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# Executive Director

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# The Opportunity

PSC Partners Seeking a Cure, a notable entity in the nonprofit sector since 2005, seeks a seasoned nonprofit leader to fill the role of Executive Director. This unique opportunity invites a mission-driven individual to make a profound impact on the lives of those affected by primary sclerosing cholangitis (PSC), a rare autoimmune liver disease.

As a 501(c)(3) nonprofit organization, PSC Partners Seeking a Cure is at the forefront of advancing research for PSC treatments and a cure while providing crucial education and support to those impacted by the condition. With a remarkable track record of growth, the organization has secured over \$16 million in donations since its inception and has an annual operating budget of over \$4 million. Its programs have significantly increased disease awareness, highlighted by hosting the largest annual conferences for PSC patients, caregivers, and medical experts globally. Additionally, the organization has allocated more than \$6 million in medical research grants and is embarking on a major 5-to-7-year medical research project, budgeted at \$13-\$15 million, to lay the groundwork for future breakthroughs.

The Executive Director, reporting directly to the CEO, will be instrumental in steering the organization's daily operations and strategic trajectory. This position oversees major medical research projects and requires a dynamic leader adept at team management and organizational growth within a mission-driven environment. The candidate must excel in building teams and volunteer groups and maintaining robust relationships across various stakeholder groups.

A few key responsibilities of the Executive Director are to foster a philanthropic culture, spearhead fundraising activities, and nurture stakeholder relationships. This involves enhancing donation income, leading grant-seeking initiatives, and identifying new funding opportunities. The role also entails comprehensive management of staff and volunteers, resource optimization, and oversight of patient education and support programs, all coupled with sound financial stewardship.

PSC Partners seeks a candidate with at least seven years of senior management experience in the nonprofit sector, preferably within healthcare. The ideal individual will display dynamic leadership, strategic foresight, strong communication skills, and a proven financial, operational, and fundraising management ability. Qualities such as compassion, empathy, inclusivity, integrity, and networking prowess are essential. This opportunity arises following the retirement of the previous Executive Director.

In collaboration with the CEO, the Executive Director will be instrumental in actualizing the organization's vision and strategic plans. The CEO will continue to foster stakeholder relationships while partnering with the Executive Director to set the organization's overall direction. The Executive Director will operationalize these strategies, ensure organizational effectiveness, and meet strategic objectives. Together, they will guide PSC Partners towards a new era of increased growth and influence.

Those interested in this role or wishing to nominate someone are encouraged to consult the "Procedure for Candidacy" section, detailed at the end of this profile.

# Organization Overview

## MISSION & VALUES

*Through collaboration with our employees and the board of directors, PSC Partners Seeking a Cure developed its guideposts – Mission and Core Values.*

### MISSION

The mission of PSC Partners Seeking a Cure is to drive research to identify treatments and a cure for primary sclerosing cholangitis (PSC) while providing education and support for those impacted by this rare disease.

### CORE VALUES:

By embodying these core values, our organization aims to create a positive and purposeful work culture that aligns with our mission and helps us make a meaningful impact.

- 1. Mission-driven:** We are dedicated to driving research to identify treatments and a cure for primary sclerosing cholangitis (PSC) while educating and supporting those impacted by this rare disease. Our approach is centered around patients and caregivers, valuing the PSC community's needs and well-being as guiding principles in our decision-making process.
- 2. Community-focused:** We strive to create a supportive and caring environment where relationships are nurtured, mutual support is given and received, and diverse perspectives are valued. We aim to ensure that no one affected by PSC ever feels lost and alone.
- 3. Inclusive:** We embrace diverse backgrounds, perspectives, and experiences. We actively foster an environment where all are welcomed, respected, and valued.
- 4. Collaborative:** We work collaboratively within and outside the organization, engaging stakeholders to achieve common goals. We share ideas, practice teamwork, and promote a positive and compassionate dynamic to enhance effectiveness, productivity, and progress.
- 5. Innovative:** We actively seek new and creative ways to advance our mission in education, support, and scientific research. We are open-minded, adaptable, and consistently strive to find inventive solutions that enhance our impact on the PSC community.
- 6. Ethical:** Integrity is at the heart of everything we do for the benefit of our community, ensuring ethical conduct in all interactions with patients, caregivers, employees, donors, researchers, volunteers, and clinicians.
- 7. Accountable:** We exercise stewardship in our operations, valuing every resource entrusted to us—time, finance, or effort. We act responsibly, thoughtfully, and prudently in our endeavors. We safeguard patient privacy in all aspects of our work.

## Summary

Founded in 2005, PSC Partners Seeking a Cure is a 501(c)(3) nonprofit organization. The various programs support patients, caregivers, families, and friends, educate patients and the medical community about primary sclerosing cholangitis (PSC), a rare autoimmune liver disease, and support groundbreaking research searching for treatments and a cure.

PSC Partners, headquartered in the United States, extends its impact globally through initiatives such as international research grants, collaborations with other PSC organizations, an international patient registry, and support of the worldwide PSC community. To date, their impact has included:

- Conference Attendees: 4,800
- Patient Registry Participants: 2,500
- Total Funds Raised: \$16 Mil+

## History

**Founding:** PSC Partners Seeking a Cure was founded in 2005 by Ricky Safer, driven by her personal experience with primary sclerosing cholangitis (PSC) and the lack of available resources and support for this condition. Safer's journey began with a struggle for accurate information and community support, which led her to connect with fellow PSC patients and caregivers through an online support group. This collective experience highlighted the urgent need for education, support, and research in PSC.



**Early Initiatives:** The organization's first major undertaking was hosting a conference for PSC patients and caregivers in April 2005. This event, organized with the help of Safer's family, David Rhodes, Lee Bria, Dr. Greg Everson, and others, began a series of successful initiatives to support the PSC community.

## Today

**Research, Support, and Education:** PSC Partners has evolved into a collaborative global network encompassing PSC patients, caregivers, healthcare professionals, and researchers. Recognized for its comprehensive support system, the organization functions as a family unit for individuals dealing with PSC, fostering community among those affected. It educates both patients and the medical community about PSC, ensuring widespread awareness and understanding of the disease. In addition, its board of directors, Scientific/Medical Advisory Committee (SMAC), and internal scientific professionals guide the organization's growing list of patient-centered strategic research initiatives.

## Financial Impact

**Funding and Contributions:** Experiencing remarkable growth since its inception, PSC Partners now boasts an average annual donation income exceeding \$2 million. This demonstrates the strong support and trust it has garnered within the community, which presents an opportunity for substantial expansion by establishing a more proactive development platform. The organization has contributed over \$6 million towards critical research initiatives, underscoring its commitment to advancing treatments and finding a cure for PSC.

**Major Research Project:** PSC Partners has embarked on an ambitious 5-to-7-year medical research project with a dedicated budget of \$13-\$15 million. This significant initiative will serve as a crucial resource for researchers worldwide in the quest for effective treatments and a cure while further positioning the organization as a global leader within the PSC community.

# Programs

PSC Partners accomplishes its mission through impactful education and research initiatives.

## Patient and Caregiver Education and Support

**Patient and Caregiver Conference:** Celebrating its 20th annual conference in 2024, this event is recognized as the largest PSC conference globally. It brings together patients, caregivers, and leading experts in PSC from the U.S. and international treatment and research centers. The conference discusses the latest research, treatments, medications, and disease outlook. Attendees also engage in support and discussion sessions with physicians and other attendees. Beyond its educational components, the conference offers a unique opportunity for networking, emotional support, and entertainment—often described as life-changing by participants.

**Mentor Program:** This program offers essential support to people impacted by PSC. Experienced individuals in the PSC community provide guidance, share experiences, and offer emotional support to those newly diagnosed or struggling with the disease.

**Support Groups:** PSC Partners facilitates both in-person meetings and online support groups, including an open and closed Facebook page as well as other social media connections. These groups provide a platform for sharing experiences, seeking advice, and gaining emotional support.

**DEI Initiatives:** PSC Partners works closely with its multi-stakeholder DEI Working Group and Patient Advisory/Ambassador Group to champion diversity, equity, and inclusion throughout all education, support, and research programs as well as throughout staff, board, and the patient/caregiver community.

**Podcasts and Blogs:** These platforms offer additional resources for education and support, featuring discussions on various aspects of living with PSC, insights from medical professionals, and personal stories from the PSC community.

## Research

### **PSC Partners Annual Research Grant Awards:**

Each year, PSC Partners Seeking a Cure, under the guidance of our Scientific/Medical Advisory Committee and internal Research Committee, provides seed grants for research projects focusing on PSC and related co-morbidities. In 2022, the organization funded four projects, including one by the PSC Partners Canadian affiliate. This program has awarded over 113 grants and \$6 million to advance medical research.

**PSC Partners Patient Registry:** This pivotal initiative securely collects anonymized data from over 2,700 patient participants in 54 countries—the world's largest patient-led registry of PSC patients. By compiling comprehensive information about PSC patients' diagnoses, treatments, and quality of life, the registry serves as a valuable resource for researchers to study trends, understand disease progression, and evaluate the effectiveness of treatments. The registry is also instrumental in identifying suitable candidates for clinical trials.

### **Clinical and Basic Science Research Studies:**

PSC Partners is leading multiple patient-centered medical research studies, aligning with its Strategic Research Plan created to fulfill its mission to find treatments and a cure for PSC. These studies aim to provide building blocks for researchers worldwide to accelerate the quest for treatments and a cure. The largest of these is the WIND PSC prospective cohort of 2,000 patients, collecting regulatory-quality data to be used as placebo data to support and accelerate drug development in PSC.

### **International Collaborative Research Network**

**(ICRN):** Launched in September 2022, this initiative unites leading PSC researchers, clinicians, and regulators with patients and caregivers. The ICRN is actively integrating international databases, facilitating patient-driven research projects, and advancing patient-focused drug development, among other initiatives, to enhance global collaboration and accelerate progress in understanding and addressing PSC.

## Leadership

PSC Partners is fortunate to have a very talented and motivated group of people on its Board of Directors and Staff. Below are a few leadership team members, and a complete list of board and staff members can be found online: <https://pscpartners.org/about-us/meet-our-team/>.

### **Ricky Safer - Founder and CEO**

Ricky is the CEO and Founder of PSC Partners, serving in a volunteer capacity. After being diagnosed with PSC in 2003 and finding limited resources, Ricky Safer, a lifelong health enthusiast, founded PSC Partners Seeking a Cure in 2004 with support from her family, Dr. Everson, and friends Lee Bria and David Rhodes. Leveraging her volunteer experience with Crohn's and Colitis Foundation (CCF) and her role on the Donor Awareness Council board, Ricky launched the organization. She has contributed to CCF's Nutritional Panel, won the CCF Sigman award, and enjoys family support, particularly cherishing time with her husband Don, their children, and grandchildren. As CEO of PSC Partners, Ricky remains dedicated to improving the lives of those with PSC. She holds a B.A. in French from the University of Michigan and a Master of Arts in Teaching from Johns Hopkins University and has a background in teaching foreign languages and cross-cultural training at the University of Denver.

### **Joanne Grieme - Board Chair**

Joanne Grieme lives in Pittsburgh, PA, and has actively volunteered with PSC Partners since attending the first PSC Partners conference in 2005. Her son was diagnosed at the age of 15 with PSC in 2001 and has had four liver transplants.

Joanne has worked with her husband in the family business in the aviation industry for over 20 years but is most fulfilled with her volunteer work helping others and raising awareness for PSC. She has also served on the Board of Directors for other liver organizations in the Pittsburgh area.

### **Scott Malat - Board Treasurer**

Scott Malat, CFA, attended his first PSC Partners Conference looking for more information after his wife was diagnosed in 2005. At that conference, he was amazed to find such a talented, dedicated group of volunteers who immediately treated him like family. Scott joined the board of directors to help the

organization manage its explosive growth and invest in finding a cure.

Scott previously served as the chief strategy officer of XPO Logistics, where he led the strategy that grew XPO from less than \$200 million in revenue to over \$17 billion in 32 countries, with 1,525 locations and more than 100,000 employees. Prior to XPO, Scott worked at Goldman Sachs, UBS, and JP Morgan Chase. Scott is a CFA® charterholder with a statistics degree and a concentration in business management from Cornell University.

### **Joanne Hatchett - Medical Science Liaison**

Joanne Hatchett, RN, FNP, ACHPN, is the Medical Science Liaison for PSC Partners. Most recently, Joanne was a family nurse practitioner. She is a strong advocate for advanced care planning and patient and family education and, before accepting the position at PSC Partners, was a member of the PSC Partners Board of Directors. Additionally, she is a PSC caregiver. Joanne graduated from San Francisco State University with a BSN and received both her MSN as a Cardiopulmonary Clinical Nurse Specialist and Family Nurse Practitioner Post-Master's certification from the University of California, San Francisco.

### **Stephen Rossi - Chief Scientific Officer**

Dr. Stephen Rossi, Pharm D, is the Chief Scientific Officer (CSO) for PSC Partners. Dr. Rossi has worked with patients with chronic liver diseases for over 30 years as a clinician and researcher. For the past 20 years, he has focused on developing new drugs for patients with liver disease, including several potential new treatments for PSC. He brings a wealth of experience in clinical research to help lead PSC Partners research programs, including the WIND-PSC study, the International Collaborative Research Network, the PSC Partners Research Grants program, and other projects critical to the mission.



# Position Summary

The Executive Director (ED) will play a crucial role in leading PSC Partners Seeking a Cure through its next growth phase. This position requires a dynamic and enthusiastic leader with extensive nonprofit leadership experience. The Executive Director will oversee the organization's administration, programs, and strategic planning. Other key duties include fundraising, marketing, staff and volunteer management, financial management, stakeholder relationships, and community outreach.

## REPORTING RELATIONSHIPS

Reporting to the CEO, the ED will lead a team of 6 direct and 8 indirect reports. Direct reports include:

- Chief Scientific Officer
- Patient Support and Education Director
- Development Director (to be filled)
- Registry Director
- Business Manager
- Communications Director

**Anticipated Compensation Range:** \$160,000 - \$180,000 including excellent benefits. Final salary determination will be based on the candidate's experience and specific qualifications.

**Location:** This position is located in Denver, Colorado, where PSC Partners maintains a hybrid working environment. The incoming ED is expected to reside within a reasonable driving distance of Denver, enabling a balance of in-office presence and the ability to travel regularly to engage with various stakeholders.



## Responsibilities

The successful Executive Director candidate will:

### Lead operations:

- Manage all aspects of operations, including hiring and retaining a dedicated team of highly qualified staff and volunteers.
- Provide career coaching, growth opportunities, and personal development to team members.
- Ensure optimal resource utilization, coordinating effective implementation and management of technology systems to enhance organizational efficiency.
- Execute notes, agreements, and other instruments made and entered into on behalf of the organization.

### Collaborate with the Board of Directors and CEO:

- Work closely with the Board to define strategic vision, set goals, and ensure the organization's financial health.
- Effectively communicate with the Board, providing necessary information for informed decision-making.
- Respond to questions regarding the quarterly and annual financial statements.

### Drive fundraising:

- Develop and expand donation income, fostering relationships with donors.
- Coordinate efforts to increase grant income from corporations, government agencies, and other non-profits.
- Oversee the identification and cultivation of new revenue streams.

### Oversee patient education and support programs:

- Direct the annual Patient Caregiver Conference, the largest PSC conference in the world in collaboration with the CEO.
- Expand patient education and support programs, such as mentorship, podcasts, and support groups, among others.

### Oversee medical research program:

- Collaborate with the internal staff and the Scientific Medical Advisory Committee (SMAC) to define and implement the medical research program aligned with the organization's mission and goals.

### Ensure financial stewardship:

- Lead financial management, including budgeting, goal setting, resource optimization, and maintaining the organization's positive financial position.
- Prepare annual budgets, operate within approved budgets, and monitor financial performance, including key performance indicators.

### Represent the organization:

- Act as a representative to the public, including media, patients, caregivers, the medical community, and other organizations.
- Provide support to patients, caregivers, families, and friends.
- Educate patients and the medical community about primary sclerosing cholangitis and relevant organizational programs.
- Advocate for groundbreaking research in the quest for treatments and a cure.

# Candidate Qualifications

## Education/Certification

- Bachelor's degree required. Ten years of experience in a substantially similar role or a combination of experience and education can be considered in lieu of an undergraduate degree.

## Knowledge and Work Experience

- 7-10+ years of senior nonprofit management experience preferred.
- Proven experience in growing a non-profit organization as an executive director or in a similar role. A history of successfully generating new revenue streams and improving financial results.
- Experience in the healthcare setting, in particular, rare diseases, would be highly desired.

## Leadership Skills and Competencies

- **Dynamic Leadership:** Embodies the organization's core values, including mission-driven focus, ethical behavior, and accountability, with a talent for inspiring and guiding teams in person and virtually.
- **Strategic Vision and Planning:** Possesses high-level strategic thinking abilities, capable of envisioning and conveying the organization's future to staff, board, volunteers, and donors.
- **Financial and Operational Management:** Demonstrates proficiency in financial management, including budget preparation, analysis, decision-making, and P&L management, while being highly organized.
- **Effective Communication:** Exhibits strong written and oral communication skills, coupled with effectively conveying the organization's mission to a diverse audience.
- **Fundraising and Donor Relations:** Active experience in fundraising, with excellent donor relation skills and knowledge of the grant writing process.
- **Public Speaking:** Strong public speaking abilities, engaging and motivating a wide range of audiences.

## Personal Characteristics

- **Compassion & Mission Alignment:** Deeply committed to the organization's mission, showing genuine concern for people affected by liver disease.
- **Inclusive & Empathetic Leadership:** Fosters an inclusive work environment, valuing diversity and demonstrating empathy towards team members and stakeholders.
- **Collaborative:** Skilled in building partnerships and fostering a collaborative environment to achieve shared organizational goals.
- **Trustworthy & Ethical:** Maintains integrity and ethical standards in all actions, earning trust through consistency and authenticity.
- **Interpersonal & Social Intelligence:** Excels in building productive internal and external relationships, navigating diverse social environments easily and tactfully.
- **Networking Ability:** Effectively builds and maintains networks, enhancing the organization's reputation and stakeholder relationship.

# The Community

## Denver, Colorado



The city of Denver and the state of Colorado are attractive destinations for business and industry. Denver holds a top-five position for best places for business and careers (*Forbes*). *Business Insider* ranked Denver second in its “50 Best Places to Live in America Right Now,” and *U.S. News and World Report* rated Colorado as the nation’s top economy. In 2022, Denver was cited as the sixth-fastest growing city in the U.S. (Kenan Institute of Private Enterprise), and it is a magnet for young professionals, with a median population age of 34 years old (U.S. Census Bureau). Colorado ranks as the third-most educated state in America (WalletHub) and is the second-best state to find a job (*U.S. News & World Report*). *U.S. News and World Report’s* 2020 Best Places to Live study ranked the city of Denver in the second spot, citing the city’s proximity to outdoor recreation, a progressive mindset, and its walkability.

With 300 days of sunshine a year, there are plenty of reasons to get outside. Not only is Colorado the country’s most popular ski and snowboarding destination, but it is also home to four national parks, 42 state parks, and many outdoor recreation areas for boating, hiking, camping, swimming, snowmobiling, bird watching, picnicking, world-class fishing, hunting, and biking. Residents enjoy countless adventures in the great outdoors of the vast Rocky Mountains and can explore the diverse cultural attractions, art galleries, concerts, sporting events, and the vibrant city scene of Colorado’s Mile High City.

To learn more, visit: <https://www.denver.org/> or <https://www.metrodenver.org/>

# How to Apply



Please direct all nominations and resumes to the WittKieffer consultants supporting this search, Ashley Buderus and Roxana Woudstra, via email to [ED\\_PSCPartners@wittkieffer.com](mailto:ED_PSCPartners@wittkieffer.com). Application materials and inquiries can also be sent through WittKieffer's Candidate Portal, accessed [here](#).

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*PSC Partners Seeking a Cure values diversity and is committed to equal opportunity for all persons regardless of age, color, disability, ethnicity, marital status, national origin, race, religion, sex, sexual orientation, veteran status or any other status protected by law. To view the complete DEI Statement, visit: <https://pscpartners.org/about-us/policies/diversity-equity-and-inclusion-statement.html>.*

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# Appendix

## About Primary Sclerosing Cholangitis (PSC)

Primary Sclerosing Cholangitis (PSC) is a rare autoimmune liver disease characterized by the inflammation and scarring of the bile ducts, leading to progressive liver damage. This scarring narrows the ducts, obstructing the flow of bile, which can cause liver cells to become damaged and eventually lead to cirrhosis or scarring of the liver. PSC is a complex condition that can vary significantly in its progression among individuals.

### Receiving a Diagnosis

Diagnosing PSC can be challenging due to its rarity and the often subtle or absent initial symptoms. Typically, the first indication of a potential issue is through abnormal liver enzyme levels identified in blood tests. As awareness and knowledge about PSC increase, diagnosing the disease improves, allowing for earlier detection and management.

### Treatments

Currently, there are no FDA-approved medications specifically for treating or curing PSC. However, various medications and procedures can help alleviate some of the symptoms associated with the disease. These treatments primarily focus on managing complications and improving the quality of life for those affected.

### Clinical Trials

The landscape of PSC treatment is evolving, with an increasing number of clinical trials underway. These trials are crucial for developing new treatments and potentially finding a cure. PSC Partners Seeking a Cure strongly advocates for patient awareness and involvement in clinical trials. Participation in these trials can offer access to new therapies and contribute significantly to advancing PSC treatment. Patients are encouraged to explore these options and discuss potential participation in clinical trials with their healthcare professionals.

By promoting and facilitating participation in clinical trials and research, PSC Partners Seeking a Cure is vital in advancing the understanding and treatment of this rare autoimmune liver disease. Through their efforts in funding research, maintaining a comprehensive patient registry, and encouraging clinical trial participation, the organization contributes significantly to the ongoing quest for effective treatments and a cure for PSC.

To learn more, visit: <https://pscpartners.org/about/the-disease/>.



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