

# **CURE**

Citizens United for Research in  
**EPILEPSY**

## **CURE CREW EVENT TOOLKIT**

A Complete Guide to Hosting an Event to Benefit CURE

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# WELCOME

We are thrilled that you have chosen to take an active role in CURE’s mission of raising funds and awareness for epilepsy research! Whether you are planning a small community event or a large gala affair, you are helping to make a difference in a real and critical way. By signing up to host an event, you join an esteemed group of individuals, the CURE Crew, who are working diligently to help us find a CURE. Thank you for uniting with us in this crucial effort.

# TIMELINE

To get started, here is a basic timeline that you may want to consider. Keep in mind that every event is different, so you will want to personalize this timeline to your event.

SIX TO TWELVE MONTHS BEFORE			
LEADER	TASKS	COMPLETE	NOTES
Host	Review toolkit		
	Schedule a call with CURE's Outreach Team		
	Sign and turn in CURE agreement		
	Consider the Big Picture		
	Assemble a committee		
All	Meet as a Committee		
	Set Goals		
	Brainstorm: Audience, Date/Time, Atmosphere, Theme, Venue, Entertainment		
Financial	Create budget, ensure expenses are 20% or less		
Logistics	Determine location and sign contract		
	Review site details		
	Review technical requirements		
Hospitality	Agree on refreshments and other needs		
Outreach	Create your Fundraising Plan and get started		
	Create your PR Plan		
	Work with CURE to create a fundraising website		
THREE TO SIX MONTHS BEFORE			
LEADER	TASKS	COMPLETE	NOTES
All	Revise schedule as needed		
	Distribute schedule to entire team		
Host	Check in with CURE		
Financial	Review budget, revenue, and expenses to date		
Logistics	Schedule vendor deposits and payments		
	Create a floor plan		
	Create an outline for the day of activities		
Hospitality	Finalize menu and beverages		
	Consider look and feel of event		
Outreach	Complete all outreach materials		
	Submit materials to CURE for approval		
	Outline program		

# TIMELINE, CONTINUED

ONE MONTH BEFORE			
LEADER	TASKS	COMPLETE	NOTES
All	Schedule volunteer training		
Host	Check in with all committee members		
	Reconcile goals to fundraising activities to date		
Financial	Review budget, fundraising, & expenses to date		
Logistics	Finalize the day of schedule & responsibilities		
	Create a day of packing list		
Outreach	Confirm and walk through program		
	Finalize any print materials, CURE gear		
Hospitality	Finalize any/all décor		
ONE WEEK BEFORE			
LEADER	TASKS	COMPLETE	NOTES
Host	Final review of project tasks		
	Check in with CURE		
All	Meet to review schedule		
	Review final tasks and day of assignments		
	Create set up / tear down checklists		
	Volunteer Training		
Outreach	Finalize guest list		
	Final outreach		
Logistics	Review set up, security and other needs		
	Confirm rehearsal times		
	Event walk through		
ONE WEEK AFTER			
LEADER	TASKS	COMPLETE	RESOURCES
Host	Follow up call with CURE staff		
	Thank you to all participants		
	Invoice and Fundraising Reconciliation		
	Submit any donations received to CURE		
	Gather all receipts and submit to CURE		
	Gather all photos and share with CURE		

# GETTING STARTED

## REACH OUT TO CURE

Our team is here to help! Set up an appointment with a member of our team by emailing [info@cureepilepsy.org](mailto:info@cureepilepsy.org). Once we receive your email, we'll set up a time to chat either by phone or in person to discuss your event and all the logistics. During this discussion, our team will also walk you through our CURE Crew Event Agreement, which we ask all of our event hosts to review and sign. We'll also walk through a communication plan with you to ensure you are supported throughout the planning of your event.

## COMMITTEE

Next, it is important to gather help! We recommend that you enlist people you can trust such as family, friends, coworkers, or classmates. To start, tell them about CURE and why this cause is so important to you. Share your vision of your event. Then, ask them to fill a specific role.

Every committee looks different, so feel free to shape it in a way that makes sense for your event. If you are unsure of your committee structure, here is a good way to start:

- **Host / Chair:** Overall visionary, planner, event executer, and contact with CURE
- **Financial:** Budget developer and monthly expense/revenue reconciler
- **Outreach:** Fundraiser and PR Leader
- **Logistics:** Contract reviewer, Creator of Timelines and Layouts, and Vendor Coordinator
- **Hospitality:** Menu and beverage taster and décor coordinator

## EVENT TYPE

Be creative and consider your skills and interests when selecting your event type. Do you or your committee members have particular interests, skills, talents, or connections? Perhaps you have a great cook in your family who can help you organize a bake sale or cook-off; or maybe a talented friend can help make an art or jewelry show a success. We encourage you to add your own personal twist utilizing the talents and interests of your committee.

# FINANCIALS

**CURE's mission in its fundraising is to keep costs very low so that the amount of money given to epilepsy research remains very high.** Make it your goal to get as many goods and services donated as you can. We can provide you with a letter affirming that your event will benefit CURE to keep with you when you make these crucial asks. Make it your goal to get as many goods and services donated as you can.

In keeping with this goal, you should keep the total expenses for your event *at or below 20% of your gross projected revenue*. For example, if your attainable fundraising goal is to raise \$5,000 for epilepsy research, your expenses (for the venue, food, supplies, etc.) should not total more than \$1,000. You can easily track your expenses and projected revenue by creating a budget for your event. Check out the **Sample Budget** in the appendix of this guide.

Please note, CURE is unable to pay for or reimburse you for costs associated with your event. CURE also has strict financial policies, which can be found in the CURE Crew Event Agreement.

## DOCUMENTATION

Keeping good records is a very important aspect of fundraising. You will want to properly thank your donors, and CURE will need this information to issue tax receipts. The following guidelines should be followed when collecting donations made to CURE:

### Check Handling

Each check received at the event should be placed in a donation envelope, with all pertinent information filled in. All checks must be made payable to “CURE.” The following guidelines apply to all checks made out to CURE in support of your event:

- **Sponsor Checks**—Ask sponsors to include your event’s name on the memo line.
- **Donation Checks**—Pure “donation checks” are checks written by people unable to attend your event. Since they are not receiving any goods or services (such as a dinner) at the event, they will receive the full tax write-off for the donation. “Donation” and your event name should be written in the memo line.
- **Registration/Donation Checks**—This refers to contributions made by people who register for your event. Tax deductions for these are the price of the ticket, less the direct cost to the participants. “Registration” and your event name should be written in the memo line.
- **Silent Auction Checks** – This refers to any checks written for the silent auction. Please write “Silent Auction,” name of the item purchased, and your event name in the memo line of the check. Please attach the checks to your spreadsheet of silent auction items, including the value of each item. Please note: when an item is purchased from a silent auction, only the amount paid above the market value is tax deductible.

Batch the checks you receive leading up to the event on a weekly basis and mail them to the CURE office for processing. Be sure to keep an accurate Master Donor List for your own records and update it accordingly before mailing donations to CURE.

### Cash Handling

Insert individual cash contributions into a remit envelope. Be sure to fill out the donor’s information and write “cash” on the envelope. This ensures that cash donors are properly acknowledged for their contributions and that they receive thank-you/tax benefit letters from CURE. At the conclusion of the event, deposit all cash into a local bank. Obtain a cashier’s check or money order to submit to CURE with all of the filled out or completed envelopes attached. Cash should never be mailed to the CURE office.

## LOGISTICS

You are now ready to delve into the logistics of your actual event! If you have chosen to plan an event with little startup cost, your venue may simply be your home, workplace, or school campus. If you are doing a larger event that requires the reservation and rental of a venue, there are a number of factors to consider:

- Rental fee?

- Does the venue provide food and liquor?
- Audio Visual Needs
- Does the venue carry adequate insurance?
- Is the venue easily accessible for guests with disabilities?
- What are the rules and regulations regarding décor?

In choosing your date, be sure to allow yourself adequate time to organize volunteers, generate publicity, send out invitations, and collect guest responses. This may mean planning several months in advance for larger events. Check with local event calendars to make sure your event doesn't conflict with area marathons, festivals, parades, major fundraising events, or major sporting events.

Once you have settled on a date and location for your event, send out a 'save the date' notice to potential guests and participants, and follow up with a formal invitation once the event details are finalized. Utilize email lists and send info electronically in order to avoid printing costs, or find a printer who will donate at least a portion of their services for formal invitations.

Please note: event hosts are responsible for signing all event contracts and are liable for the content within. Additionally, we recommend that each host consider purchasing event insurance for their event.

## **TIMELINE**

Your event timeline (see sample on pages 2-3) will help you keep track of important due dates leading up to the event. Additional items to consider, include:

- Venue deposit and payments
- Invitation Print and Mail deadlines
- Caterer deposits, payments, and headcounts
- Entertainment, Audio Visual, Photographer, and other vendor deposits and payments
- Signage due dates
- Dates and times of your volunteer or committee meetings

Also, start putting together a timeline for your event's day-of order of events. Depending on your event type, you may have a video presentation, a dinner, a silent auction, games, or other activities.

## **REGISTRATION**

In order to ensure that the day-of-the-event proceedings run smoothly, create a clean registration list to be checked off by a volunteer at the entrance to your event. The most efficient way to do this is by creating a Microsoft Excel spreadsheet. If you have solicited a corporate sponsorship, be sure to include their attendees.

## **DAY OF PREPARATION**

To properly prep for the day of, review your pre-event and day-of-event timelines. Hold a final meeting with your committee and volunteers to answer questions and confirm volunteer roles. Make contact with your vendors to confirm their service and time of arrival to the event. Make a checklist of everything you need to bring with you to the venue on the big day.

# OUTREACH

It's time to fundraise! Especially if this is your first time planning an event, it is important to set realistic expectations. What group are you targeting with your event and what is its interest level and charitable giving potential? How many participants can you and your volunteers recruit to support your event? Consider the following tips:

- **Share Your Story.** Chances are if you have decided to plan a fundraiser benefiting CURE, you or someone close to you has been touched by epilepsy. Share with your potential donors why funding epilepsy research is so important to you.
- **Educate Yourself and Others.** The facts about epilepsy are compelling. Review the Fact Sheet on epilepsy and CURE included in this appendix, and share what you've learned with your potential donors. Stress to others that by donating, they are truly helping to make a difference in the lives of many people.
- **Make the First Donation.** The size doesn't matter. It is much easier to ask others to do something you have already done yourself.
- **Just Ask!** The more you ask, the more confident you will feel. Don't start out by apologizing or feeling guilty. You are not asking for yourself. You are asking on behalf of 3 million Americans and 65 million people worldwide who desperately need a cure in this lifetime.

## TICKET SALES AND DONATIONS

Keeping your expenses and a realistic estimate of guest turnout in mind, establish ticket prices that will be acceptable to your target audience and that will help you turn a profit. A good formula to consider is taking the cost per person and doubling it. Further, designate a number of tickets that you will ask each of your volunteers to be responsible for selling. Remember to share the cost per person or fair market value with CURE staff.

## SOLICIT SPONSORSHIPS

The best place to start in identifying potential sponsors will always be with your own personal contacts as well as those of your committee. Where do you work? Where do your friends and family members work? What schools do you or your children attend (or have attended)? What places of business do you frequent? Where do you go for medical treatment? Have your committee members ask themselves these same questions. Identify the relevant points of contact at these places. You now have a list of solid leads!

Before reaching out to the potential sponsors, please share your list of sponsors with the CURE team to ensure that there are no duplicate asks. Next, determine what levels of sponsorship and accompanying 'benefit packages' you will offer.

## SILENT AUCTION

Silent auctions can be very profitable to your fundraising endeavors. The key here is to *get goods and services donated*. Follow the same strategy that we advise above for soliciting sponsorships—that is, utilize your personal contacts to generate leads and ask! Ask stores that you frequent: electronics, sporting goods, salons, restaurants, and more.

## RAFFLE

We do not recommend selling raffle tickets. To sell raffle tickets, it is necessary procure any non-profit raffle licenses required in an area ahead of time (60 days before an event). This information can generally be found through the state Attorney General's Office website. To conduct a raffle, you will need to show documentation of any required licenses to CURE for approval. Please note that raffle ticket purchases are not tax-deductible.

## PUBLICITY

Publicize your efforts and this cause. Start by placing fliers inside your local coffee shops, grocery stores, shops, gyms, and on your school or workplace bulletin board. Put together a short article on your event and submit it to your school or employee newsletter, church bulletin, or any other publications put out by groups you or your committee members are involved with. Be sure to send the name, date, time, location, and short description of your event to the calendar editor of your local newspaper. Post with any online local calendars as well. Don't forget social media (such as Facebook and Twitter) is great ways to get the word out to a large audience.

Your next step is to reach out to your local news media. A press release serves two purposes—to announce the event ahead of time and also to get the media to cover your event. We have included a **Sample Press Release** which you can tailor to your event in the appendix of this guide. Make a list of the appropriate contacts at your local print, radio, and television outlets—particularly city or health editors—and send them each a press release at least a week in advance. Follow up with phone calls to make sure that the release was received and to see if you can provide any further information. Don't forget – any materials with CURE's name or logo must be approved by staff.

## WRAP UP

Congratulations, you've done it! Now it's time to wrap up final details for your event. Make sure to submit all donations and lists to the CURE office within 14 days of your event.

CURE will issue thank-you letters that double as tax-receipts to your donors. Electronic gifts will receive a thank you via email, while gifts sent to our office will receive a thank you letter via regular mail. You may also consider sending your own hand-written thank-you notes to your event's supporters. Incorporate your story to show them how critical their help is to you and to those living with epilepsy.

Follow up with any press coverage that your event received or still may receive. Submit a write-up and photograph from your event to local news media and businesses or organizations you are involved with to include in their publications. Also make contact with the CURE office so that we may include a write-up on your event on our website and in a future CURE newsletter. Don't forget to send your CURE contact photos of your event.

Finally, set up a conference call or in-person meeting with CURE's Outreach Team for final wrap-up and a review of your event's proceedings. We are so grateful that you have chosen to collaborate with us and rally for a cure, and we want you to remain part of the CURE family. **Thank you!**



# CURE AND EPILEPSY FACT SHEET

## ABOUT EPILEPSY

1 in 26 will develop epilepsy in their lifetime. Almost 500 new cases of epilepsy are diagnosed every day in the United States. Epilepsy affects 65,000,000 people worldwide.

Epilepsy can develop at any age and can be a result of genetics, stroke, head injury, and many other factors. In two-thirds of patients diagnosed with epilepsy, the cause remains unknown.

In forty percent of patients, seizures cannot be controlled with treatment. Uncontrolled seizures may lead to brain damage and death. Many more have only partial control of their seizures.

The severe epilepsy syndromes of childhood can cause developmental delay and brain damage, leading to a lifetime of dependency and continually accruing costs—both medical and societal.

It is estimated that up to 50,000 deaths occur annually in the U.S. from status epilepticus (prolonged seizures), Sudden Unexplained Death in Epilepsy (SUDEP), and other seizure-related causes such as drowning and other accidents.

For many soldiers suffering traumatic brain injury on the battlefield, epilepsy will be a long-term consequence.

## ABOUT CURE

### Our Mission

Our mission is to cure epilepsy, transforming and saving millions of lives. We identify and fund cutting-edge research, challenging scientists worldwide to collaborate and innovate in pursuit of this goal. Our commitment is unrelenting.

### Who We Are

CURE, Citizens United for Research in Epilepsy, is a volunteer-based nonprofit organization founded by parents of children with epilepsy who were frustrated with their inability to protect their children from seizures and the side effects of medications. Unwilling to sit back and accept the debilitating effects of epilepsy, these parents joined forces to spearhead the search for a cure. CURE's mission remains dedicated to finding a cure for epilepsy by raising funds for research and by increasing awareness of the prevalence and devastation of this disease.

### CURE Research Grants

Since its inception in 1998, CURE has raised over \$32 million to fund research initiatives that will lead the way to a cure for epilepsy. CURE's research program addresses the goals of "no seizures, no side effects," with specific focus on the following areas: prevention of epilepsy, including post-traumatic epilepsy; advancement of the search for a cure; elimination of treatment side effects; and elimination of deficits caused by frequent seizures. More than 88 cents of every dollar contributed to CURE is invested in our mission - among the highest percentage for charities nationwide.

### CURE Advocacy

Through its advocacy efforts, CURE has helped raise federal expenditures by the NIH on epilepsy research from \$68 million in 1998 to over \$100 million so far. CURE was instrumental in the creation of the Epilepsy Research Benchmarks, which were created to help guide the research community toward a cure for epilepsy. CURE has also worked to establish epilepsy as a disease which merits and now receives crucial funding support for research through the Department of Defense.

### Increasing Public Awareness

CURE is dedicated to raising public awareness about epilepsy and the fact that so many patients are severely impacted by the disease. Without a strong voice, epilepsy research will continue to lag behind that of other diseases. Through the Annual Benefits in Chicago and the recent growth of volunteers' fundraising efforts around the country, CURE is spreading the word that the only solution is an increased focus on epilepsy research.

# SAMPLE EVENT BUDGET

## Fundraising Income and Expenses

**EVENT NAME:**

**EVENT DATE:**

	BUDGET	ACTUAL
<b>EVENT REVENUE</b>		
Sponsorships	_____	_____
Individual Ticket Sales	_____	_____
Table Sales	_____	_____
Silent Auction	_____	_____
Raffle	_____	_____
<b>Total Revenue</b>	_____	_____
<b>EVENT EXPENSES</b>		
Audio Visual and Lighting	_____	_____
Awards/Gifts	_____	_____
Equipment Rental	_____	_____
Food and Beverage	_____	_____
Insurance	_____	_____
Licenses and Permits	_____	_____
Merchant Fees	_____	_____
Miscellaneous	_____	_____
Music and Entertainment	_____	_____
Other Promo Materials	_____	_____
Parking and Transportation	_____	_____
Photography/Video	_____	_____
Promo Materials Postage	_____	_____
Promo Materials Printing	_____	_____
Public Relations	_____	_____
Silent Auction/Raffle	_____	_____
Subcontracted Labor	_____	_____
Supplies/Decorations	_____	_____
Travel	_____	_____
Venue Fee/Deposit	_____	_____
<b>Total Expenses</b>	_____	_____
<b>Net Event Income</b>	_____	_____
<b>Operating Margin</b>	_____	_____

Note: Keep the Operating Margin (Expense Percentage) at or below 20%