



An Executive Search by The Angeletti Group, LLC



The Opportunity

The Angeletti group invites nominations and applications for the role of Vice President of Development of EB Research Partnership. EB Research Partnership (EBRP) is on a mission to cure Epidermolysis Bullosa (EB) by 2030 and pioneer a path for the more than 400 million people affected by rare diseases worldwide. Its innovative Venture Philanthropy Model transforms traditional nonprofit funding by reinvesting financial returns from successful research projects into new initiatives, ensuring a sustainable cycle of impact.

With a proven track record – investing \$70+ million in research in the last seven years, funding 140+ projects in over 20 countries, and driving two FDA-approved treatments – EBRP is laser-focused on delivering healing, innovation, and breakthroughs and is setting a new standard for disease-focused philanthropy.

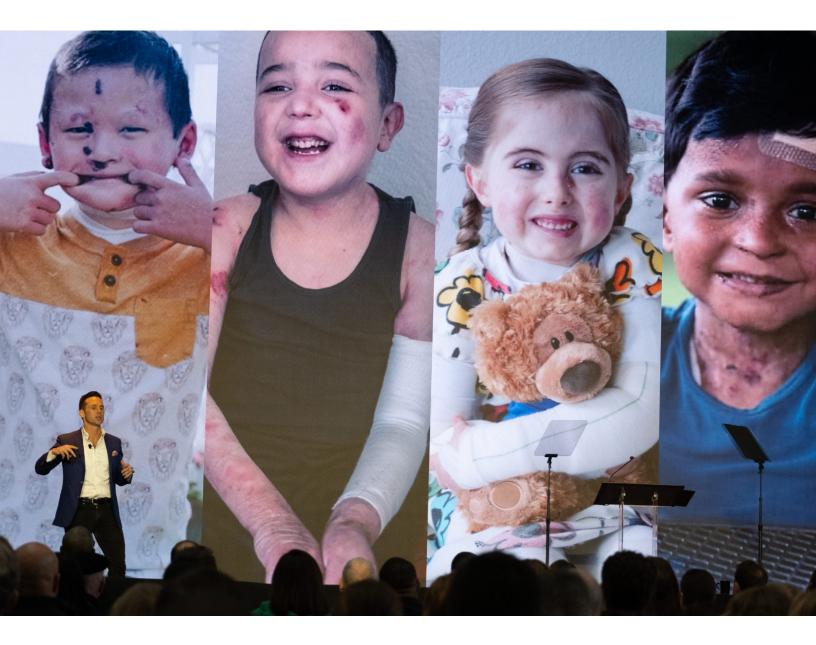




Reporting to the CEO, the Vice President of Development will be dynamic, strategic, and mission-driven and will lead EBRP's fundraising efforts, drive revenue growth, and expand its donor network. This is an unparalleled opportunity to collaborate with an exceptional leadership team, transform lives, and be part of a movement that is revolutionizing how nonprofits operate.

EBRP: A Bold And Impact-Driven Organization

Founded in 2010 by a dedicated group of parents and Jill and Eddie Vedder (Pearl Jam), **EB Research Partnership** is the largest nonprofit in the world dedicated to funding research to treat and cure Epidermolysis Bullosa, a group of devastating and lifethreatening genetic skin disorders that affect children from birth. Today, there is no cure for individuals battling EB, but EB Research Partnership is dedicated to changing that. Its work has been recognized by Harvard Business School, Yale University, MIT, and the Milken Institute for pioneering a new model of philanthropic investment that is reshaping how to cure diseases. EBRP is at a pivotal moment as it evolves its venture capital inspired funding model to expand beyond EB and create a blueprint that can cure thousands of other rare diseases.



The EBRP Mindset: A Culture of Impact

EBRP doesn't just fund research - it reinvents the way cures are found. The EBRP team is driven by urgency, fearless innovation, and an unshakable commitment to EB families. EBRP operates with the mindset that impossible is just an opportunity waiting to be disrupted.

- **It Hustles for a Cure:** Every moment matters. EBRP works with urgency because EB families can't wait.
- It Thinks Big and Takes Action: EBRP challenges the status quo, embraces risk, and pushes boundaries to accelerate impact.
- It Builds Game-Changing Partnerships: Cures don't happen alone. EBRP collaborates with researchers, investors, and donors to fund life-changing treatments.
- It is Data-Driven: Every dollar raised is maximized for impact. EBRP invests in what works and tracks progress relentlessly.
- **It Cares Deeply:** EBRP's work is more than a job. It shows up for EB families every single day, driven by purpose and passion.

EBRP is a fast paced, results-driven, and impact focused organization. It moves quickly, measures outcomes, and refines its strategies to turn hope into reality.



The EBRP Mission:

Building a Faster Path to Curing Epidermolysis Bullosa.

EB Research Partnership (EBRP) is the largest global organization dedicated to funding research to treat and cure Epidermolysis Bullosa (EB).

EB attacks the skin – not just the skin we see, but also the skin inside of us. The resulting wounds never heal. Disfigurement, blisters, bleeding, and ever-present pain follow.

It is lethal for many of the children born with it.

But that is changing. Through the hard work of scientists, we're on the precipice of a cure. Not only that, but the methodology we've pioneered to develop a cure holds the key to helping millions suffering from rare diseases.

Read about EBRP's latest breakthroughs

Learn more about EBRP's mission



The Venture Philanthropy Model: A Game Changer In Nonprofit Funding

EB Research Partnership utilizes an innovative business model of venture philanthropy. It doesn't just write checks - it operates like a venture capitalist with a focus on a different kind of ROI: **Return on Impact.** When EBRP funds a research project, any revenue from a commercially successful therapy or product is then directed back to the organization to fund additional research. This self-sustaining funding model allows EBRP to not only help to cure EB but also creates a model that can be replicated across thousands of other rare diseases. The EBRP model ensures that:

- Every dollar donated is multiplied, creating a self-sustaining research pipeline.
- EBRP has a financial stake in success, helping to ensure that promising treatments don't stall due to lack of funding.
- Its work extends beyond EB research investments fuel treatments for thousands of other rare diseases.

This trailblazing model has positioned EBRP as one of the most innovative nonprofits in the world, proving that philanthropy can be both impact-driven and financially sustainable.

> Explore how the EBRP model is disrupting philanthropy

THE VICE PRESIDENT OF DEVELOPMENT

The Vice President of Development will serve as the chief architect of EBRP's fundraising strategy, driving transformational philanthropic support. This senior leader will report to the CEO and work closely with the Board of Directors and volunteers. Alongside a strong and startup-minded team, the VP of Development will be charged with leading and growing the development team and fundraising functions within EB Research Partnership. The VP of Development will bring strategic vision, a data-driven approach, and a passion for disruptive innovation. The ideal candidate is both a builder and a doer, capable of leading a team while also driving frontline fundraising efforts. They will be passionate about the mission, deeply engaged with the work and highly accountable. EBRP operates in a dynamic, fast-paced environment that requires resilience and adaptability. The ideal candidate will bring a polished, innovative approach while embracing the organization's disruptive and forward-thinking mindset.



KEY RESPONSIBILITIES

STRATEGIC LEADERSHIP AND FUNDRAISING

- Develop and execute a comprehensive fundraising and marketing plan aligned with EBRP's bold, high-energy brand identity that will leverage opportunities for planned giving, annual fund, social media, cause marketing, and community events.
- Expand and diversify EBRP's donor base with a focus on major gifts, institutional funding, corporate partnerships, and venture philanthropy investors.
- Collaborate with the Board and Development team to Identify, cultivate, solicit, and steward relationships with high-net worth individuals, six- toeight figure donors, foundations, and corporate partners.
- Serve as a lead fundraiser, partnering with the CEO and EBRP team to secure transformational gifts and create compelling donor engagement opportunities through presentations, proposals, grants, impact reports, website, and social media.
- Work closely with the CEO to transition and maintain key donor relationships, ensuring seamless engagement and ongoing philanthropic support.
- Oversee and enhance national EB Research Partnership-led signature special events and communityorganized initiatives.
- Partner with the Board Chair and the CEO to develop a high-performing fundraising Board, equipping members

with tools to serve as strong advocates and fundraisers in alignment with EBRP's high-impact goals.

- Assess and strengthen the fundraising team structure, ensuring a highperformance, growth-oriented culture while identifying key hires necessary for long-term sustainability.
- Foster a culture of continuous improvement, collaboration, and excellence aligned with the mission and values of EB Research Partnership.
- Recruit, develop, and retain a best-inclass team to achieve ambitious goals.

OPERATIONAL EXCELLENCE AND DATA-DRIVEN STRATEGY

- Implement best-in-class donor management systems to track donor engagement, retention, and giving trends across all revenue streams (individuals, foundations, corporations, and Board members) in partnership with the finance team, CEO, and development staff.
- Develop clear KPI's and performance metrics to evaluate fundraising progress and optimize strategy.
- Collaborate with the marketing team to craft compelling storytelling, impact reports, and donor materials that align with EBRP's voice.

QUALIFICATIONS AND PREFERENCES

 A mission-driven leader with a deep commitment to EBRP's vision and experience in healthcare, medical research, or rare disease philanthropy.

- A proven fundraiser with a track record of cultivating, soliciting, closing, and stewarding six to sevenfigure+ gifts, and capital campaign, annual fund, leadership, and board management experience.
- Minimum of three to five years of experience in fundraising or a related field, preferably in healthcare, rare disease philanthropy, or children's cause organizations.
- A creative, entrepreneurial, and strategic mindset with the skills and experiences necessary to think big, move quickly, and see opportunities where others see challenges.
- Sophisticated personal presence, exceptional interpersonal skills, and a proven ability to inspire donors, engage high-profile philanthropists, and develop corporate partnerships.
- Resilient and compassionate with a high level of emotional intelligence and ability to balance high-performance fundraising with empathy for patients and families who are living with EB.
- Availability to travel up to 20% annually, primarily within the U.S., with occasional international travel.
 Some evening and weekend work at special events is required.
- Experience with CRM tools and systems; Raiser's Edge preferred.
- Excellent written and verbal communication skills.
- Bachelor's degree required; advanced degree or relevant certifications preferred.



APPLICATION PROCEDURE

Applications will be accepted until the position is filled but candidates are encouraged to apply before April 25, 2025. To be considered, candidates should submit a statement of interest and resume to The Angeletti Group at search@theangelettigroup.com.

Nominations and confidential inquiries can be made to:

The Angeletti Group 365 South Street - Suite 100 Morristown, NJ 07960 (973) 540-1400 search@theangelettigroup.com

Salary commensurate with experience and will range from \$150,000 - \$225,000.

EB Research Partnership is an Equal Opportunity Employer and does not discriminate on the basis of age, color, national origin, ethnic origin, citizenship status, disability, race, religion, creed, gender, sex, sexual orientation, gender identity and/or expression, marital status, veteran status, or any other characteristic protected by federal, state, or local law in its employment policies. In addition, EB Research Partnership will provide reasonable accommodations for qualified individuals with disabilities.