



Title	Haem Arginate (Normosang®) – obtaining supply including Out of Hours requests
Document Type	Standard Operating Procedure
Version number	V1
Approval/Issue date	July 2021
Review date	July 2023
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Developed by	Hazel Gueldner, Clinical Pharmacist
Reviewed by	Kyna Harvey, Clinical Pharmacist
Healthcare Inequality Impact Assessed (statutory for policies)	N/R

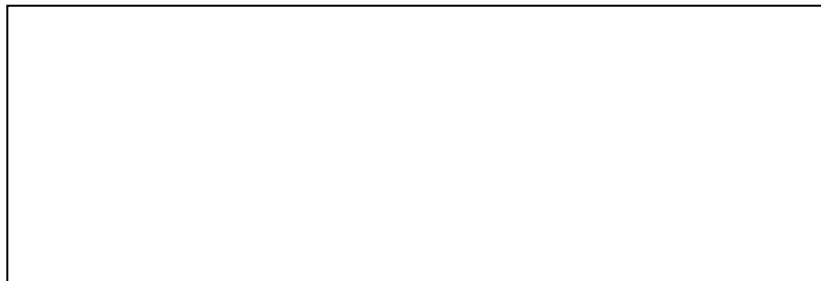
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Pharmacy Department, Borders General Hospital, Melrose

Standard Operating Procedure

Obtaining Haem Arginate (Normosang®) supply including Out of Hours requests

Date of Issue: June 2021	Document No: SOP-OOH001	Written by: Hazel Gueldner Clinical Pharmacist	Sign e-signed (pdf SOPs)
Revision Date: June 2023	Supersedes: New	Approved by: Kyna Harvey Clinical Pharmacist	Sign e-signed (pdf SOPs)



Purpose: To aid pharmacy staff to source Haem arginate(Normosang®) in a timely manner, including in the on call period.

Relevant to: Oncall pharmacists

Background:

Haem Arginate (Normosang®) is used for the treatment of acute porphyrias (see BNFCurrent edition Chapter 9, Nutrition and metabolic disorders, Section 2.1 Acute Porphyrias, or BNF online via medicines Complete <https://www.medicinescomplete.com/#/content/bnf/158857908> It is administered by short intravenous infusion as haem replacement in moderate, severe or unremitting acute porphyria crises.

In the United Kingdom the National Acute Porphyria Service (NAPS) provides clinical support and treatment with haem arginate from two centres (University Hospital of Wales, and King's College Hospital, London). NAPS can be contacted for clinical advice at any time on 029 2184 7747. Wales also hosts the UK Porphyria Medicines Information Service UKPMIS), contact phone number 029 2184 2251 (Mon-Fri 9am-5.30pm Sat/Sun 9am -12.45pm website www.wmic.wales.nhs.uk/specialist-services/drugs-in-porphyria/

Indications and Dose: Acute porphyrias/ Acute Intermittent porphyria/ Porphyria variegata/Hereditary coproporphyria
> BY INTRAVENOUS INFUSION

> Adult: Initially 3mg/kg once daily for 4 days, if response inadequate, repeat 4-day course with close biochemical monitoring; maximum 250 mg per day.

Directions for administration: For intravenous infusion (Normosang®), give intermittently in Sodium chloride 0.9%; dilute requisite dose in 100mL infusion fluid in glass bottle and give over at least 30 minutes through a 15micron filter (normal giving set) via large antebrachial or central vein; administer within 1 hour after dilution.

It is **ESSENTIAL** to read the Medusa Monograph for further information on IV administration, (, On the Intranet, search in the Application drop down menu for the iv drugs Monograph (Medusa) site, search in the intraVENOUS drugs tab for adult administration and Paediatric intraVENOUS drugs tab for paediatric administration as appropriate for Haem Arginate).

Saline 0.9% 100ml in glass bottles haven't been available for at least 15 years. Unlicensed use using a plastic iv Saline 0.9%100ml bag to administer is practical but it must be given immediately and protected from light. It is also recommended that the name and batch number of the product are recorded in the patient's notes. See <https://www.sps.nhs.uk/articles/how-should-haem-arginate-human-hemin-be-administered-in-the-management-of-acute-porphyrria/> for further guidance from the UKPMIS.

AVAILABILITY

It is NOT stocked in BGH.

It is not stocked by the Edinburgh Hospitals (checked January 2021)

It is a refrigerated product so needs to be couriered under cold-chain conditions.

Procedure:

The preferred arrangements (depending on time constraints) are:-

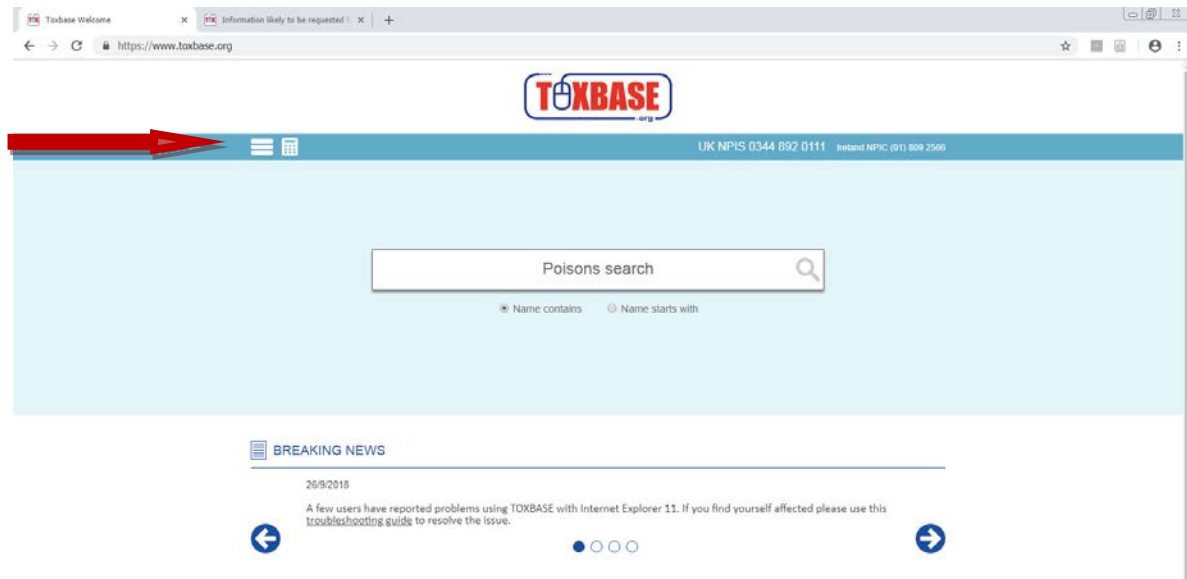
1) Via Recordati (previously Orphan Europe)

Contact Recordati by email:- orders.uk@recordati.com or phone 01491 414333 to check stock availability during office hours Monday to Friday 9am – 5pm, using normal Pharmacy procurement procedures. Stock is held by Recordati in the UK and can be delivered on a Monday, Wednesday or Friday to the BGH. Orders ideally should be placed before 2pm 2-3 working days before delivery is needed.

2) via another Hospital

Haem arginate is listed on the Rarely Used Urgent Medicines (RUUM) list Scotland

- a. Log into toxbase: <https://www.toxbase.org/> using the username: 27001 and password END55M
- b. Select the main menu bar



- c. Select General info tab, Rarely Used urgent Medicines(RUUM) list which opens in a new window.
- d. Select [Click here for information on the RUUM list and report form for Scotland](#)
- e. Select [Click here](#) for RUUM list as of 10 Dec 2020 (NB date may change)
- f. Select tab for Stock Holdings and/or or Contact details to access information.

RUUM list is intended primarily for the out of hours period when conventional supply routes are unavailable but could also be used during normal working hours if business as usual supply routes could result in delays to patient care. The RUUM list is not intended to bypass usual procurement routes nor be distributed to non-pharmacy staff.

RUUM has 3 holding sites – Hairmyers, Ninewells and the Queen Elizabeth University Hospital, Glasgow. The list states that ‘stock can be accessed 24/7 from King’s College Hospital London or University Hospital of Wales, Cardiff. To access:
1 Telephone University Hospital of Wales switchboard 029 2074 7747 and ask for the National Acute Porphyria Service.
2 The switchboard will advise the caller which centre is providing the emergency cover and provide the caller with a telephone contact number or long range pager number”

SMPC Normosang®
<https://www.medicines.org.uk/emc/medicine/20795/SPC/normosang/#gref>

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Western road,
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www.recordati.com

References:

BNF 80 September 2020 – March 2021

RUUM List Scotland Version 1.46 Updated 10/12/2020 via Toxbase

Sources of Information:

Email correspondence, between HG , Pharmacy Stores (BGH) and Recordati
January 2021