



FOP is a rare medical condition and most medical professionals have never heard of the condition, or treated a patient with it. **In the event of an emergency, all medical professionals should protect the life of the patient with FOP as if FOP was not an issue.** However, in some medical situations there are precautions that can be taken to prevent further harm to the patient and potentially reduce the fall-out from FOP.

The Ambulance Services can be notified of a patient's medical condition so that in the event of an ambulance being called to the home address, they have the necessary medical information prior to attending the emergency. A 'marker', 'flag', or 'alert' can be put on the address. Below are the specific requirements of each Service/Trust. All require a referral from a medical specialist.

The information below is provided in good faith. **It is the responsibility of the patient or their family/carer to ensure that all medical details are kept up to date and the flags are reviewed in accordance with the Service's process.** NHS services regularly review their procedures so it is the responsibility of the patient or their family/carer to check that the systems in place continue to meet their needs. **FOP Friends cannot be held liable in the event of an emergency and the appropriate procedures not being followed. Patients and their family/carer use this information at their own risk. June 2020**



NHS
East of England Ambulance Service
NHS Trust

eoasnt.cadflags@nhs.net; CADflags@eastamb.nhs.uk

They require the patient's name, address, date of birth, and NHS number. They also require a care plan from the patient's GP/Consultant to confirm the diagnosis, along with a brief outline of FOP and what course of action needs to be followed in the event of an ambulance being required.



NHS
East Midlands Ambulance Service
NHS Trust

East Midlands Ambulance Service NHS Trust, 1 Horizon Place, Mellors Way Nottingham, NG8 6PY cadadmin@nhs.net

They require the patient's GP/Consultant to write to the EOC Systems Team at the above address. They require the patient's name, address, NHS number, a brief outline of FOP, the treatment that would be required from the ambulance personnel, and the destination they would prefer to be transported to, if different to A&E. An alert will then be placed on their control system.



NHS
London Ambulance Service
NHS Trust

ped@londonambulance.nhs.uk

Information can be held. You will need to contact your GP or clinician responsible for your care for them to enter the information onto Coordinate My Care (CMC) <https://www.coordinatemycare.co.uk/> All frontline clinicians have access to CMC via their tablets now and can quickly access up to date medical information about the patient they are attending and treat them accordingly.



NHS
North East Ambulance Service
NHS Foundation Trust

special.patient.notes@nhs.net

All flags are placed through the patient's GP. Patients need to go to their GP and request a flag to be put on their address. Using the Special Patients Notes system, GPs need to email the patient's requirements and medical needs using the secure email system.

GPs should use the Special Patients Notes email address.



North West Ambulance Service **NHS**
NHS Trust

address.base@nwas.nhs.uk

The patient or carer needs to ask their Health Care Practitioner to contact Nwas on the above email address, outlining the condition and the emergency treatment guidelines. They cannot accept requests from patients or carers. The case will be reviewed by a Consulting Paramedic and a marker will be put on the home address and the school address for 12 months. Please contact Nwas to have the marker extended.



NHS
South Central
Ambulance Service
NHS Foundation Trust

scas.aacp@nhs.net

They are able to put a flag on home and school addresses. Send the patient's details, NHS number, and information about FOP to the above address.

Where possible, email a specific care plan so crews can have access to the information, prior to attending an emergency.



South East Coast
Ambulance Service **NHS**
NHS Trust

PatientAlert.secamb@nhs.net

A marker can be placed on a home address. Please send the patient's specific information to the above address.

They will then send you further information advising to how to register with the Service.



NHS
South Western
Ambulance Service
NHS Foundation Trust

features@swast.nhs.uk

A warning can be put on an address in this area. They can also add alerts to school, family or regular holiday addresses. Send patient details and information relating to FOP to the above email address. They can also store documents such as Child and Family Wishes, and care plans.

GP surgeries with an nhs.net account can send these documents in a secure manner to **swasnt.clinical-alerts@nhs.net**.



NHS

**West Midlands
Ambulance Service**
University NHS Foundation Trust

helen.willan@wmas.nhs.uk

They require notification from a clinician, usually the patient's GP or Consultant, advising of the medical condition. They also require the patient's name, date of birth, NHS number and the address to be flagged.

They can also flag a second address such as a school or workplace. The flag will be valid for 12 months, and will be subject to annual review.



Yorkshire Ambulance Service **NHS**
NHS Trust

yas.patientrelations@nhs.net

The Yorkshire Ambulance Service are working with the LCHRE team to develop the Yorkshire and Humber Care Record. All frontline clinicians have access to the Summary Care Record and attached care plans. Speak to your GP to ensure all your information and emergency medical information is up to date.



**Scottish
Ambulance
Service**
Taking Care to the Patient

scotamb.dataadmin@nhs.net

For all warnings of this type you should email the Data Admin team at SAS on the above email address and they will be pleased to undertake your request.

Send the patient's name, address, and details of the condition. They will then use the information to put a flag on the requested addresses.



HSC Northern Ireland
Ambulance Service

nigel.ruddell@nias.hscni.net

Send an email to the Trust Medical Director with the name of the patient, date of birth, telephone number, and the specific clinical information to be followed. The flag will be placed on the patient's nominated home address. A secondary address can be added for a school etc. Patients are advised to carry additional information with them in case of an emergency. The flag will be reviewed annually.



GIG Ymddiriedolaeth GIG
Gwasanaethau Ambwlans Cymru
NHS Welsh Ambulance Services
NHS Trust

chris.jones16@wales.nhs.uk

They are able to flag addresses on their system. Medical information is reviewed by their regional clinical support officers. They require name, DOB, and medical information. Please email the above address or contact FOP Friends. Flags are reviewed annually.



International Clinical Council for FOP

The ICC is comprised of medical practitioners around the world who are expert and knowledgeable in the field of FOP. They have produced a set of MEDICAL GUIDELINES for professionals to support them when treating a patient with FOP, either in a routine or emergency capacity. All patients and carers should have access to these guidelines. Scan the Code to download the latest guide.



Lions Club: Message in a Bottle Scheme

The Lions Message In a Bottle scheme is a simple idea designed to encourage people to keep their personal and medical details on a standard form and in a common location – the fridge, where the emergency services will be able to find it in the event of being called to your home.

For more information visit:

www.lionsclubs.co/MemberArea/message-in-a-bottle/



Medic Alert

Some people with FOP have a MedicAlert bracelet or necklace to alert emergency medical professionals to their condition and specific needs. MedicAlert is a UK charity that offers this service.

For more information visit: www.medicalert.org.uk



Personalised Medical Information

The ICC and IFOPA have produced an editable Personalised Medical Information leaflet which can be completed with your specific medical information and needs. For the UK-specific version, contact FOP Friends.

An example poster, for display at a child's school for example, is shared in the back of the School Guide. Contact FOP Friends for an editable version.



Should you find any of the details or processes on this leaflet have changed or are out of date, please let us know so we can update the information for future patients and make our families aware.

It is advised that all medical information is reviewed regularly - at least twice a year, or more regularly if your condition changes - to ensure that in the event of an emergency you receive the best treatment and care possible.