Title: Program Specialist

Location: United States

Organization's Mission: To fund research to find a cure for FOP while supporting, connecting and advocating for individuals with FOP and their families, and raising awareness worldwide.

About the Organization: The International Fibrodysplasia Ossificans Progressiva Association (IFOPA) is an international nonprofit organization fostering medical research and providing education and support for those afflicted by the rare genetic condition fibrodysplasia ossificans progressiva (FOP). A volunteer board of directors governs the IFOPA. We hold ourselves accountable to the FOP community. As an organization, we work closely with patients and families, national FOP organizations around the world, and leading clinicians, scientists and drug developers.

Position Overview: The IFOPA’s Program Specialist is responsible for fundraising, communications and programmatic administrative duties throughout the organization.

Hours, Supervision and the IFOPA Office: This full-time salaried position reports to the IFOPA’s Executive Director with project-specific supervision by assigned IFOPA staff. All IFOPA staff members work remotely from their homes.

Salary Range and Benefits: The salary range for this position is $40,000 - $50,000 with annual opportunities for cost-of-living raises; health, life, dental and vision insurance; short-term and long-term disability; generous PTO policy and paid holidays.

Position Responsibilities:

Communications and Awareness
- Build articles, attach lists and deploy the eNewsletter
- Package awareness items and send them via USPS
- Website updates: Update fundraising totals and other fundraiser recognition
- Pull reports for various email campaigns

Gift Administration and Donor Relations
- Gift processing for online and offline gifts including verifying the accuracy of gift tributes and restrictions
- Monthly verification of monthly donations
- Prepare all thank you letters, including in-kind donations and coordinate mailing with printer
- Prepare monthly in honor/memory reports and update family web pages
- Prepare annual contribution statement and coordinate mailing with printer
- Maintain Salsa CRM database, including repermission campaign and data clean-up, regular upload of outside data
- Run reports and prepare cultivation and stewardship materials (thank you notes, call lists, etc.)
- Fundraising event administration support as needed
- Bad address research and address updates in database

**Family Services**
- Check online patient submissions and add to database and patient directory
- Verify links and maintain the online database of adaptive tools
- Coordinate communication with the committee and recipients for an individual grant award program, make approved award purchases
- Coordinate monthly birthday cards
- Send flowers and make administrative updates for bereaved families

**Meeting Support**
- Coordinate event logistics, including air travel and ground transportation, hotel reservations, food and beverage, audio-visual, etc. for the annual IFOPA Board meeting
- Work with staff and committee chairs to schedule and manage Board and committee meetings
- Collect and file Board and committee minutes and materials electronically
- Travel to and assist with staffing of IFOPA-led meetings, as needed

**Administrative and Finance**
- Administrative support on projects as assigned
- Coordinate translation support for programs
- Assist with vendor and volunteer appreciation efforts
- Initiate electronic signatures on various organizational documents
- Regularly pull finance statements and receipts, invoice coding

**Position Qualifications:**
- BS/BA degree preferred
- Nonprofit experience required
- Relevant experience in donor relations and digital communications
- Strong project management and general organizational skills
- Ability to work independently and effectively in a virtual setting
- Excellent attention to detail, strong written and verbal communication skills
- Expertise with Microsoft Office (Word, Excel and PowerPoint) and Google Workspace

To apply, please send your resume along with a cover letter to careers@ifopa.org by April 21, 2023.

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The IFOPA is an equal employment opportunity employer and strives to comply with all applicable laws prohibiting discrimination based on race, color, creed, sex, age, national origin or ancestry, physical or mental disability, veteran status, marital status, etc., as well as any other category protected by federal, state, or local laws.

The job profile in no way states or implied that these are the only duties to be performed by the jobholder; the Program Specialist will be required to follow instructions and perform other duties as requested by the Executive Director. Essential elements may change when necessary.