

EMERGENCY MEDICAL INFORMATION

Name:

Date of Birth:

NHS Number:

I have FIBRODYSPLASIA OSSIFICANS PROGRESSIVA (FOP)

FOP is accelerated by trauma (including intra-muscular injections) so handle me gently at all times and prevent falls. Evaluate the emergency and

Protect my life as if FOP was not an issue.

PLEASE: follow these emergency guidelines at all times. Any unnecessary physical trauma to me can cause irreparable restrictions to my body and movement.

1. **Avoid deep tissue trauma** including intramuscular (IM) injections, if possible.
2. **Stabilise & treat.** No IM injections; venipuncture, subcutaneous & intravenous medications are ok.
3. **Take intubation precautions:** Protect the jaw and get expert anaesthesia assistance since the jaw and neck may be completely or partly locked. **If airway management is needed, the preferred approach is naso-tracheal intubation with fiberoptic guidance.** Many patients with FOP have restricted jaw and neck mobility, so intubation must be done in as gentle a fashion as possible. **Follow intubation by steroids** (prednisolone 2mg/kg/day for 4 days) **to prevent fatal airway swelling from the trauma**
4. **Consulting of expert doctors is strongly recommended** regarding potential risks of any surgical or medical interventions being considered.
5. **Consider administering prophylactic (precautionary) steroids in cases of major trauma**

I have the following FOP-related physical restrictions.

Allergies:

Medications:

Weight:

If time permits, please take me to

If injuries are potentially life-threatening, please take to nearest
Accident and Emergency Department.

EMERGENCY CONTACTS

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FOP is a rare genetic disorder characterized by progressive bone formation in muscles, tendons, and ligaments, leading to progressive loss of mobility.

FOP is a disease in which the body produces not just too much bone, but an extra skeleton that immobilises the joints of the body, leading to stiffness and permanent immobility. Extra bone growth can occur without any warning or as a result of trauma, which can be as minimal as a knock, bump, fall or forced movement to locked limbs.

Efforts to remove this extra bone are fruitless and will cause more bone to grow. Malformations of the great toe are commonly noted at birth. Ectopic bone formation usually begins in the first decade of life and progresses episodically in characteristic anatomic patterns.

To view current treatment guidelines, including medical management information for medical professionals, go to:

<https://www.fopfriends.com/living-with-fop/emergency-help/>



Additional contacts:

A paramedic or emergency medical professional is likely to have no knowledge or understanding of the implications of FOP.

The adult in charge of my care, must take on the role of advocate in the case of an emergency, prior to my parents/carers arriving, or an FOP expert being consulted.