REPORTS TO:

SPECIMEN COLLECTION

I certify that the pathology accompanying the request was collected from the patient stated above as established by direct inquiry.

SIGNATURE: DATE:

LOCATION:

Patient copy and sample collection details

PATIENT DETAILS

LAST NAME: GIVEN NAME:

ADDRESS:

POSTCODE:

TEST REQUESTED *prepair 3 carrier screening*

Privacy note

The information provided will be used to assess any Medicare benefit payable for the services rendered and to facilitate the proper administration of government health programs, and may be used to update enrolment records. Its collection is authorised by the provisions of the Health Insurance Act 1973. The information may be disclosed to the Department of Health or to a person in the medical practice associated with this claim, or as authorised/required by law.

4Cyte Pathology Sample Collection Service

Scan the QR code to find a 4Cyte Pathology blood collection site.

View collection sites

Payment:

VCGS will send an SMS link to arrange payment.

Ensure your mobile number is above.

Payment queries can be directed to the VCGS accounts team.

P 1300 557 779

E vcgs.accounts@vcgs.org.au

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Victorian Clinical Genetics Services
The Royal Children's Hospital
Flemington Road, Parkville VIC 3052
P +61 1300 118 247 F +61 3 8341 6366
W vcgs.org.au

Genetic counselling with a VCGS genetic counsellor is available to anyone considering this screening test
P 9936 6402 | **E** carrierscreening@vcgs.org.au

Purpose of the test

- *prepair 3* will identify individuals who are carriers for cystic fibrosis (CF), fragile X syndrome (FXS) and spinal muscular atrophy (SMA). People who are carriers for these conditions have a greater chance of having a child affected with that condition.
- **For CF and SMA:** If the patient is a carrier, it is recommended that their parter is offered testing for the same condition. If both members of a couple are carriers for the same condition, the couple has a 1 in 4 (25%) chance for each pregnancy of having children with that condition.
- **For FXS:** women who carry a FXS gene of increased size have a greater chance of having children with FXS. This chance may be up to 50% depending on the woman's specific result.

Test process

- A blood OR saliva sample will be collected and sent to VCGS. Usually the female partner is tested first, as carrier screening for FXS is less relevant for males.
- A report will be sent to the healthcare provider who requested the test and they will discuss your results with you. VCGS genetic counsellors are also available to discuss your results.

Test limitations

- *prepair 3* will identify most carriers for CF, FXS and SMA. Testing only identifies common genetic changes that cause these conditions meaning that rare and/or family-specific genetic changes may be missed.
- The test does not detect other inherited genetic or chromosomal conditions or any genetic conditions which are not inherited.
- If you have a family history of CF, FXS and/or SMA, please provide as much information as possible on the test request form so we can ensure we are performing the correct test for your circumstances. If you have any questions regarding your family history, please contact the VCGS prepair genetic counselling team.
- **Unless notified,** we assume: there is no family history of the conditions tested and the individuals are at population risk, the person and their partner are not blood relatives and the person screened has not undergone a bone marrow transplant or a blood transfusion.

Privacy, confidentiality and use of information

- Your test results will be kept confidential. Results will only be released to your healthcare provider, other healthcare providers involved in your medical care, or to another healthcare provider as directed by you, or otherwise as required or authorised by applicable law.
- Collecting information on your pregnancy after testing is part of our laboratory's standard practice for quality purposes and test evaluation. VCGS may contact your healthcare provider to obtain this information.

Retention and use of samples

- In line with best practices and clinical laboratory standards, leftover de-identified specimens (unless prohibited by law), de-identified genetic material, as well as other information learned from your testing, may be used by VCGS for purposes of quality control, laboratory operations, laboratory test development, laboratory improvement, and generation of new scientific knowledge. All such uses will be in compliance with applicable law.

Financial responsibility

- You are responsible for fees incurred with VCGS for services performed.
- Medicare rebates may apply in some cases.

KEY MESSAGES

prepair 3 will show if you are a carrier for cystic fibrosis (CF), fragile X syndrome (FXS), or spinal muscular atrophy (SMA). Being a carrier for these conditions usually does not affect your health.

- prepair 3 does not look for any other genetic or chromosome conditions (such as Down syndrome).
- If you and your reproductive partner are both carriers for CF or SMA, your children have a higher chance of having CF or SMA. For each pregnancy, there is a 1 in 4 (25%) chance of having a child with CF or SMA.
- If you're female and you carry a FXS gene of increased size, you have an increased chance of having children with FXS.
- Your results will be sent to the healthcare practitioner that ordered your test. If you're found to be a carrier for CF, FXS or SMA, we will work with you and your practitioner to help you understand your results and any further testing that may be needed.
- This test will identify most, but not all carriers for CF, FXS and SMA. Testing looks for the most common genetic changes that cause these conditions. Less common genetic changes may be missed.
- Unless you tell us, we assume:
  – you have no family history of CF, FXS or SMA
  – you and your reproductive partner are not blood relatives
  – you have not had a bone marrow transplant or blood transfusion
- Your test results are confidential. We can only disclose your results with your consent, or as required by law.
- VCGS may contact your healthcare practitioner for information about your pregnancy. This helps us maintain a high quality test and service.
- We keep your samples and information according to laboratory and legal requirements. If we use your sample or information as permitted by law, it will be de-identified (i.e anonymous).