



## National Director of Development

### ABOUT CURE DUCHENNE

Duchenne is one of the more common yet severest forms of muscular dystrophy that affects more than 300,000 children and young adults worldwide. Duchenne muscular dystrophy, or simply Duchenne, is a genetic condition that almost exclusively affects boys, usually diagnosed between the ages of three to six. Most affected boys around age 12 must deal with progressive muscle weakness that necessitates power wheelchairs for mobility into their adulthood. Most young adults do not live past their mid-twenties.

CureDuchenne is the world's leader in the search for a cure for Duchenne. This nonprofit organization was founded in 2003 by Debra and Paul Miller after their only son Hawken was diagnosed with Duchenne. This diagnosis sent the Millers on a single-minded mission: to cure Duchenne. In its first year alone, CureDuchenne raised \$1.3 million in donations for research, including a \$250,000 gift. Over time, the once small-scale organization helped to create the first Duchenne-specific physical therapy program and funded the first-ever FDA approved drug for Duchenne patients. Within 16 years, CureDuchenne redefined the level of care for families, built a community for all those impacted by Duchenne, and remains dedicated to finding a cure for this devastating disease.

#### Key Facts

- \$5 million annual budget
- 20 staff with offices in five states
- 4 development staff positions
- \$4.5 million raised in FY 2020; \$5.3 million raised in FY 2019
- Over 30,000 donors nationwide

#### Mission

*CureDuchenne's mission is to save this generation of children and young adults with Duchenne muscular dystrophy.*

#### Visit



CureDuchenne breaks the traditional charity model by utilizing passion and business acumen to build an innovative venture philanthropy model that fuels groundbreaking research, early diagnosis, and treatment access. CureDuchenne combines fundraising with venture philanthropy, leveraging donor dollars to maximize support for research into effective treatments for Duchenne patients and provide care, education, and support for patients and families.

CureDuchenne Cares is an interactive education and outreach program where patients, families, and healthcare professionals can get information, resources, and training to improve patients' lives. Hosting over 20 workshops and conferences nationally, CureDuchenne Cares is free for families and caregivers. DuchenneXchange is an innovative, collaborative digital social platform for patients, families, caregivers, and learned advocates to connect and share a wealth of knowledge. DuchenneXchange provides the most current education, peer support, clinical trial information, and news in a neutral, friendly, and safe community environment.

CureDuchenne Ventures, the investment arm of CureDuchenne, funds ground-breaking research into next-gen drug and treatment development and ensures their investment and funding partners share their fundamental goals of accelerating innovative research to hurry treatments to children who need it the most. The success of these research projects amplifies their own biotech investments, allowing them to reinvest even more money back into Duchenne research. With transparency as a core value, CureDuchenne ensures 90% of their investment proceeds are redeployed into expanding these research programs.

As of 2018, CureDuchenne's portfolio includes 16 wide-ranging projects with four successful exits. In only five years, CureDuchenne has provided seed funding that has leveraged more than \$2 billion in follow-on investment from venture capital, biotech, and pharmaceutical companies to fund research. In June 2019, Exonics Therapeutics, one of their venture philanthropy collaborations, was purchased by Vertex Pharmaceuticals, a leader in pioneering rare disease research, the same company that the Cystic Fibrosis Foundation in 2014 sold their royalty rights for treatments for \$3.3 billion.

Today, CureDuchenne is recognized as the global leader in research, patient care, and innovation for improving and extending the lives of those with Duchenne. With an ultimate vision to cure Duchenne permanently, CureDuchenne continues to rapidly move and build a future that will ensure quality care to Duchenne families and fuel biomedical research impacting future generations.

We invite you to learn more at [www.cureduchenne.org](http://www.cureduchenne.org)



## THE POSITION

The amazing success and growth of CureDuchenne is undeniable. Every one of its donors and investors has played an instrumental role in providing significant philanthropic support to propel its boundless growth. Serving in a frontline position, the National Director of Development will play a critical role in elevating the CureDuchenne's philanthropic revenue streams. This dynamic, entrepreneurial donor strategist will build on CureDuchenne's existing success with events-based fundraising and provide overall direction for its national major and principal gifts programs that help to ensure the advancement and vitality of CureDuchenne. The National Director of Development, a skilled relationship builder, will identify, qualify, solicit, and steward strategic gifts to support biomedical research support and funding. This position reports to CureDuchenne's CEO and Founder. The ideal candidate will be a mission-driven leader who thrives in a role that is both autonomous and highly collaborative, brings maturity and authenticity in engaging with affluent communities, and exhibits the highest level of trust, confidence, and professionalism. This position will be based in CureDuchenne's national headquarters in Newport Beach, California.

## RESPONSIBILITIES

The National Director of Development will have the following primary responsibilities:

- Plan, develop, and execute a national cultivation plan that will generate major and principal gift revenue from high-level, sophisticated donors and prospects nationally.
- Build and maintain a portfolio of at least 75-100 major and principal gift prospects, with capacity of \$10,000 and greater.
- Provide oversight of the signature events team to leverage successful donor events into pipelines for transformative partnership opportunities.
- Serve as a trusted, respected senior philanthropic advisor to CureDuchenne's CEO and Founder as necessary.
- Work closely with board members, top donors and prospects, and volunteers to identify new major donors, increase personal giving, and train and assist in CureDuchenne's fundraising efforts.
- Assist in setting and meeting annual revenue goals for major and principal gifts prospects in partnership with the CEO and Founder.



- Cultivate planned giving relationships with new and existing donors in close coordination with the CEO and Founder.
- Travel regularly to establish relationships with donors and prospects through planned meetings and CureDuchenne's signature events.

## MAJOR OBJECTIVES

Within the first 12 to 18 months, the National Director of Development will achieve the following major objectives.

- Cultivate high-net worth donors from the assigned portfolio, ensuring at least three to five major gifts in the first year, with a goal of raising at least \$2 to \$3 million annually within the next three years, specifically from new donors or donations that are incrementally above a donor's current contributions.
- Identify, qualify, cultivate, solicit, and steward major gift donors and prospects that meet and exceed all activity metrics and revenue goals.
- Develop high-quality cultivations materials where donors and volunteers can see how their money is making a difference in fueling biomedical research and care support.
- Build strong, collaborative working relationships with each member of the CureDuchenne team that inspire trust and confidence.

## QUALIFICATIONS

The ideal candidate will possess most of the following qualifications:

- A deep, passionate commitment to CureDuchenne's mission.
- A minimum of five to seven years of successful fundraising experience in managing high-level donor and prospect relationships with a proven record of soliciting major gifts at the six-figure or greater level. Experience fundraising in a healthcare-related environment would be an advantage.
- A collaborative, energetic, self-starter with the ability to partner closely with sophisticated, affluent donors and investors who may have only engaged with an organization through their signature events.
- A strong listener with integrity, tact, and sensitivity to engage well with a diverse range of donors, volunteers, patients, and families.
- Excellent communication and verbal skills with a persuasive ability to generate support on



behalf of CureDuchenne.

- A capacity to acquire an understanding of Duchenne muscular dystrophy, as well as issues surrounding biomedical research, drug development, clinical studies, and patient services.
- Ability to work flexible hours and travel as necessary, including some evenings and weekends.
- A bachelor's degree from an accredited university or college.

## APPLICATION

CureDuchenne has retained Campbell & Company to conduct this search. The team for this project includes Dan Nevez, Senior Consultant, and Emily Thompson, Associate Consultant. CureDuchenne offers a highly attractive compensation and benefits package. To be considered for this opportunity, please send a letter of interest and resume to:

### EMILY THOMPSON

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*CureDuchenne is an Equal Opportunity Employer.*



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