



www.JoshuasFOP.com

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Dear Friend,

January 5, 2024

Hey everybody! It's me, Joshua Scoble! I am the young man who was born with FOP (Fibrodysplasia Ossificans Progressiva). In case you forgot, FOP is an ultra-rare genetic disorder that causes my muscles, tendons, and ligaments to turn to bone.

2024 is our sweetest year yet. It is our **16th Bingo For A Cure!** We are very excited to see everyone this year. We hope you are just as eager to join us! Thank you for your unwavering support throughout these sixteen years! I'm seventeen now and a senior at Emmaus High School. I'll be graduating this year and plan to take classes at Lehigh Carbon Community College in Business Management. 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. It is understood 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. Over the past year, I have participated in a lot of exciting things: I started playing hockey for the Philadelphia Flyers PowerPlay team. I was gifted the chance, thanks to a generous and awesome friend, to see half a season's worth of the Lehigh Valley Phantoms' hockey games. I even got to sit on the bench for warm-ups before a game! A few of my family members and I went on a trip to Niagara Falls. That was amazing to see! I also had the opportunity to see a Phillies game and a Flyers game. I went camping and fishing this past summer as well as attending some of my favorite artist's concerts.



Great strides continue to be made in FOP research. Currently, there are several clinical trials and multiple drugs being generated. In August 2023, IPSEN received approval from the U.S. Food & Drug Administration (FDA) for the drug SOHONOS (palovarotene). It is used for the reduction in volume of new ossification in adults and pediatric patients suffering from FOP. This is a huge milestone in a long journey to help improve the management of FOP. There is a multitude of treatment drugs in the works from several different drug companies, each in different phases. Each new drug has to go through four phases; Phase I focuses on safety and proper dosage. Phase II focuses on the effectiveness and side effects. Phase III compares the new treatment to any existing treatment. And the final phase, Phase IV, is that the treatment was approved and available; in this phase long-term effects are observed. The willingness of families participating in clinical trial research is the only way to ever learn if the drugs are safe and effective treatments for FOP. I myself have participated in clinical trials. I'm currently enrolled in a Phase II clinical study now. Fingers crossed! These are just a few reasons why we continue to raise funds for research. Our funding, with your help, is truly making a difference.

My website is still the best 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 here: www.JoshuasFOP.com.

Right now, my Aunt Chrissy is busy organizing my 16th annual **Bingo For A Cure!**, being held on March 17, 2024, at the Allentown Fairgrounds Agri-Plex. Tickets went on sale in December! We are looking forward to having another strong crowd this year! **All proceeds generated from all of our fundraising events will go directly to Joshua's Future of Promises which benefits FOP research.**

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 16th annual **Bingo For A Cure** on March 17, 2024!

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!

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: Crayola, dog lover, and Italian themed baskets are just a few examples. They can be assembled by you or us: just drop the purchased contents off and we will assemble the basket on your behalf. Please be sure to include your name and the monetary value of your items! The basket can be made up of any items, size or value. Another way to contribute to the 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 from restaurants, VISA, Kohl's, Amazon, 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 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, so it is important that we receive the table prizes in that amount. 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 that 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! 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 are 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, 2024

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

*****Please note, if we receive a monetary donation for the Bingo Event after March 1, 2024, it will NOT appear in the Bingo Program.*****