

A Few Faces of FOP

Miranda, 4 yrs old



Brooke, 8 yrs old



Adam, 21 yrs old



Valerie, 21 yrs old



Our Mission

To increase awareness and raise money to continue new 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 (CFOPN) is a volunteer charity founded in 2008 by parents of children with FOP. Since then, friends, family and our communities have stepped up and joined us in our efforts to bring hope to children and adults afflicted with FOP.

Ways to Help

Volunteer - We are a small 100% volunteer organization and we are always looking for people with great ideas and big hearts to help with a variety of opportunities.

Become a member of CFOPN - Join us to help bring attention and hope to kids and adults afflicted with FOP.

Make a donation - With such an ultra-rare disease every donation, no matter how small, means so much. Tax receipts are available.

Contact Us

Canadian FOP Network

101 Brixham Crescent
London, Ontario N6K 1K9
Phone: 519-641-5742

E-mail: Canadianfopnetwork@live.com

Website: www.cfopn.org

CFOPN

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 which is one of the rarest and most disabling genetic conditions known to medicine.

FOP causes bone to form in muscles, tendons, ligaments, and other connective tissues, progressively causing immobility and fusing joints. Eventually, ribbons, sheets, and plates of bone cross the joints, locking them in place, and rendering movement impossible.

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 seem normal at birth, except for telltale malformations of the great toes that look like congenital bunions. Early in childhood because of a short-circuit in the wound repair system the body begins to destroy muscle and connective tissue. Painful swellings appear, often mistaken for tumors, and seize the skeletal muscles and transform them into a second skeleton.

“Magic Mountain Toys” Helps Fund a Cure for FOP www.magicmountaintoys.com

A secure, price competitive place to shop online for a broad range of educational toys and books delivered right to your door. Amusing games and puzzles help children and youth develop logic, reasoning, and problem solving while having fun! **100% of profit is donated to find a cure for FOP.**

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 Gene Discovery!

Researchers at the University of Pennsylvania School of Medicine discovered the FOP gene April 23, 2006. **This gene discovery immediately suggested approaches to developing better treatments and eventually a cure for FOP.**

This knowledge may someday be used for treating many common disorders of the skeleton such as osteoarthritis, osteoporosis, non-genetic forms of extra bone growth that can develop in response to a traumatic injury including head injuries, spinal cord injuries, war injuries, and even hip replacements.

Awareness is Key....



90% of the children with FOP are misdiagnosed, often as having cancer. The average time to correctly diagnose is 4 years and **many undergo inappropriate medical interventions like surgery that exacerbate their condition.**

YES, I Want to Help!

An online donation can be made directly from our website www.cfopn.org through 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. We are always happy to meet new people and have fun while raising money for this important cause.

Learn more about:

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

Name: _____

Address: _____

City: _____ Prov: _____

Postal Code: _____

Phone: _____

E-mail: _____

Thank you for your support.