

Issued by JPAC: 26 April 2022

Implementation: To be determined by each Service

Change Notification UK National Blood Services No. 25 - 2022

Narcolepsy

These changes apply to the Whole Blood and Components Donor Selection Guidelines.

Please amend the following entries:

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| <i>Obligatory</i> | <p>Must not donate if:</p> <p>Sleep attacks or cataplexy in the previous 12 months</p> <p>On treatment with Modafinil (Provigil)</p> |
| <i>Discretionary</i> | <p>If free from sleep attacks or cataplexy for 12 months or more, even if on medication, accept.</p> <p>If free from sleep attacks or cataplexy for 12 months or more, and it is more than 7 days from the last dose of modafinil, accept</p> |
| <i>Additional Information</i> | <p>Narcolepsy is a rare neurological condition that affects the brain's ability to regulate the normal sleep-wake cycle. This can lead to symptoms such as disturbed night-time sleep, excessive daytime sleepiness and cataplexy. Consequently, narcolepsy is often thought of as a sleep disorder, but its underlying cause means that it is better classified as a disorder of the central nervous system.</p> <p>Some affected individuals may fall asleep without warning (sleep attacks) or lose muscular control that can result in falling to the ground (cataplexy). In some cases cataplexy may have the appearance of a stroke, though recovery usually occurs within minutes.</p> <p>Modafinil is a drug used to treat excessive daytime sleepiness in some patients with narcolepsy. It is associated with an increase in congenital abnormalities if taken during pregnancy. Individuals taking Modafinil are deferred to avoid the risk of components made from their donation being transfused to someone who is pregnant.</p> |

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| | <p>Some individuals only have minor narcolepsy symptoms that should not interfere with donation. Sleep attacks and cataplexy may obviously cause problems during and after the donation process. However, some individuals have good control of symptoms through lifestyle adaptations and/or taking medication. If these problems are well controlled (no attacks for 12 or more months) the donor may be accepted. This includes individuals on medication to prevent attacks, with the exception of anyone taking Modafinil.</p> |
| <i>Reason for change</i> | <p>The additional information section has been updated with more information about the nature of Narcolepsy.</p> <p>A deferral for individuals treated with Modafinil has been added.</p> |

Neurobehavioral Disorders

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| <i>Obligatory</i> | <p>Must not donate if on treatment with Modafinil</p> |
| <i>Discretionary</i> | <p>Provided the potential donor is able to give valid consent and their disorder will not interfere with the collection process, even if on medication, accept.</p> <p>If the potential donor is able to give valid consent; their disorder will not interfere with the collection process, and they have not taken Modafinil (Provigil) for 7 days, accept.</p> |
| <i>See if Relevant</i> | <p>Communication Difficulties</p> |
| <i>Additional Information</i> | <p>If the donor suffers from involuntary movements (tics) it is important to ensure that these will not interfere with the donation process.</p> <p>Donors can usually be accepted even if on medication to treat a neurobehavioral disorder.</p> <p>Modafinil is licensed for the treatment of narcolepsy but can be used off-licence for other disorders including ADHD. Modafinil is associated with an increase in congenital abnormalities if taken during pregnancy. Individuals taking Modafinil are deferred to avoid the risk of components made from their donation being transfused to someone who is pregnant.</p> |
| <i>Reason for change</i> | <p>This is a new entry.</p> <p>A deferral has been added for donors on treatment with Modafinil.</p> |

A-Z index changes:

Please also add the following terms to the WBDSG index

- 'Modafinil', to direct to Narcolepsy
- 'Provigil', to direct to Narcolepsy



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