Leadership Profile

Chief Executive Officer

CONFIDENTIAL

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This Leadership Profile is intended to provide information about Foundation for Prader-Willi Research and the position of Chief Executive Officer. It is designed to assist qualified individuals in assessing their interest.
Foundation for Prader-Willi Research: An Overview

The Foundation for Prader-Willi Research (FPWR) was established in 2003 by a small group of parents who saw the need to foster research that would help their children with Prader-Willi Syndrome (PWS) lead healthier and more fulfilling lives. Today, FPWR community is composed of hundreds of parents, family members, researchers, and others interested in addressing the many issues related to PWS, including childhood obesity, developmental delays and psychiatric disorders.

The mission of FPWR is to eliminate the challenges of Prader-Willi syndrome through the advancement of research and therapeutic development. FPWR’s research program has grown from funding small pilot studies to encompassing a robust and diverse research portfolio that facilitates and guides the PWS research agenda. The Foundation has played an instrumental role in advancing the field of PWS research by supporting innovative research, encouraging collaboration, engaging pharmaceutical companies and enabling a research-ready community.

It is clear that high-quality research will lead to more effective treatments and as all hope, an eventual cure for this disorder. By forging collaborations and driving breakthrough research, FPWR intends to free all those affected from the burdens of PWS, enabling everyone to lead full and independent lives.

How the Foundation for Prader-Willi Research Operates

Under the guidance of FPWR’s Research Team and Scientific Advisory Board, and through a carefully managed grants process, FPWR selects research projects based on the collaborative input of researchers and parents, choosing projects that are both scientifically meritorious and highly relevant for individuals with PWS and their families.

Going forward, FPWR plans to take an increasingly directed approach to accelerate development of new therapies for PWS. FPWR has added to its current world-class grant program an active translational research program aimed at streamlining the therapeutic development path. The grant program will continue to fund highly innovative, early stage and basic science studies, while the translational research program will focus on efficiently transforming the most promising approaches into new therapies. Shorter-term goals of evaluating existing approaches to improve health and quality of life will be balanced with support of longer-term, potentially transformative therapeutic development.

To date, FPWR has committed more than $7,000,000 to support PWS-related research. More than 120 research projects have been funded since 2003, covering these topics:

- the genetics and pathophysiology of PWS
- the development of mouse models of PWS
- hunger, obesity and reward circuits of the brain
- the development and testing of new therapies for PWS
- understanding sleep disturbances in PWS
- understanding and treating clinical complications of PWS
improving academic and learning skills for children with PWS

Research funded by FPWR has been published in top medical journals, including Nature Neuroscience, Proceedings of the National Academy of Sciences, Molecular Cell, PLoS One, Endocrinology, and Human Molecular Genetics.

For more information on the Foundation, grants and the research, please visit: www.fpwr.org

Opportunity and Summary of Position

As FPWR has grown in size, complexity and financial requirements, the need for proven business leadership and the urgency in raising the necessary capital to aggressively drive the research agenda are at an all-time high. The Board has decided to launch a national search to find a Chief Executive Officer who can skillfully position and lead the Foundation through this crucial next phase. The CEO will need to identify promising funding sources with the capacity, passion and vision to support FPWR’s research strategy, including a target of $27M over the next five years.

She/he must drive a high impact development strategy. The CEO must nurture the existing fundraising platforms, while developing new pipelines beyond the friends and family networks. This requires a leader who can successfully inform, engage and develop these funding sources, building credibility and trust. This next growth stage will require a data and metrics-oriented leader, someone with proven experience establishing the key performance indicators, communicating them with the team and holding the organization accountable.

FPWR utilizes a virtual workforce today and finding a leader who understands how to hold virtual teams accountable and drive a positive, collaborative culture across such an organization is important. The successful candidate will be exceptional in managing growth, while advancing the mission with greater velocity and greater resources and simultaneously balancing the resources/realities of an early stage not-for-profit operation with business sustainability.

As breakthroughs in genetics and other areas of study create new opportunities to address PWS, the Foundation is positioned ideally to guide and catalyze a new wave of translational research. Communicating this focused research effort, as well as the grant program, to the right audiences and forging the appropriate partnerships to encourage and engage the scientific community and business partners will be another point of emphasis for the CEO. Utilizing exceptional relationship building and communications skills, this executive will facilitate the dissemination of information about PWS, treatment and its grants program in order to support and inspire ingenuity in research.

Skilled financial guidance as well as the ability to use technology to effectively connect and leverage the resources of the Foundation and strategically collaborate with an exceptional research team will be key responsibilities. FPWR’s CEO will need to be a strong, and passionate advocate for PWS research in the industry, someone comfortable serving as the voice and face of the Foundation and compelled by delivering results with a sense of urgency equal to, if not greater than, the parents of those facing the challenges of PWS in their lives.
The Role of the Chief Executive Officer

Reporting to the Board of Directors, the Chief Executive Officer will be responsible for effective financial and operational leadership, while instilling a culture of accountability across the Foundation. This leader will have demonstrated experience in successfully building or scaling early stage businesses or organizations with research as a core element/competency. Strategic business planning and follow-through are needed, along with the ability to adapt and leverage emerging opportunities. Attention to culture, community and mission must also be a continual focus. This leader will bring experience developing and implementing strategic plans, performance measurements and management controls, while building trust and credibility across a broad stakeholder group.

Fundraising, finding the capital and identifying collaborative efforts to advance research for PWS will be priorities for the CEO. There needs to be a focus on the cultivation, solicitation, and stewardship of major gift prospects and a proactive approach to exploring creative partnership constructs with other rare disease organizations or foundations to share the risk and maximize resources. She/he should have the expected stature, intellect, and professional acumen to serve as the strategic leader and architect in effectively growing and diversifying the Foundation’s philanthropic support. The CEO will lead and position FPWR so it is seen as a vibrant, sustainable organization built to last with a strong funding model. The Foundation aspires to generate game-changing, disease-ending research and highly effective therapies. The CEO will be the leader inspiring the team and creating urgency across all activities, especially with FPWR’s ultimate goal of enabling research to eliminate the challenges of Prader-Willi Syndrome.

Goals and Objectives

During the first 12 to 24 months, the CEO will be expected to achieve the following:

- Advance the message of FPWR for the increased funding necessary to support the research strategy
- Deliver revenue growth to sufficiently fund the research plan objective of at least $5 million per year. This includes cultivating an existing database of donors, developing new major gift opportunities and creating foundations and pharma/biotech/research collaborations.
- Provide strategic leadership and establish priorities and budgets, with a focus on optimizing team performance, operational execution, and planning for long term organizational growth.
- Build credibility and have sustained, regular dialogues with the FPWR research community.
- Elevate the profile of the Foundation and engage new researchers, business partners, investors and talent to advance the FPWR agenda to a higher level in all activities.

**Additional responsibilities include:**

- Advocate for increased support from funders, research partners, state and federal governmental agencies, and other key influencers.
Develop the financial controls and budgets, balancing what needs to happen operationally, without an over-emphasis on policies.

Deliver on the objectives outlined in the Scientific Research Plan that was created in 2016 as well as the overall Strategic Plan that was created in 2017.

Develop and implement a multi-faceted communications plan to build awareness, alignment and support throughout the various networks and constituencies. Includes traditional and social media communications.

Provide leadership for FPWR team, focusing on strategies to maximize team performance, and develop and recruit high caliber talent to support organizational growth. Maintain an effective structure that optimally supports the organization to meet the goals of its mission.

Develop a strong relationship with the Board, especially as it relates to the development and implementation of strategic plans, and regularly report on advocacy outcomes.

QUALIFICATIONS

Education

A bachelor’s degree and a master’s degree in business administration, healthcare administration, or related scientific field are required.

Experience and Skills

- Ten plus years relevant management experience, including fundraising, ideally with an organization with a complex or rare disease research component. Should have served as a leader/influencer of a successful, innovative organization where entrepreneurial drive and an inherent sense of urgency were demonstrated.

- Not-For-Profit, early stage or rapidly scaling organization experience is needed, with research as a key component of the business. Rare disease, biotech, pharmaceutical or relevant healthcare experience will be considered.

- Significant experience in financial management, with sufficient financial acumen and business literacy to make strategic decisions in allocating resources for emergent and current needs and provide overall stewardship for FPWR.

- Organizational skills with experience establishing and managing business processes to track and report out the allocation and impact of research and other investments. Experience managing systems conversion or deploying new technologies a plus.

- Ability to effectively communicate breakthrough ideas based upon scientific research. Must have the personal drive and interest to learn about the advances being made in PWS research or related outcomes from other research that could be influential to FPWR.
• A track record of developing productive relationships with member volunteers, medical leaders, researchers, and/or scientific faculty; a demonstrated ability to creatively engage and motivate member volunteers, donors, and prospects; an ability to inspire confidence with internal and external constituencies.

• Developed innovative strategies to identify and engage pipelines of new prospects to further research.

• Demonstrated understanding of public policy, community mobilization, effective media communications, brand-building campaigns and grassroots outreach.

• Strong communication skills: ability to lead meetings, deliver presentations, give speeches and represent FPWR to external audiences.

• Excellent written and oral communication skills; persuasive communicator with the ability to effectively build consensus among multiple stakeholders.

Personal Characteristics

• Focused, resourceful, hands-on leader who thrives on the opportunity to lead a high-performance and impactful organization.

• Driven by excellence and results; by nature, a supportive, collaborative, inclusive individual with an ego under control and impeccable values. Imparts trust and integrity and guides others in the same vein.

• A bright, articulate individual who fosters interest and engagement with everyone he/she meets. Operates with a sense of partnership and able to gel quickly within the organization as part of an evolving team.

• Team oriented and can pivot quickly.

• Strong interpersonal skills to work effectively with volunteers, boards, and the public. Straightforward, shares information easily; listens as well as offers advice; respects the abilities of others.

• Diplomatically relentless and able to work resourcefully and comfortably with strong-willed personalities and egos.

• Operates as a mature, grounded, and credible professional who builds relationships naturally.

• Able to think and act like an entrepreneur, but experienced in how larger organizations function.

• Openness to change and the capacity to affect change; an aptitude for, and the ability to, move agendas forward while dealing with differing levels of ambiguity.
Procedure for Candidacy

Nominations and resumes should be submitted in confidence to the Foundation for Prader Willi Research CEO search team of Rachel Polhemus and John Fazekas at:

FPWR-CEO@WittKieffer.com

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