

# Crizanlizumab

## Information and advice for patients

### Sickle Cell and Thalassaemia Centre

Crizanlizumab (Adakveo, Novartis) is a drug treatment recommended by the National Institute for Health and Care Excellence (NICE) as another treatment option for preventing recurrent sickle cell crises in people aged 16 or over.

#### How does Crizanlizumab work?

Crizanlizumab works by binding to a protein in the blood called P-selectin. This protein is what causes the blood cells to stick together. Blocking the P-selectin prevents blood cell restrictions and therefore improves blood supply throughout the body. This also lowers the risk of a pain crisis needing a hospital stay.

#### How effective is Crizanlizumab?

People treated with Crizanlizumab can reduce the amount of sickle cell crises by up to 50% in a year when compared to those receiving other standard treatment options. The long-term effectiveness is not yet known.

#### Who is eligible?

- People with a confirmed diagnosis of sickle cell disease.
- Aged 16 and over and had 2 or more confirmed sickle cell crises (vaso-occlusive crises or VOC) in the previous 12 months. (A sickle cell crisis is an acute painful episode that requires pain relief medication to manage at home or in hospital).
- People who would have been offered or had Hydroxycarbamide for at least 6 months and it has not adequately reduced crises or who are unsuitable for Hydroxycarbamide.
- People who have been assessed by a member of the specialist team responsible for your care to identify those who are most likely to benefit from treatment and to ensure fairness for patients in all areas of the country.

Crizanlizumab can only be used according to the restrictions outlined nationally by NICE.

#### Who is not eligible?

People on regular transfusions are currently not eligible for Crizanlizumab as there is insufficient evidence that it is effective.

#### Where is Crizanlizumab being used?

Crizanlizumab has been used since at least 2016. Initially in clinical trials, then routinely in the US. The drug was licensed in the UK in 2021 and then NICE approved its use in November 2021.

# Crizanlizumab

## Information and advice for patients

### Sickle Cell and Thalassaemia Centre

#### How is it given?

Crizanlizumab is given as an intravenous (IV) drip into your arm. The infusion will take about 30 minutes but you will be monitored for an hour after your dose for any side effects. You may be given medications prior to the infusion to lower the chances of an infusion reaction. The dose is calculated based on your weight.

The first month of treatment has 2 doses – the initial dose followed by a second dose two weeks later. After that, you will get a dose once every four weeks. It is important to stick to this schedule. The appointments will be given to you by your haematology team.

Your medication will be administered in a day case infusion unit facility with staff specifically trained to give these infusions.

#### What are the common side effects?

The most frequently reported adverse reactions ( $\geq 10\%$ ) in patients treated with Crizanlizumab were nausea (18%), arthralgia (joint pain) (18%), back pain (15%), abdominal pain (12%), and pyrexia (fever) (11%). Most of these side effects should go away within a few days or a couple of weeks. But if they become more severe or don't go away, talk with your haematology team. Infusion-related reactions may happen during or within 24 hours of receiving an infusion of Crizanlizumab. Your clinical team may slow down, temporarily stop, or completely stop your Crizanlizumab infusion if this occurs. You may continue to receive Crizanlizumab but at a slower infusion rate, or have certain medicines before your infusion to lower your risk of getting an infusion-related reaction. Tell your health care provider right away if you get any of the following signs and symptoms of an infusion-related reaction. These symptoms include fever, chills or shivering, nausea, vomiting, diarrhoea, dizziness, sweating, hives, itching, shortness of breath or wheezing.

#### Special considerations

If you are pregnant or planning a pregnancy, talk with your doctor before starting the treatment. If you are sexually active and you or your partner can become pregnant, talk with your doctor about your birth control needs whilst you're on this treatment.

It is not known if this treatment is safe to use during pregnancy. Because of this, you should only use Crizanlizumab if the benefits are greater than the possible risk of harm to your baby. It is also important to note that, in rare cases, sickle cell disease may raise the risk of miscarriage. If you have any concerns about this, please speak to your doctor.

It is also unknown whether the treatment is safe to use while breastfeeding. It has not yet been studied to see if it passes into breastmilk. If you are breastfeeding, consider the benefit versus

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## Information and advice for patients

### Sickle Cell and Thalassaemia Centre

the risks of harm to your baby while taking the drug. Talk with your doctor about the benefits and risks of being on this treatment while breastfeeding.

There are no known interactions between Crizanlizumab and alcohol. Alcohol, however, is a trigger of sickle cell disease and drinking alcohol may raise your risk of pain crisis related to sickle cell disease.

### Ongoing treatment with Crizanlizumab

The current arrangements for Crizanlizumab are for 12 months of treatment. This is to establish whether it is beneficial for the UK patients. Please speak to your clinical team about longer term treatment.

Further information: please discuss with your team of nurses and doctors.

### References

National Institute for Health and Care Excellence (2021). Crizanlizumab for preventing sickle cell crises in sickle cell disease - guidance (TA743). Available at: <https://www.nice.org.uk/guidance/ta743> (Accessed: 16 February 2022).

Novartis (2021). Adakveo Crizanlizumab-tmca for IV infusion – 10mg/ml. Available at: <https://www.hcp.novartis.com/products/adakveo/sickle-cell-disease/> (Accessed 16 February 2022).

### Further Information

#### Sickle Cell Society

Crizanlizumab – A simple guide

Website: <https://www.sicklecellsociety.org/crizanlizumab/>

(Website checked and accessed 16 February 2022).

If you would like to suggest any amendments or improvements to this leaflet please contact SWB Library Services on ext 3587 or email [swbh.library@nhs.net](mailto:swbh.library@nhs.net).



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