Desmopressin response test for children

This leaflet aims to answer your questions about having a desmopressin response test. It explains the benefits, risks and alternatives, as well as what you can expect when your child comes to hospital.

If you have any further questions, please speak to a doctor or nurse caring for your child.

What is desmopressin (DDAVP)?
Desmopressin is a man-made hormone that produces a temporary rise in the amount of clotting factor in your child’s bloodstream. It does this by helping the body to release the stores of von Willebrand factor and factor VIII. Von Willebrand factor is a protein that acts like a glue to make platelets stick to the areas of the blood vessel that are damaged. If there is not enough von Willebrand factor in the blood, the platelets will not stick properly, which means that bleeding will continue for longer. Desmopressin is therefore given to assist with blood-clotting.

What is a desmopressin response test?
A desmopressin response test will assess the body’s reaction to desmopressin to see if it is fine for your child to take it to help with their blood disorder. Once your child’s response to desmopressin is known it may be possible to use it as an intranasal (into the nose) spray or as an injection under the skin to prevent abnormal bleeding when surgery is required.

The test is considered for people who have been diagnosed with:
- moderate/mild haemophilia A
- some forms of von Willebrand disease
- some forms of platelet function disorder.

Why should my child take desmopressin?
Desmopressin is one of the most frequently used treatments for milder types of von Willebrand disease and mild haemophilia A. It can help to reduce the need for blood transfusions and can also be used to treat abnormal bleeding episodes, such as prolonged nose bleeds, large bruises and cuts that are stubborn to heal.

What happens during the test?
On arrival your child will be offered some cream which will help numb the area of skin where the blood test will be.
Following the doctor’s advice it will be decided how your child will receive the desmopressin. There are three methods of receiving desmopressin:

- an infusion into a vein
- an intranasal spray
- an subcutaneous (under the skin) injection.

Whichever method is chosen, the first thing that will happen is that a specialist nurse will take your child’s blood pressure and pulse, and a nurse or doctor will insert a small needle to take a sample of blood from your child’s vein.

**If your child is receiving an infusion of desmopressin:**
The infusion will be given slowly over approximately 30 minutes. Your child’s blood pressure and pulse will be taken during this time. 30 minutes after the infusion has finished, the nurse or doctor will take another blood sample, with further blood samples taken at one hour, four hours and possibly six hours after the infusion has finished. Your doctor or nurse will inform you if this is necessary.

**If your child is receiving desmopressin intranasally:**
This means that desmopressin will be given as a nasal spray – one or two puffs into each nostril. Your child’s blood pressure and pulse will be monitored at intervals following its administration. One hour after receiving the nasal spray, a blood sample will be taken, with further samples taken at four hours and possibly six hours after receiving the nasal spray. Your doctor or nurse will inform you if this is necessary.

**If your child is receiving desmopressin subcutaneously:**
The subcutaneous injection is a single injection just under the skin. Your child’s blood pressure and pulse will be monitored at intervals following its administration. One hour after receiving the injection a blood sample will be taken, with further samples taken at four hours and possibly six hours after receiving the nasal spray. Your doctor or nurse will inform you if this is necessary.

**What are the risks?**
Desmopressin may cause some temporary mild side effects, including:

- facial flushing (common)
- facial warmth
- low blood pressure
- mild headache
- nausea (rare)
- allergic skin reactions (rare)
- fluid retention (rare)
- fits (very rare)

Please let us know if you have any concerns – these side effects can be explained in more detail by the doctor or nurse responsible for your child’s care.
Are there any alternatives?
An alternative treatment is treatment to replace the missing clotting factor or to replace the defective platelets with ones that work normally. These are often blood products and it is wise to try to avoid these unless it is really necessary.

How can I prepare for the test?
- It is important that you inform us if your child is unwell on the day of the test, as the appointment may need to be rearranged.
- Some medicines may interfere with the test results. Therefore please let us know if your child is currently taking, or has recently taken, any medicines.
- Your child will be able to eat and drink normally before the test.
- Please read this information carefully. If you have any questions you can call the number provided.

What happens after the test?
You will be asked to remain in clinic for approximately 30 minutes after the last blood test so that we can observe your child.

You will be advised to reduce your child’s fluid intake for 24 hours after the test is finished. This will help to ensure your child does not experience fluid retention.

You will then be able to go home and an appointment will be made for you and your child to return to clinic to discuss the results with the doctor.

What should I do if I have a problem?
If, within 24 hours of receiving desmopressin, your child experiences vomiting, severe headache or drowsiness you should contact the haemophilia nurses or the on-call doctor (details given below).

If your child suffers from a fit, you should call the emergency services and also the on-call doctor immediately.

Contact us
If you have any questions or concerns following your child’s desmopressin response test, please contact the haemophilia centre on 020 7188 2781 (Monday to Friday, 9am to 5pm).

Out of hours, please contact 020 7188 7188 and ask for the bleep desk. Ask for the doctor on-call for haemophilia on bleep number 0122 and wait for a response.

Further information
The Haemophilia Society
Provides advice and information for people with haemophilia and related bleeding disorders.
t: 0800 018 6068, 10am–4pm, Tuesday–Friday
e: info@haemophilia.org.uk
w: www.haemophilia.org.uk
Pharmacy medicines helpline
For information about any medicines that you have been prescribed at Guy's and St Thomas' hospitals, you can speak to the staff caring for you or call our helpline.
t: 020 7188 8748 9am to 5pm, Monday to Friday.

Patient Advice and Liaison Service (PALS) – To make comments or raise concerns about the Trust’s services, please contact PALS. Ask a member of staff to direct you to the PALS office or:
t: 020 7188 8801 at St Thomas’  t: 020 7188 8803 at Guy’s  e: pals@gstt.nhs.uk

Knowledge & Information Centre (KIC) – For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas’ Hospital.
t: 020 7188 3416

Language support services – If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.
t: 020 7188 8815  fax: 020 7188 5953

NHS Direct – Offers health information and advice from specially trained nurses over the phone 24 hours a day.
t: 0845 4647  w: www.nhsdirect.nhs.uk