

## Faces of FOP

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## Our Mission

To increase awareness and fund research to find disease modifying therapies and eventually a cure for kids and adults with Fibrodysplasia Ossificans Progressiva (FOP).

## About the Network

The Canadian FOP Network is a 100% volunteer charity founded in 2008 by parents of children with FOP. Since then, we have been joined by caring family, friends and our communities bringing hope to children and adults afflicted with FOP.

## We Need Your Help

In the small but global world of FOP, our most coveted aspiration is a simple four-letter word, *CURE*. We need your help now more than ever to make this a reality.

Volunteer, become a member, make a donation. We are a small grassroots organization and we are happy to welcome people with big hearts and helping hands in a variety of opportunities.

With such an ultra-rare disease every donation, no matter how small, means so much.

## Contact Us

### Canadian FOP Network

101 Brixham Crescent  
London, Ontario N6K 1K9

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E-mail: [Canadianfopnetwork@live.com](mailto:Canadianfopnetwork@live.com)

Website: [www.cfopn.org](http://www.cfopn.org)

Join us on Facebook

# CFOPN

[www.cfopn.org](http://www.cfopn.org)



# The Canadian FOP Network

*In these rarest of children  
mother nature has hidden secrets that, if  
uncovered, would impact all other bone  
diseases that affect the masses.*

Charity Registration # 83433 8691 RR0001

## What is FOP?

FOP is short for Fibrodysplasia Ossificans Progressiva and it is one of the rarest and most disabling musculoskeletal condition known to medicine.

FOP causes bone to form in muscles, tendons, ligaments and other connective tissues, progressively fusing joints and causing immobility. The bone growth progresses from the top downward, just as bones grow in fetuses.

A child with FOP will typically develop bones starting at the neck, then on the shoulders, arms, chest area and finally on the feet.

Attempts to remove the extra bone leads to further explosive growth of new bone. Even the slightest viral or physical traumas such as the flu, bumps, bruises, childhood immunizations and dental injections can cause the muscles to turn to bone.

Children with FOP appear normal at birth, except for telltale malformations of the great toes that look like congenital bunions. Early in childhood painful swellings appear, often mistaken for tumors, and seize the skeletal muscles and transform them into a second skeleton.

## Awareness is Key....

90% of the children with FOP are misdiagnosed, often as having cancer and **many undergo inappropriate medical interventions like surgery that exacerbate their condition.**

## How is FOP Treated?

At this time, there is no treatment for FOP. There is a drug currently under development which may one day be used to help control extra bone growth. For now, medication is only helpful to manage the symptoms of FOP like pain and inflammation.

## FOP Research News

Researchers at the University of Pennsylvania School of Medicine discovered the FOP gene April 23, 2006.

In 2010, promising new research revealed a potentially highly effective treatment for the abnormal build up of bone tissue. Current animal studies involve a drug that may interrupt the signaling pathway to prevent the ossification process.

Through FOP research it may someday be possible to harness the FOP gene and create bone in a controlled way for fractures that do not heal, surgical spine fusions, severe bone loss from trauma, osteoporosis, tumors, and congenital malformations.

We need your help to support the researchers and ensure their success, to do more, to do it faster, to expand horizons and to make sure that no clue is ignored. It could be the clue that leads to a cure.

Visit our website at:  
[www.cfopn.org](http://www.cfopn.org)  
or join us on Facebook at:  
**Canadian FOP Network**

## YES, I Want to Help!

**An online donation** can be made directly from our website [www.cfopn.org](http://www.cfopn.org) through [CanadaHelps.org](http://CanadaHelps.org). Tax receipts will be issued immediately and an e-mail will be received by CFOPN letting us know of your gift.

**A cheque can be mailed** directly to:  
The Canadian FOP Network  
101 Brixham Cr., London, ON  
N6K 1K9

**A direct deposit** can be made at any TD Canada Trust bank to:  
The Canadian FOP Network  
**Branch:** 2864, **Account No.** 5002365

**Host a fundraiser** or contact us with your ideas. Third Party Fundraiser forms can be downloaded from our website. We are always happy to meet new people and have fun while raising money for this important research.

### Learn more about:



- Becoming a volunteer
- Becoming a member of CFOPN
- FOP
- Donor/sponsor opportunities

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

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

City: \_\_\_\_\_ Prov: \_\_\_\_\_

Postal Code: \_\_\_\_\_

Phone: \_\_\_\_\_

E-mail: \_\_\_\_\_

*Thank you for your support.*