

# Guide to Charitable Giving for People with Epilepsy

*by Jeanette B. Herting*



## Summary

During this historic economic downturn, epilepsy nonprofit organizations are increasingly doing more with less, as donors—both corporate and individual—tighten their belts. The epilepsy community needs our help more than ever, but we are less able to give what we'd like, even to nonprofits in which we believe strongly. This article offers practical advice about “giving smart” in a recession by matching our skill sets more closely to the needs of epilepsy nonprofits, analyzing which charities may be positioned to use our assistance most effectively in this challenging financial environment, looking at ways to help other than writing a check, and expanding our horizons to non-typical fundraising, networking, and advocacy activities for epilepsy.

This article neither recommends nor advises

against any particular mission or organization in any discipline; its sole intent is to give readers the tools to decide for themselves how to allocate their personal charitable resources with the most leverage. My perspective comes from almost twenty years of charitable giving in the United States and overseas to a wide variety of nonprofits, including those for epilepsy and seizures.

## What You Bring to the Table

Before you start looking at specific organizations, it's a good idea to take stock of what you have to offer. What makes you unique as a charitable contributor for both cash and non-cash gifts?

### ■ Your personal history

What's your epilepsy story? You own it and only you can articulate it in a way that's compelling and valuable to an epilepsy non-

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profit. As much as other people—doctors, researchers, policymakers, even family—may care about epilepsy as a condition, few of them have ever experienced a seizure or know what it's like to have epilepsy be a major factor in their life decisions. This real window into epilepsy, more than any other factor, helps potential donors, volunteers, and advocates understand why the nonprofit exists and why it's important that they support it. The vague notion most people have about what epilepsy is and how it relates to them now becomes a name, a face, an occupation, a family life in a hometown, just like them. The message is: we do everything you do, except with seizures.

There are as many different experiences with epilepsy as there are people. Some have had seizures since infancy; others, like me, were diagnosed as adults. Some have achieved good seizure control with medicines and/or surgery; others are still struggling to find a treatment that works for them. We all have different school, job, and family commitments. Take time to construct your one- to two-sentence "epilepsy bio."

### ■ Your passions

Even among epilepsy nonprofits, there are different focus areas. Some organizations

offer direct community services for people with epilepsy. Others are education- or advocacy-based and work at the policy level. Still others focus on medical research and new treatments for epilepsy. Some nonprofits specialize in a particular demographic, most notably children and their parents. Your most effective contributions to epilepsy philanthropy will be to an organization whose mission resonates with you personally.

### ■ Your professional skill set

The following are just a few examples of how your work experience and contacts might translate into a contribution to an epilepsy nonprofit.

**Financial.** Financial expertise is expensive. Add to that the accounting and paperwork requirements a nonprofit has, reporting on grants it's received. Nothing turns off donors faster than believing a charity has sloppy accounting practices and will misuse their donations. Save a nonprofit from having to hire someone at the market rate. Financial advisors, bankers, and CPAs lend credibility by giving advice and producing formal statements that donors and grant makers need.

**Legal.** Legal expertise, too, is an expensive

billable hours proposition. If you're an attorney or paralegal, consider doing pro bono work for an epilepsy nonprofit. Many different areas of legal expertise (e.g., employment, contracts, licensing, or insurance) may be needed, depending on the nonprofit's specific mission.

**Subject matter expertise.** Epilepsy nonprofits deal in various aspects of medicine, science, and health. Are you qualified to review a grant for medical research funding or make a scientific presentation at a conference? Could you use your policy expertise to address a discrimination issue? If you work in the medical field as a primary health care provider—nurse, physician, or physician's assistant—you can speak to the challenges of patient care. Teachers have experience educating students about other students with disabilities and could do the same with adults, too.

**Administration.** Not geographically nearby your charity of choice? Calling all receptionists, project assistants, and office managers! Today, we have the virtual front desk. You can receive email and phone calls anywhere and Web tools can keep virtual teams in touch 24x7 anywhere in the country (and overseas using Skype). Free Web-based document management tools such as GoogleDocs and DropBox allow easy document exchange and collaboration.

**Fundraising.** Fundraising is

the lifeblood of any nonprofit. If you have experience asking people for money, whether it be collecting donations for the local library or raising capital for a new business venture, your skills are essential. Technology allows many aspects of fundraising to be done remotely, although in-person visits (and your personal donor list) are very valuable. Grant writing is a great remote volunteer opportunity. For social networking enthusiasts, anyone with Facebook and Twitter accounts can raise money for a nonprofit.

**Event planning.** I cringe when I hear that an epilepsy nonprofit event cost more in expenses than it collected in donations. There's no reason for that ever to happen; event planning expertise is out there in the epilepsy community. For those of you who have event planning experience; step up to organize an epilepsy charitable event, especially for a small nonprofit, since they're the most likely to fall down here. Suppliers to event planners, including caterers, temporary staffing agencies, and facilities managers; ask how you can contribute in-kind



(with non-cash goods and services). The rest of us can host epilepsy fundraising dinners in our homes.

### **Marketing, public relations, and media.**

Whether you're an advertising account manager at an agency or a media representative for your corporation, your skills and contacts are highly valued. Journalists, public speakers, speech writers, copywriters, and new media public relations experts all have transferable talents. Product marketers help nonprofits position themselves in the charitable universe in a way consumer health donors can understand. Can you help build that epilepsy nonprofit's brand? Can you put together a press kit? Can you give interviews, or do live podcasts about epilepsy? Can you gather and publish testimonials of people with epilepsy?

**Community organizing.** Anyone who's gone up against the city council or the school board is perfect in this role. You know how to articulate an objective and get other people behind it. You reach out with ease to people you don't know and can get things done on a tiny budget. Visible business and social leaders with epilepsy can be effective community advocates. Social workers familiar with agencies that assist people with epilepsy have valuable contacts.

**IT/Web.** Information technology is another specialized, expensive skill to hire at market rate. Experts in hardware, software, wired/wireless networking, Web 2.0 technology, and site development and maintenance are

welcome. If you're a retailer or supplier in the IT field, consider donating hardware or software. Volunteers who can train epilepsy nonprofit staff to use their systems are also needed. Recently, I helped a nonprofit with a five-minute fix to an easy but not obvious software problem. The executive director told me later that I had saved their tiny nonprofit over \$500 in consulting fees.

**Trades.** Nonprofits, like all of us, appreciate handy people who can fix anything. If your expertise is plumbing, electrical, painting, even gardening, you may be able either to do repairs at the actual nonprofit site or donate supplies or equipment. When the heat goes out just hours before my winter dinner/auction fundraiser, who can I call who won't break the bank? You.

### ■ **Your network**

Who do you know who can be helpful to this nonprofit for free? More on networks below.

### ■ **Your road-tested plans**

Reinvention is expensive; recycling is cheap! If you can provide a nonprofit with a fairly foolproof template to accomplish a goal, that's a gift that keeps on giving year after year. For example, take a successful plan from your past—for example, everything and everybody you need to know to organize a local sporting event—and modify it to raise money, specifically for epilepsy.

## **How to Choose Which Epilepsy Nonprofit to Help**

Now that you've figured out what you have

to offer and where your interests lie, it's time to choose an epilepsy nonprofit and offer your help. This recession is particularly hard for those of us with epilepsy because our medical costs remain high regardless of our incomes and when we lose jobs it's more difficult for us to find new ones. Even so, your charitable gifts to epilepsy organizations are a good investment. Because they require tradeoffs of your budget and time, it's worth doing a little research first before committing. Here are some guidelines to consider.

#### ■ Look at its mission statement

Is the organization's mission clear to you? Is it a mission that you're passionate about, in which you personally believe and that you can wholeheartedly endorse? There's nothing wrong with a mission to raise awareness about epilepsy, but that's too vague. You need to be able to understand easily this nonprofit's specific reason for being and what it specifically intends to do. A good test is to try completing the following sentence from what you've learned: "This organization works in <what aspect of epilepsy> by doing <what > <for whom> <over what period of time> to accomplish <what goals, short- and long-term>."

#### ■ Look at its target market

On the recipient side, who within the epilepsy community is the charity helping, and how? Are there other nonprofits that benefit this same group? Are they competitive or collaborative? Your viewpoint as a person with epilepsy is that you just want solutions;

## How to Choose Which Nonprofit to Help

- Look at its mission statement
- Look at its target market
- Look at its charitable partnerships
- Look at its success rate
- Look at its Board of Directors
- Look at its tax status
- Look at its bottom line



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you don't necessarily care which organizations provide them.

On the donor side, from whom is this charity soliciting donations for epilepsy? Have they cultivated a healthy mix of potential donors, e.g., high-value (five- and six-figure) donors, corporate sponsorships, individuals and groups through social media promotion, in-kind giving?

### ■ Look at its charitable partnerships

Does the epilepsy nonprofit you're considering champion joint efforts with non-epilepsy charities that support conditions in which seizures also occur? *We in the epilepsy community should be thinking about how to manage and reduce seizures in general, not just seizures in people with epilepsy.* Examples include charities for autism, cerebral palsy, traumatic brain injury (notably veterans groups), even Alzheimer's. Maybe you're the right person to strengthen those connections between nonprofits.

### ■ Look at its success rate

Success at a nonprofit organization, as in a for-profit business, can be defined in many different ways. Numbers of services provided to people with epilepsy, of laws passed that benefit people with epilepsy, or of med-

icines approved that reduce seizures and make living with epilepsy easier. Success can also be a percentage increase in public awareness or in fundraising by a certain dollar amount. Just evaluate the data in light of the mission statement and goals from the previous year and ask yourself, "Does what I'm reading make logical sense?"

### ■ Look at its board of directors

The composition of the board of directors and their level of engagement say a lot about an epilepsy nonprofit. Three key attributes are balance, longevity, and commitment. If the board is skewed toward one industry, one viewpoint, or one aspect of the mission, that will impact its effectiveness. While constant churn is distracting, a healthy turnover rate on the board injects new energy and new perspectives. Board members should believe enough in the nonprofit to be donors and fundraisers themselves.

### ■ Look at its tax status

Require current 501c3 status. These organizations must comply with IRS reporting rules on expenses and income. Organizations without 501c3 status are not accountable to donors or volunteers. You can't write off donations or volunteer-related expenses

for a non-501c3 charity on your tax return, either.

### ■ Look at its bottom line

Some charities state that every dollar of your donation goes to the cause. That may be true if the staff is 100 percent volunteer or if salaries plus expenses are funded by a donor, grant, or trust. Otherwise, it's normal and expected that charities will use some donated dollars for salaries, administration, marketing, and other non-program expenses. Just find out what those percentages are for your nonprofit. Some nonprofits post their annual reports on the Web. The American Institute of Philanthropy [charity-watch.org](http://charity-watch.org) and GuideStar [guidestar.org](http://guidestar.org) have good reputations for thorough and objective evaluations of nonprofit organizations.

## Ways to Contribute to Epilepsy Nonprofits

### ■ Your money

This is easiest for both you and the epilepsy nonprofit. While nonprofits always prefer unrestricted cash gifts, you can stipulate that your donation be applied to a particular project. If you're short on cash because of the recession, consider committing to a \$250 donation at \$50 per year over five years, for example, or combine your cash donation with a non-cash gift. You can also donate money through auction sales, such as eBay Giving Works.

### ■ Your time

We discussed earlier how you can match your skills and experience to an epilepsy

nonprofit's needs. How does that translate into time? Some tasks require your physical presence somewhere for a certain number of hours. Others can be done online at your convenience; that's easiest for people with epilepsy who can't drive. You could also make yourself available to the nonprofit on demand, as needs arise. If you're planning a trip, maybe your itinerary could include a donor visit, or a hearing at your state capitol.

### ■ Your contacts

This may be the most valuable gift you can give to a nonprofit. Ask yourself: who do I know—friend, colleague, family member, industry contact, or customer—who knows something or someone useful in this case? With a simple phone call to the right person, you might easily save the nonprofit days of work or thousands of dollars on an issue.



### ■ Your in-kind gift

For individual donors, some charities post a wish list on their Web site for items such as printers, children's toys, and gift cards. For business owners, consider whether your product or service could be useful to the epilepsy nonprofit. If you own a design firm, could you produce the charity's fundraising materials? If you own a restaurant, could you host an event, or provide catering? You can also consider giving a percentage of your sales to an epilepsy nonprofit. Your help means the epilepsy nonprofit's cash donations go less to expenses and more to programs.

### ■ Your employer's matching gift

Some employers will match your donation up to a predetermined limit—find out if yours does. Once the nonprofit receives your initial donation, it must send an acknowledgement with its 501c3 tax ID number to your employer. Once your employer receives that form, it will pay the matching amount. This process can take weeks to months. Follow up with the nonprofit to ensure they submitted the form and received the matching gift. The match can be forfeited if the nonprofit doesn't request it within a certain time period. It's free money; make sure they get it!

### ■ Your input on the future

Your epilepsy situation and needs change over time and so do those of others in the epilepsy community that nonprofits exist to help. Working professionals today might prioritize Americans for Disabilities

Act compliance in the workplace and health insurance that covers epilepsy prescription drugs, but as our population ages, we may start thinking more about elder care community services for people with epilepsy and their caregivers. If you're a parent of a very young child with epilepsy, your immediate concern is likely to be treatments for effective seizure control, but once your child is in school, your focus may shift to inclusion in school programs or epilepsy family advocacy at various levels of government. Ask about the nonprofit's adaptability and offer your insights.

### ■ Your bequest

Talk to your attorney about including in your will gifts of cash, stock, real estate, valuable artwork, or other assets to one or more epilepsy charities, depending upon your areas of interest.

### ■ Your personal endorsement

Nonprofits gain many new supporters by referral. If you have confidence in the nonprofit, tell others! As the pool of volunteers, donors, and advocates increases, epilepsy nonprofits can continue to do their valuable work, even in this recession.

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