



## Citizens United for Research in Epilepsy (CURE)

CEO

Chicago, IL

### EXECUTIVE SUMMARY

Citizens United for Research in Epilepsy (CURE), the leading nongovernmental agency committed to finding a cure for epilepsy through the funding of long-range, cutting edge research, seeks nominations and applications for its next Chief Executive Officer. Poised to build upon a 20-year legacy of dedicated research funding and strong and continuing partnerships, CURE seeks a CEO who will elevate its reach nationally and internationally to ensure research toward a cure remains an international priority and the advancement of that research transforms and saves millions of lives.

CURE has raised more than \$60 million toward **epilepsy research** since its inception in 1998, placing the organization on the front lines of new knowledge in the treatment of epilepsy. Translating its fundraising into action, CURE has awarded over 220 cutting-edge projects in 15 countries around the world and consistently commits more than 88% of its expenditures directly to its mission, a track record that results in gold-star ratings in nonprofit evaluative tools like Charity Navigator. This smart and effective investment in science has consistently brought new attention and talent to the field. The epilepsy research community is strong and poised to make true strides towards eliminating seizures and their consequences, but more is needed. One in 26 people will develop epilepsy in their lifetime and the greatest burden of impact is on children. Yet, while epilepsy affects more people than multiple sclerosis, cerebral palsy, muscular dystrophy, and Parkinson's combined, it receives fewer federal dollars per patient than each of these. Through collaborative evaluation and expansion of CURE's Signature Programs, strategic identification and implementation of new mission-consistent initiatives, alignment of field resources and programs, and elevation of CURE's brand to increase its community of supporters and strategic partnerships, the next CEO at CURE is positioned to advance work that will affect millions of lives for the better.

The new CEO will be a compassionate leader who is deeply committed to working with families affected by epilepsy, who understands their stories and lived experiences and has the ability to reflect this in CURE's fundraising and strategic priorities. With an intuitive understanding of the nuances that exist within this community, s/he will promote a vision for the sector that elevates the profile of the disease and critical research associated with it. The CEO will work collaboratively with the board, staff, and community stakeholders to develop and execute an organizational development and fundraising strategy for CURE and will flawlessly steward funding relationships. Joining a small and highly dedicated team committed to finding a cure for epilepsy, and in partnership with the Chief Scientific Officer, the CEO will leverage CURE's leadership in innovative research and position to build strategic partnerships across a wide range of non-profit, governmental, advocacy and industry forums. Internally, s/he will



have operational, financial and staff oversight, promoting a culture of collaboration and effectiveness and ensuring the team is continually moved by the work.

The successful candidate will be an inspiring, compassionate, strategic, and emotionally intelligent leader who is committed to the advancement of epilepsy research. S/he/they will have proven and successful experience fundraising combined with the ability to manage and mentor a results-oriented team that holds the work of the organization to the highest standards. S/he/they will be committed to the field of epilepsy as a whole, will inspire alignment of resources and relationships as the leading public representative of CURE, and will honor and engage communities personally affected by the disease in the ardent fight for its eradication.

This search is being conducted by [NPAG](#). Application instructions can be found at the end of this document.

## ORGANIZATIONAL OVERVIEW

CURE was founded by a small group of parents of children with epilepsy who were frustrated by their inability to protect their children from seizures and the side effects of medications. Unwilling to sit back and wait, they joined forces to share stories and support and search for a cure. This early group was spearheaded by Susan Axelrod, who leveraged these families' connections, resources, and experiences in the early years of CURE to create what has now become a 20-year legacy of funding research.

In 2000, CURE co-sponsored the National Institutes of Health Conference, *Curing Epilepsy: Focus on the Future in March of 2000* –the first of its kind to focus on a cure for epilepsy. In addition, CURE was one of the key sponsors involved in shaping the direction and outcome of a newly commissioned report released in March 2012, *The Public Health Dimensions of the Epilepsies*. The organization was instrumental in the creation of the NIH Epilepsy Research Benchmarks, which were created to help guide the community toward a cure, and also invests in the pipeline of future epilepsy researchers through various mechanisms that support young investigators

CURE has led a dramatic shift in the epilepsy research community from simply treating seizures to enhancing understanding of underlying mechanisms and causes, so that cures and preventative strategies can be found. CURE's research program is cutting-edge, dynamic and responsive to new scientific opportunities and directions through both investigator-initiated grants and innovative scientific programs and initiatives.

As the pioneer in **Sudden Unexpected Death in Epilepsy** research, CURE has awarded more than \$4 million to over 40 investigators since 2004. In 2012, CURE launched the **Infantile Spasms (IS) Research Initiative**, a team science approach to this rare but devastating epilepsy syndrome, which is designed to accelerate discovery and advance a new, innovative therapy into the clinic. An investment of \$4.5 million in teams of investigators at multiple institutions around the country has encouraged collaboration and multi- disciplinary approaches to advancing this critically important science

In May 2014, CURE launched a 3 year pilot program, the **Epilepsy Genetics Initiative (EGI)**. With an initial \$1.25 million in funding, EGI created a comprehensive, interactive database where patients can have their genetic data



repeatedly analyzed in an effort to identify the cause of their epilepsy. This data will also be made available to epilepsy researchers in an effort to find new causes of epilepsy and use these findings to guide treatment. EGI brings patients, medical professionals, and researchers together in a mutually beneficial way to advance the genetics of epilepsy and help create a culture of personalized medicine for people with epilepsy.

In 2015, CURE secured a **\$10 million grant** over five years from the Department of Defense, Psychological Health and Traumatic Brain Injury Research Program and launched a new research program dedicated to epilepsy research in veterans with traumatic brain injury. The Post-Traumatic Epilepsy Initiative is a team science multi-disciplinary program that will expand the knowledge around the types of injuries that predispose the brain to epilepsy, as well as develop new models to study epilepsy resulting from brain injury.

Today, with the leadership of Chief Scientific Officer Dr. Laura Lubbers, CURE's internal science team, is committed to leading the organization's efforts, identifying new opportunities and stewarding ongoing research investments. A Scientific Advisory Council comprised of five esteemed epilepsy specialists and more than 300 scientist volunteers, also lend their energy and expertise to CURE's research program. A Lay Review Council made up of volunteers who have a special interest in understanding epilepsy research participates in CURE's grant review process to ensure the stakeholder and patient point of view is always prioritized.

The last few years have brought a number of promising research trends. Collaboration has increased throughout the field and the community of epilepsy researchers is strong and growing. There have been meaningful strides in driving accountability and an increase in epilepsy-related research publications. Most importantly, recent scientific advances have provided renewed hope that a disease-modifying therapy or cure is within reach. Given these promising developments, CURE continues hold a place of prominence in the sector by building a more advanced organizational and research structure that engages a broad range of interested families nationally and invites them into the pursuit for a cure for epilepsy, undergirding its influence and impact in epilepsy research.

## OPPORTUNITIES AND CHALLENGES FACING THE NEW POSITION

CURE's commitment to funding research to find a cure for epilepsy by promoting and funding patient-focused research has been a hallmark over its twenty years of service. Recognizing the increasingly complex demands of the sector and the need to balance external demands with a strategic growth plan, focus on sustainability, and invest in internal capacity to support its research and programs, this CEO transition is an exciting opportunity for an entrepreneurial professional to lead an organization through a period of changing demographics, research and funding realities. The Board of Directors is deeply committed to a strategic assessment of the organization and outlining the opportunities that lay ahead. This position provides an exciting opportunity for the successful candidate to work collaboratively with CURE's internal and external stakeholders, alongside the medical and scientific leadership in the field, to advance patient-focused research to find a cure of epilepsy.



The CEO's responsibilities include:

### Vision and Leadership

Working in close partnership with CURE's Board of Directors, staff, and founding partners the CEO will develop and articulate a vision for an organizational and funding strategy that builds on CURE's existing funder support and core research legacy. The new CEO will understand the field of epilepsy and work collaboratively with advocates and partners to raise awareness of the disease with the goal of enhancing funding and resources in pursuit of innovative research and a cure. The new CEO will advance a vision for CURE that expands the scope of its research funding and engages deeply with those affected by the disease. This includes creating a clear plan to elevate CURE's role in the field of epilepsy and working in partnership with peer organizations to raise awareness and harness the power of governmental resources, the promise of research and academic partnerships, and the will and wishes of families affected by epilepsy nationally and internationally.

### Develop and Support a Strong Team

The CEO will be a natural mentor and coach, building a culture in which team members feel valued, recognize pathways for growth, and are rewarded, retained, and developed as individual contributors. S/he will also review current internal organizational needs and opportunities to help build momentum and capacity for the future direction of CURE. This will include overseeing effective operational management and fiscal responsibility. The CEO will help develop an organizational design that ensures workload and workflow is maintained through the various cycles of external activities of CURE. S/he will help to articulate and implement CURE's vision internally to motivate staff and develop an organizational culture that is supportive of the organization's mission.

### Develop a Strategy for Fundraising and Resource Development

The CEO will work with the Board to nurture existing relationships while cultivating new sources of revenue. S/he will work to strengthen and diversify strategic funding sources and grow revenue over the next five years. While CURE enjoys support from a core group of donors and advisors, the CEO will work with the director of development and the chief scientific officer to identify and expand this donor base. The CEO will work to expand CURE's reach by generating new sources of revenue from individuals, corporations and foundations, by creatively exploring funding opportunities through collaboration with other organizations.

### Community Relations & External Partnerships

The incoming CEO will be an effective steward and partner with others in the field of epilepsy to ensure that the field is aligned and supportive of advancement in research to find a cure for epilepsy. As chief spokesperson, the CEO will be expected to navigate and maintain mutually beneficial relationships that provide long term benefits for CURE. Specifically, s/he will develop opportunities to expand the organizations profile through broad and diverse engagement with professional associations, advocacy organizations, prospective partners, corporate and nonprofit partners, public officials, policymakers, the media and the public-at-large.



## QUALIFICATIONS OF THE IDEAL CANDIDATE

While no one candidate will embody all the qualifications enumerated below, the ideal candidate will possess many of the following professional and personal abilities, attributes and experiences:

- Commitment to and respect for CURE's mission and history. Familiarity with the disease and medical research context and demonstrated skills and development and fundraising is desired. A solid business mind paired with sound judgment and a commitment to CURE's values, desired. A Bachelor's degree is required; an advanced degree in a related field is preferred.
- A strategic and comprehensive approach to planning and decision making; the ability to lead an organization through periods of growth and change, requiring creative and innovative solutions to on-the-ground challenges. Ability to recognize and capitalize on growth opportunities while staying mission-aligned.
- A successful track record in identifying and securing private and public funding through diverse sources including government relationships and fundraising. A commitment to maintaining current funders and cultivating new donors, and a history of successfully taking organizations to the next level of sustained philanthropic support. Ability and enthusiasm to involve and solicit the Board and other community leaders in the solicitation process.
- An illustrated understanding of sound board governance, gained from direct experience working with professional boards or through active board involvement. Maturity and wisdom to engage and leverage a board's diverse knowledge and expertise to hone the organization's strategic direction.
- A management style that embodies respect, transparency, teamwork and accountability. Flexibility, humility and sense of humor; ability to share credit and spotlight others' contributions.
- Exceptional written and verbal communication and interpersonal skills with a high emotional IQ. Ability to understand, translate and adapt content for multiple audiences.
- A leadership style that supports staff of different cultural and educational backgrounds.
- Gravitas, intelligence, compassion, and executive presence to represent CURE to a variety of constituencies.
- A commitment to the mission of improving patient outcomes through enhanced research, education and collaboration.



## TO APPLY

More information about the CURE may be found at: <https://www.cureepilepsy.org/>.

Due to the pace of this search, candidates are strongly encouraged to apply as soon as possible. Applications including a cover letter describing your interest and qualifications, your resume (in Word format), and where you learned of the position should be sent to: [CURE-CEO@nonprofitprofessionals.com](mailto:CURE-CEO@nonprofitprofessionals.com). In order to expedite the internal sorting and reviewing process, please type your name (Last, First) as the only contents in the subject line of your e-mail.

**CURE is an equal opportunity employer and proudly values diversity.  
Candidates of all backgrounds are encouraged to apply.**