Important changes to the Australian Red Cross Blood Service (ARCBS) protocol on donations from family members of individuals who have had CJD or other prion disease.

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What does that this mean for you if a blood relative died of CJD or other prion disease?

A blood relative had a genetic form of CJD or other prion disease:

If your relative died of confirmed genetic CJD or other prion disease you will be deferred from donating blood unless you have undergone predictive genetic testing and had a normal prion protein gene (*PRNP)* result (no mutation detected).

A blood relative with confirmed or suspected CJD or other prion disease without testing of the *PRNP* gene:

If your relative died from confirmed or suspected CJD or other prion disease without *PRNP* testing on DNA to rule out a mutation for prion disease you will be deferred from donating blood unless you undergone predictive genetic testing and had a normal *PRNP* result (no mutation detected).

A blood relative with confirmed or suspected CJD or other prion disease with documented normal testing of the *PRNP* gene (No mutation detected):

If your relative died of confirmed or suspected CJD or other prion disease and diagnostic *PRNP* testing confirmed that your relative did not have a mutation for genetic prion disease you and other first and second degree blood relatives can donate blood.

If I now qualify to donate blood what do I need to provide to the ARCBS?

You will have to provide documentation of *PRNP* test results, or a letter from a genetic service which confirms that either you, or your relative who died of CJD or other prion disease, had a normal *PRNP* test result (no proven mutation for prion disease). Once this is logged on the ARCBS database you will no longer be deferred from donating.

If you are not sure if testing was been done or your family received the results verbally but have no documentation please call 1800 052466 or email contactus@cjdsupport.org.au.

The ARCBS has advised the following:

To clarify the precise change, the previous guideline stated that prospective donors were excluded if they had a family history of CJD in a first or second degree relative, with the following three specific exceptions:

1. The relative had variant CJD.
2. The relative had a recognised iatrogenic cause for their CJD.
3. The donor has a documented normal genetic polymorphism for PrPc (i.e. in the *PRNP* gene).

The new updated guideline, as of 13 March 2016, expands the third exception to include the affected relative as well as the donor:

1. The relative had variant CJD.
2. The relative had a recognised iatrogenic cause for their CJD.
3. The donor, or their affected relative (index case), has a documented normal sequencing of the *PRNP* gene and no abnormal mutation was found.