

# PERSONALIZED

## EMERGENCY MEDICAL INFORMATION

FIBRODYSPLASIA OSSIFICANS PROGRESSIVA



INFORMATION ON THIS CARD WAS UPDATED ON THIS DATE: \_\_\_\_\_

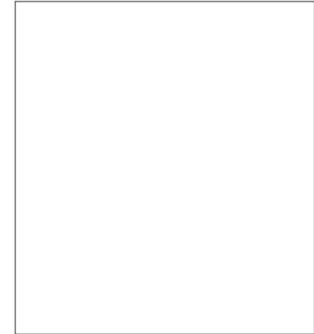
NAME OF FOP PATIENT: \_\_\_\_\_

Home Address: \_\_\_\_\_

City, State/Province, Zip/Postal: \_\_\_\_\_

Mobile #: \_\_\_\_\_

Email: \_\_\_\_\_



Click to add photo

### MY FAMILY CONTACTS ARE:

Name	Relationship	Mobile #
_____	Mother	_____
_____	Father	_____
_____	Spouse	_____
_____	Sibling	_____
_____	Caregiver	_____
_____	Other: _____	_____

### I HAVE AN ULTRA RARE CONDITION KNOWN AS FIBRODYSPLASIA OSSIFICANS PROGRESSIVA (FOP)

The person holding this document and pictured above has an ultra-rare condition known as fibrodysplasia ossificans progressiva (FOP).

FOP is a genetic disorder in which bone forms in muscles, tendons, ligaments, and other connective tissues. Bridges of extra bone form across the joints in characteristic patterns, progressively restricting movement. FOP is a disease in which the body produces not just too much bone, but an extra skeleton that immobilizes the joints of the body, leading to stiffness and permanent immobility.

#### MINIMIZE RISK with EXTRA CARE IN ALL SITUATIONS

Extra bone growth can occur without any warning or as a result of trauma. For example, deep invasive procedures, repeated or excessive blood pressure cuff inflation, or forced movement or stress on a joint can trigger a FOP flare. Care should be used to provide appropriate medical care while minimizing trauma (e.g., phlebotomy by experienced personnel only; decreasing blood pressure measurements to the lowest necessary frequency.) These episodes of bone formation may be preceded by severe inflammation ("flares"). Efforts to remove this extra bone 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.

**It is critical for people with FOP to have their family and caregivers accompany/provide care and advice for them in hospitals and at appointments.**

### MUST READ HEALTH PRECAUTIONS:

1. Avoid all IM (intramuscular) injections unless necessary for survival of the patient. IM injections will likely cause flare-ups and subsequent ossification.
2. Stabilize and Treat: Venipuncture, subcutaneous and intravenous treatments are OK. Experienced staff or guided IV placement is highly recommended.
3. Peripheral IV's are permissible. Use smallest needle possible with brief tourniquet time. Avoid central venous access unless necessary for survival of the patient.
4. In case of major trauma, begin corticosteroids immediately. Prednisone - 2 mg/kg/day (oral) or methylprednisolone 1.6 mg/kg/day (IV) for 4 days. Evaluate for other potential causes of the flare such as infection.
5. **Intubation precautions:** The cervical spine is often partially or completely ankylosed from FOP. The jaw is likely limited in movement or functionally ankylosed. Even if it is mobile, it is extremely susceptible to trauma. Do not passively manipulate. If non-invasive airway support is not possible, secure the airway with fiberoptic nasotracheal intubation by an experienced anesthesiologist. A surgeon should be immediately available to perform a tracheostomy if indicated. Steroids should be given if intubation is performed.
6. Consulting of FOP Expert Clinicians is strongly recommended.

**MUST READ "FOP TREATMENT GUIDELINES"** [ifopa.org/emergency](http://ifopa.org/emergency) or [ICCFOP.org](http://ICCFOP.org)



## **CONTACT FOP EXPERTS FOR CARE ADVICE:**

### **MY PRIMARY DOCTOR IS:**

Name: \_\_\_\_\_

Hospital/practice: \_\_\_\_\_

Tel: \_\_\_\_\_

Email: \_\_\_\_\_

### **MY FOP DOCTOR IS:**

Name: \_\_\_\_\_

Hospital/practice: \_\_\_\_\_

Tel: \_\_\_\_\_

Email: \_\_\_\_\_

### **INTERNATIONAL FOP EXPERT CLINICIANS TO CALL FOR ADVICE:**

#### **Frederick S. Kaplan, M.D.**

Director, Center for Research in FOP & Related Disorders

The Perelman School of Medicine - The University of Pennsylvania  
Department of Orthopaedic Surgery  
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#### **Robert J. Pignolo, M.D., Ph.D.**

Chair, Division of Geriatric Medicine & Gerontology  
Robert and Arlene Kogod Professor of Geriatric Medicine

Mayo Clinic College of Medicine

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#### **Edward Hsiao, M.D., Ph.D.**

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### **INTERNATIONAL FOP EXPERT ON ANESTHESIA:**

#### **Zvi Grunwald, M.D.**

The James D. Wentzler Professor of Anesthesiology  
Thomas Jefferson University and Jefferson Hospitals

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Mobile: +1 215-206-7362

Email: [zvi.grunwald@jefferson.edu](mailto:zvi.grunwald@jefferson.edu)

### **INTERNATIONAL DENTAL CARE ADVICE:**

#### **Clive Friedman, BDS (Diplomate AAPD)**

Asst. Clinical Professor Schulich School of Medicine and Dentistry

Pediatric Oral Health and Dentistry

Tel: +1 519-679-9860

Email: [clivesf@mac.com](mailto:clivesf@mac.com)

### **INTERNATIONAL ORAL AND MAXILLOFACIAL SURGERY ADVICE:**

#### **Robert J Diecidue, DMD MD MBA MSPH**

The Cohen Reichlin Professor of Dental Biosciences  
Chair Oral and Maxillofacial Surgery

Sidney Kimmel Medical College

Thomas Jefferson University

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Email: [Robert.diecidue@jefferson.edu](mailto:Robert.diecidue@jefferson.edu)

# PERSONALIZED MEDICAL INFORMATION

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

My blood type is: \_\_\_\_\_

**Current medications I am taking: (list medication/dose)**

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**List all allergies to medications: (list allergy/reaction)**

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**Food allergies:**

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**Latex Allergy:**  YES  NO

**Immunizations: (list vaccine/date given)**

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**Medical conditions that I have other than FOP: (list all)**

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**The following parts of my body have restricted movement due to ossification:**

- |                                    |   |                                      |                                      |
|------------------------------------|---|--------------------------------------|--------------------------------------|
| <input type="checkbox"/> Jaw       | <input type="checkbox"/> Left Shoulder  | <input type="checkbox"/> Left Knee   | <input type="checkbox"/> Left Ankle  |
| <input type="checkbox"/> Neck      | <input type="checkbox"/> Right Shoulder | <input type="checkbox"/> Right Knee  | <input type="checkbox"/> Right Ankle |
| <input type="checkbox"/> Back      | <input type="checkbox"/> Left Elbow     | <input type="checkbox"/> Left Wrist  |                                      |
| <input type="checkbox"/> Left Hip  | <input type="checkbox"/> Right Elbow    | <input type="checkbox"/> Right Wrist |                                      |
| <input type="checkbox"/> Right Hip | <input type="checkbox"/> Other: _____   |                                      |                                      |

**I am currently enrolled in a clinical trial:**

Name of study drug: \_\_\_\_\_

Study Doctor name: \_\_\_\_\_

Study Doctor contact number: \_\_\_\_\_

Clinical trial site: \_\_\_\_\_

**I have had the following surgeries: (surgery/date)**

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**My most recent pulmonary function test results were: (date of last test/results)**

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**I have a signed health directive:**  YES  NO

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