

Dear Friend,

January 6, 2019

Hello, it's me, Joshua Scoble! Remember me??? I am the little boy who was born with FOP (Fibrodysplasia Ossificans Progressiva). Just to refresh your memory, FOP is a genetic disorder which causes my muscles and ligaments to turn to bone permanently. I would like to thank you in advance for your continued support.

This past year was a very busy year for me. I turned twelve-years-old and attend seventh grade at Lower Macungie Middle School. I am very fortunate to have the parents, family and friends that I do. They all work together to keep me as active as possible, considering my situation. They all understand that maybe someday I will not be able to do certain things because of my inability to be mobile. Lucky for me everyone is so generous and because of this, opportunities present themselves for me to keep doing things that I love. I want to thank my special guardian angel and all my friends who helped me to get a new handicapped van!! I'm not sure if you know this but it was really difficult for me to go anywhere, even just to run to the store. But that all changed with my new wheels!! My new van allowed me to go to Madison Square Garden to see a WWE wrestling match! I was also able to attend the FOP gathering in Baltimore, Maryland this year. That was a fun trip getting to hang out with other people affected by FOP and getting to know their families. Though some of the proceeds from my GoFund Me account went to purchasing my van, some of the money went to finishing the modifications on my house. I can now freely move about my own home in my wheelchair!!



Unfortunately, with all this good stuff there sometimes is bad. This past year was rough on me. I had continual flare-ups from the beginning of the year until the past couple of months. However, since I am enrolled in the clinical trial program for palovarotene, I am currently on a daily maintenance of the drug. Palovarotene has been showing great success in preventing extra bone growth throughout the entire study. If all goes well and it is approved by the FDA, palovarotene should be available for prescription use for everyone affected by FOP. Very exciting things are still happening in the FOP lab. Great strides continue to be made with FOP research; studies have progressed to the point where they are in the final chapter of Phase 3 in the Clinical Study. There are two FOP drugs currently being established and a third one should begin clinical trials by the spring!! My website is still a good place to check on me, find out information on all the upcoming events my non-profit organization is planning, as well as, updates on research. Please be sure to check it out at: www.JoshuasFOP.com.

Right now, my Aunt Chrissy is busy organizing my 12th annual **Bingo For A Cure!**, being held on March 17, 2019, at the Allentown Fairgrounds, Agri-Plex Hall. Tickets are on sale now! We anticipate a crowd of over 1,600 people again this year! **All proceeds generated from all of our fundraising events will go directly to Joshua's Future of Promises which benefits FOP research.**

Will you help us find a cure for FOP? Please consider making a donation to one or any of our upcoming fundraising events. Please refer to the next page to see the numerous ways you can help be a part of finding a cure!

Any contribution is greatly appreciated! Please remember you can mail or drop off your donation to: **Buss Paint & Wallpaper Attn: Joshua's FOP 327 Main Street, Emmaus, PA, 18049. Checks can be made payable to: Joshua's Future of Promises.** If you have any other questions, please feel free to contact Chrissy at 610-349-8479 or via email auntchrissy@joshuasfop.com. Thank you for your support and we hope to see you at our 12th annual **Bingo For A Cure!** on March 17, 2019!!!

Sincerely,
Joshua Scoble

Here is a list of different ways you can help find a cure for FOP.

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.

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 lover basket, an Italian 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. Another way to contribute to the basket raffle is by donating a professional service. For example, painters can donate painting a room or a hair stylist can donate a cut and style, etc.

Gift Cards – Gift cards are needed for restaurants, iTunes, Kohl's, Wal-Mart, Wawa, etc. Any denomination is welcome. These items will be used at any of our fundraising events.

Baker's Needed – We are always in need of baked goods to sell at our bake sale. It is greatly appreciated if items are individually wrapped. If you are interested in baking, please contact Sharon at 610-336-8485 or email her at sharononeill@rcn.com for more details.

Table Prizes – We are in need of items and/or gift cards in groups of 24. There are 24 people per table, it is important that we receive the table prizes in groups of 24. The items should be identical in value. We have learned from previous years that individual door prizes are too time consuming. Therefore, we have come up with the idea of handing out table prizes! Each table has a number and when a winning table number is picked everyone seated at that table will win the prize. For example, last year many restaurants donated gift cards for table prizes, one being Red Robin. When the winning table number is drawn, everyone at the table received a \$10 Red Robin gift card. This turned out to be a favorite for most businesses. Table prizes are only used at the Bingo Event.

Businesses should be aware of this cost-effective advertising opportunity! This will be the most rewarding way to advertise your business this year and help change lives!!!! We anticipate a crowd of over 1,600 people again this year. Space is limited so don't miss out on getting your business recognized!

Bingo Game Sponsorship – We are in need of individuals/businesses to sponsor our "Cash Game Prize Money." Every game of Bingo played has a "Cash" prize. There is a total of 25 games that need to be sponsored. There are **20 Regular** games with a cash prize of **\$200** and **5 Special** games with a cash prize of **\$250**. Our **Grand Prize** game will have a cash prize of **\$1,000**. If you sponsor a game your name will be printed in the program and announced during the bingo to recognize your generosity. Please contact Chrissy Flexer to reserve a game. Games are sponsored on a first come first serve basis!

Other Ways You Can Help – There are many other ways to donate to our fundraisers, it could be as simple as attending the fundraiser, selling tickets, hanging flyers at work, soliciting donations, or just spreading the word to raise awareness!

Any questions you may have feel free to contact Chrissy Flexer at 610-349-8479 or you can email auntchrissy@joshuasfop.com. **Please make checks payable to: "Joshua's Future of Promises!"** All donations can be mailed or dropped off at:

Buss Paint & Wallpaper
Attn: Joshua's FOP
327 Main Street
Emmaus, PA 18049



Save the date – March 17, 2019

Please include your name, address and phone number when dropping/mailing any donations.

****Please note if we receive a monetary donation for the Bingo Event after **March 1, 2019**, it will **NOT** appear in the Bingo Program.****