NHS
The Leeds Teaching Hospitals
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# How a Desmopressin (DDAVP) trial is performed

## Information for patients, parents, and carers


leeds children's hospital
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## What is Desmopressin?

Desmopressin is a synthetic substance which has actions like an anti-diuretic hormone (ADH) produced naturally in the body. One of its actions is to reduce the amount of urine produced by the body. At much higher doses, Desmopressin increases the levels of some of the factors which help the blood clotting process to work more effectively.

Desmopressin is used for patients with **mild haemophilia A** and certain types of **von Willebrand disease.** Desmopressin can raise the clotting factor levels three/fourfold, within 30-60 minutes and lasts for 8-10 hours. It can be given on successive days (usually 3-4) before the response becomes temporarily exhausted. However, not everyone's clotting factor levels rise sufficiently after Desmopressin is given. Therefore, your doctor has requested that a trial is performed to determine whether Desmopressin is an effective treatment for your child. The trial will be performed once your child is over two years of age.

Desmopressin is sometimes referred to as DDAVP.

**Before the trial with Desmopressin is performed it is important to tell your doctor or nurse if you would answer 'yes' to any of the following questions:**

***Are you or your child:***

- Living with a diagnosis of Type IIb von Willebrand disease?
- Living with a diagnosis of serious heart or kidney disease?
- Having trouble passing urine?
- Drinking large amounts during the day or night?
- Taking medication for high blood pressure or have been told that your blood pressure is abnormal?
- Taking any other medicines including over-the-counter medicines?
- On medication for depression or epilepsy?
- Taking diuretics (water tablets)?
- Taking a medicine for pain or inflammation containing non-steroidal anti-inflammatory drugs

## How to prepare for the trial:

If your child has previously experienced procedural distress or is needle phobic, please discuss this with us so we can help to prepare for this. Where possible a play therapist will be available to offer distraction whilst the trial is being performed. We will usually use numbing cream (Emla cream) at the site where the cannula is to be placed and where the injection of Desmopressin will be given. This is to ensure it is more comfortable for your child as the skin will become numb. However, they may feel some stinging when the Desmopressin injection is given. You can assist us by making sure your child is well hydrated and warm when they attend their appointment.

Your appointment will take place at the **Paediatric Haematology and Oncology Day Unit, Level C, Clarendon Wing, Leeds General Infirmary.** You must arrive for your appointment no later than 09.30 on the appointment date.

## How is the trial performed:

Written consent for the procedure will be obtained on arrival to the day unit.

Your child's blood pressure and heart rate will be taken, this will be monitored during the trial.

A cannula will need to be placed to take blood samples from. Numbing cream (Emla cream) will be applied where the cannula is to be placed. Cream will be applied in more than one place, but every effort is made to site a usable cannula at the first attempt and then the cream in other areas will not be needed.

Where possible a play therapist will be available to offer distraction whilst the cannula is being placed and the desmopressin is being given.

Three blood samples will be taken in total. This is to measure the rise in the clotting factor levels and the length of time they are sustained for.

**Sample 1:** taken before the Desmopressin is given to give a baseline line level

**Sample 2:** taken one hour after the Desmopressin is given

**Sample 3:** taken four hours after the Desmopressin is given

Once the first blood sample has been taken the Desmopressin is given as an injection under the skin (subcutaneously). This is usually given into the thigh. Numbing cream (Emla cream) will be applied to the injection site.

After blood sample 2 has been taken you will be able to leave the department for a short while but must return in good time for blood sample three to be taken.

Once the third blood sample has been obtained the cannula will be removed and you will be able to go home.

## Precautions and warnings following the desmopressin trial:

Desmopressin makes your body hold on to fluids. It is **therefore important to reduce fluid intake for a period of 24 hours following administration of the desmopressin.** The recommended maximum fluid intake during this time is:

- 2-4 years: 750mls
- 5-10 years: 1 litre
- Over 10 years: 1.5 litres

The reason for restricting fluids following Desmopressin is to prevent an imbalance of salts (hyponatraemia) in the blood which rarely can cause fitting.

If any of the following symptoms occur following the trial with Desmopressin your child should avoid drinking any more fluid and contact the clinic/ward 31 or the nearest A and E department at once:

- Fitting
- Unexplained weight loss
- An unusually bad or prolonged headache
- Nausea and/or vomiting
- Confusion
- Not passing urine for longer than six hours.

**Side-effects:** Patients often become hot and flushed; eyes may appear watery or bloodshot. These symptoms usually subside quickly once the treatment is complete. Less common side effects are an increased heart rate, alterations in blood pressure, headache, stomach pain and nausea. If your child experiences any of these side-effects or any other undesirable effect, please tell the doctor or nurse.

## When will the results of the trial be available?

The results will be discussed with you at your child's next doctor's appointment.

Please let us know as soon as possible if you are unable to attend the appointment so that we can offer the appointment to someone else.

If you have any questions, please do not hesitate to get in touch on the telephone numbers below.

## Contact details:

**Clinical Nurse Specialists:** 0113 392 6863 / 0113 3922724

**Clinic Reception:** 0113 3927179

**Ward 31:** 0113 392 7431 (out of hours)

## What did you think of your care?

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