

FOP is a rare medical condition. Most medical professionals will never have 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 harm to the patient and potentially reduce the fall-out from FOP.

The patient's local ambulance service can be notified of their medical condition so that in the event of an ambulance being called to the home address, they have the necessary medical information prior to arriving. This is called a 'marker', 'flag' or 'alert'. They can be placed on a school, a workplace or second home address. Below are the requirements of each trust. All require a referral from a medical professional.

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 up to date and 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 any event. Patients and their family/carer use this information at their own risk.**



NHS
East of England Ambulance Service
NHS Trust

cadflags@eastamb.nhs.uk

East of England Ambulance service can only receive medical marker requests from a Healthcare Professional. They do not accept them from patients. If specific action is required which is outside of their normal treatment/guidelines, then a Patient Specific Protocol needs to be created and approved. Speak to your GP or consultant to arrange for the Medical Marker to be arranged.



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. A clinical advisor will then create a marker.



NHS
London Ambulance Service
NHS Trust

<https://www.coordinatemycare.co.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

Flags are placed through the patient's GP, hospital consultant, or community nursing team. They are able to notify the ambulance service using the Special Patients Notes system. Please email the patient's requirements and medical needs using the secure email system and 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 GP 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 put on the home and school address for 12 months. This process is currently under review so please contact FOP Friends if you need further assistance.



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.uk

South East Coast ambulance service can arrange to have a flag put on a patient's address where their treatment steps outside of the normal scope of practice for SECamb clinicians. This is arranged through your GP or hospital consultant. Contact FOP Friends for further information or email the above address.



NHS
South Western
Ambulance Service
NHS Foundation Trust

features@swast.nhs.uk

A warning marker can be applied to addresses. They last for one year, then it is the patient's responsibility to renew to the marker for another year and also to update with any changes. Please complete a **Patient Information Form** or email the above address or FOP Friends for a copy. Please send a consultant's letter confirming the condition.



NHS
West Midlands
Ambulance Service
University NHS Foundation Trust

cadadminservicesdeskmailbox@wmas.nhs.uk

Patients 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

Contact your GP

To have a flag or marker placed on your address, please contact your GP and ensure all the relevant emergency information in place.

Your GP will then contact the Scottish Ambulance Service directly on your behalf.



HSC Northern Ireland
Ambulance Service

nigel.ruddell@nias.hscni.net

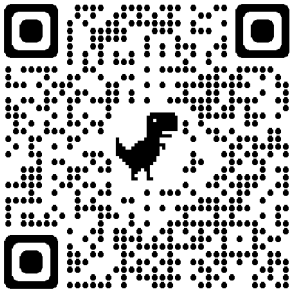
Send an email to the Trust Medical Director with the name of the patient, date of birth, telephone number, and the specific clinical information to be followed. The flag will be placed on the patient's nominated home address. A secondary address can be added for a school etc. Patients are advised to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



GIG Ymddiriedolaeth GIG
Gwasanaethau Ambwiliwlans Cymru
NHS Welsh Ambulance Services
Wales NHS Trust

chris.jones16@wales.nhs.uk

They are able to flag addresses on their system. They require name, DOB, and medical information. Please send to the above address. Information sent to this email will be forwarded on to the clinical support officers who will develop a patient specific directive. Please email the above address. 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. Information to complete the form can be found here: <https://www.fopfriends.com/emergency-help/> 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. Date compiled 20/07/2023

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