

# Golf for a Cure

In honor of Shane Terry in helping to fight FOP

[www.shaneterryfop.com](http://www.shaneterryfop.com)

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Dear Friend,

Hello, it's me, Shane Terry! I am the little boy who was born with FOP Fibrodysplasia Ossificans Progressiva. I am now seven and doing okay. Just to refresh your memory, FOP is a rare genetic condition. It causes muscles and other connective tissue to turn into bone, eventually causing **immobility as FOP bone fuses joints**. Last year, you were very generous and made a donation on my behalf, and for that I would like to say thank you.

Since last year I have been doing okay, my flare-ups have become more consistent. My left arm has become more stiff preventing me from lifting my arms and I have extra bone forming on my back. Despite everything I continue to be a very active little boy. I have been accepted by the Make-A-Wish foundation and am looking forward to visiting my friends in California in August.

The International FOP Association, or IFOPA, is a nonprofit support organization for families dealing with FOP. There has been a very important break through in the research this year. Research revealed a potentially highly effective treatment for Heterotopic Ossification (HO), an abnormal build up of bone tissue. HO comes in two main forms, one in FOP and another that strikes wounded military personnel and surgery patients as it is triggered by severe injuries and wounds. An animal study shows that a drug that interrupts a signaling-nuclear protein pathway can prevent HO. Fred Kaplan, M.D., states that this study "provides great hope, insight and direction for the development of effective medications for FOP." **Researching** this rare disorder may one day also **benefit** people who suffer from more common bone-related conditions, such as **osteoporosis, arthritis, post-amputation treatment, certain spinal cord injuries** and some **heart valve disorders**. That is why I am sending you this letter, I need your help to raise money for research to allow the scientists to find a cure. Your help is needed in our fight against FOP.

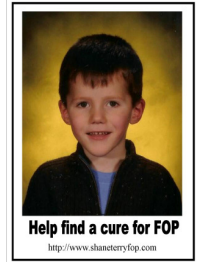
Will you help us find a cure for FOP? Please consider making a donation again this year for our 2011 **Golf For a Cure! There are many ways you can help! Here are some of them!**

- **Monetary Donations**—We are accepting monetary donations in any amount. No donation is too small! These donations will be used to help cover any costs we may encounter for the Golf event and money left over will be sent to the IFOPA. If you make a monetary donation your name will be recognized in the golf program for your generosity. (checks payable to Kim Hayes)
- **Raffle Baskets**—We are in need of baskets to raffle off, you can fill the basket(s) with anything you choose. In the past, some donors made up their basket using a theme; such as, a Crayola basket, a dog lovers basket, and Italian themed basket, a Christmas themed basket. The basket can be put together by you or just drop the purchased contents off and we will assemble a basket on your behalf. The basket can be made up of any items, size and value.
- **Gift Cards**—Gift cards are needed for restaurants, Kohl's, Wal-Mart, Target. Etc. Any denomination is welcome. These items will be used in our Basket Raffle.
- **Sponsor A Hole**— There will be signs placed at each hole with the names of those who sponsor that hole. A hole sponsor can be any amount from \$25.00 and up. If you sponsor a hole for \$500.00 or more it will include a free entry fee for a team of four players, dinner, hole sponsorship sign, and name in pamphlet as a sponsor.
- **Enter a team**— see next page for details.
- **Chinese Auction**—Will be going on through out the day. So if you do not golf you can still come and participate in the auction as well as the dinner.
- **Dinner**— Join us for dinner. Please RSVP so we have an idea of how much food we will need. Dinner will be served around 3:00 PM.

# WOULDN'T YOU LIKE TO BE PART OF THIS GREAT EVENT!!

Please use the form below for:

- Participating in the tournament
- Sponsoring a hole
- Donating a basket/item for the Chinese auction
- Partake in the Chinese auction July 23, 2011 and have dinner



**Date:** Saturday July 23, 2011

**Where:** Highland Meadows Golf and Country Club 24201 Route 342 Watertown, NY 13601

**Time:** 8:00 AM Registration and check in 9:00 AM Tee off – Shot gun start

**Cost:** \$65.00 Entry fee per person (\$260.00 per team)

**RESERVE YOUR TEAM SPOT TODAY!!!**

Call, email, mail form to Kim today! Payment due the day of tournament or before.

(Includes 18 holes, cart, dinner, prizes, longest drive, closest to the pin)

Go to [www.shaneterryfop.com](http://www.shaneterryfop.com) for registration forms and to learn more about Shane and FOP

IFOPA Non-profit 501C(3) 59-2918100

**All proceeds of this tournament will be donated to support the IFOPA**

Tear off bottom portion and return to: *Shane Terry 107 Boulton Beach Road Sackets Harbor, NY 13685*

Checks payable to: IFOPA

For Information contact: Kim Hayes 408-4689 or [khayes23@twcnny.rr.com](mailto:khayes23@twcnny.rr.com)

**Hole Sponsorship:** \$25 \$50 \$75 \$100 \$300 \$500 Other (can be any amt.): \_\_\_\_\_  
(\$500 and above includes free entry of 4 player team)

What would you like your hole sign to say?(amount is not listed on sign): \_\_\_\_\_

**Captain and Crew:** \_\_\_\_\_

\_\_\_\_\_ Contact number: \_\_\_\_\_

**Dinner only for non-golfers(approx.3:00pm)**

Name(s): \_\_\_\_\_

\$20.00 per person \_\_\_\_\_  
(This also includes 10 Chinese auction tickets)

**Donate basket/item for auction**

I will donate \_\_\_\_\_

(when your basket/item is ready call Kim 408-4689 or email [khayes23@twcnny.rr.com](mailto:khayes23@twcnny.rr.com) and she will arrange for pick-up)



International  
Fibrodysplasia  
Ossificans  
Progressiva  
Association