



Scottish Cutaneous Porphyria Service

National Service
dedicated to diagnosis
and monitoring of
cutaneous porphyrias.



The **Scottish Cutaneous Porphyria Service** is a National Service dedicated to the diagnosis and monitoring of cutaneous porphyrias.

We offer a complete cutaneous porphyrin analysis program, including:

- Plasma porphyrin screen
- Blood cell porphyrin screen
- Quantification of total blood, urine and faecal porphyrins
- HPLC analysis of urine and stool

Quality Assurance

The Scottish Cutaneous Porphyria Service is now a **UKAS accredited medical laboratory** No. 10306 and The Photobiology Unit is BSI registered under ISO 9001:2008.

We participate in two porphyrin External Quality Assurance Programmes provided by EPNET and RCPA and our performance is well within assigned limits.

Factors affecting performance

Porphyrins are light sensitive, therefore all samples for porphyrin analysis **must be protected from light at all times.** The easiest way to do this is to wrap samples in foil.

Turnaround time

Sample analysis will be completed as quickly as possible. The turnaround time is 5-10 working days for plasma/ blood cell porphyrin screening and total porphyrin quantification from blood or urine. Urgent samples can be processed within 24 hours upon request.

Quantification of total porphyrins from faecal samples and more extensive investigations of urine and faecal samples by HPLC profiling take longer, so the turnaround times for these are 15 and 20 working days respectively.

Sample requirements

Sending the correct sample types for porphyria diagnosis is critical. Please refer to the sample selection guide overleaf for assistance with this.

Providing relevant clinical details on the Porphyrin Request Form will assist us in selecting the most efficient sample analysis strategy and help ensure a timely turnaround.

Request forms are available to download from our website (www.scps.scot.nhs.uk) or by contacting us directly. Please note, we are unable to accept verbal requests for examinations.

Samples must be **clearly labelled** with the patient's name, date of birth/CHI and the date of collection.

Sample selection guide

Screening for any cutaneous porphyria (when low clinical suspicion)

- Whole blood (5 ml) in EDTA (or lithium heparin) vacutainer

Diagnosis of bullous / fragility cutaneous porphyria, such as porphyria cutanea tarda, or acute porphyria with cutaneous features:

- Whole blood (5 ml) in EDTA (or lithium heparin) vacutainer
- Urine (5ml)
- A stool sample (~5 g / half Universal container) may be requested to confirm a diagnosis

Diagnosis of a phototoxic cutaneous porphyria such as erythropoietic Protoporphyrin (EPP), X-linked Protoporphyrin (XLP) or protoporphyria associated with myelodysplasia :

- Whole blood (5 ml) in EDTA (or lithium heparin) vacutainer

Monitoring of cutaneous porphyria including porphyria Cutanea Tarda (PCT)

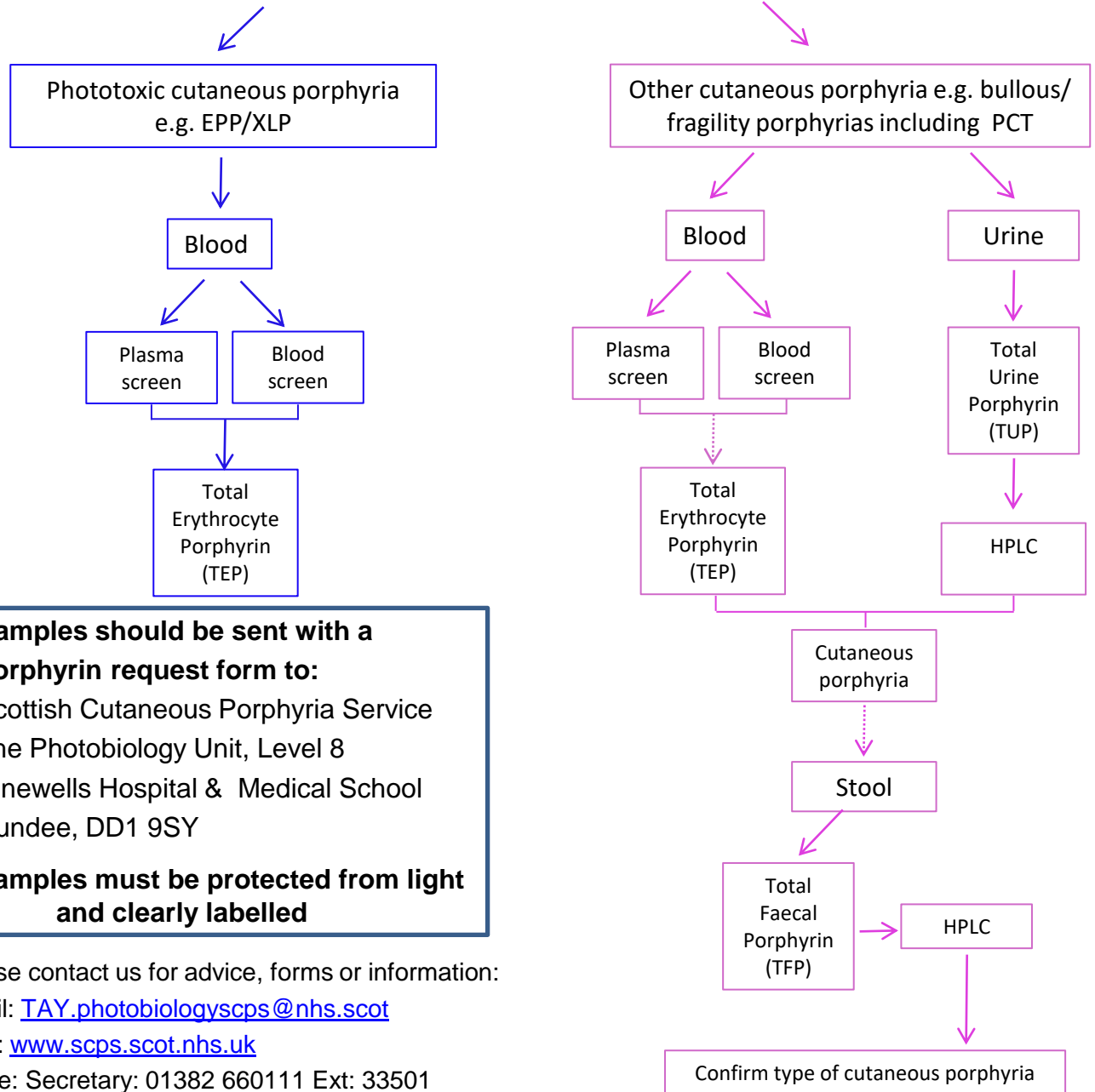
- Urine (5 ml)

Monitoring of photosensitive porphyria e.g. erythropoietic Protoporphyrin (EPP):

- Whole blood (5 ml) in EDTA (or lithium heparin) vacutainer

In exceptional circumstances we may be able to analyse smaller sample volumes. Please contact us for advice.

Sample analysis strategy for cutaneous porphyrias



Samples should be sent with a porphyrin request form to:
 Scottish Cutaneous Porphyria Service
 The Photobiology Unit, Level 8
 Ninewells Hospital & Medical School
 Dundee, DD1 9SY

Samples must be protected from light and clearly labelled

Please contact us for advice, forms or information:
 Email: TAY.photobiologyscps@nhs.scot
 Web: www.scps.scot.nhs.uk
 Phone: Secretary: 01382 660111 Ext: 33501
 Laboratory: 01382 632239

Image: Fluorescent urine
 Courtesy of Ninewells Hospital