

TOOLKIT

A COMPLETE GUIDE TO RAISING FUNDS AND INCREASING AWARENESS FOR EPILEPSY RESEARCH

WELCOME



Dear CURE Champion,

As a CURE Champion, you are raising awareness and funds that support the CURE mission – to find a cure for epilepsy, by promoting and funding patient-focused research. As you probably know, CURE is the leading non-governmental funder of epilepsy research and is dedicated solely to finding a cure for epilepsy.

Over the last several years, we have embarked on an aggressive strategy that includes funding research in the areas of infantile spasms, epilepsy genetics, post-traumatic epilepsy, and SUDEP.

I want to personally thank you for joining us for this exciting opportunity to make a difference in the lives of the 1 in 26 Americans who struggle with epilepsy, as well as their friends and family. Your philanthropic leadership will help us raise critical funds for epilepsy research and spread awareness about this devastating disease.

In this toolkit, you will find all the resources you need to put together a spectacular event – whether it be a lemonade stand on your neighborhood street, a community run/walk with hundreds of participants, or an upscale gala with thousands of attendees. Also, please remember CURE is here to help you every step of the way. Don't hesitate to utilize the talented individuals within our organization who are eager to assist.

Thank you and best of luck,

Jucan Ayuroch

Susan Axelrod Founder

THE NEED FOR FURTHER RESEARCH

ABOUT CURE

CURE was founded as a grassroots movement in 1998 by Susan Axelrod and a small group of parents whose children were living with epilepsy. Frustrated with their inability to protect their children from seizures and the side effects of medications, these parents took action.

Since then, CURE continues to challenge scientists worldwide to transform and save the lives of millions by collaborating and innovating in pursuit of discoveries.

Our commitment to finding a cure for epilepsy is unrelenting.

OUR RESEARCH

CURE is the leading nongovernmental agency fully committed to funding research in epilepsy.



CURE has raised more than \$60 million and counting.



We have funded more than 220 grants in 15 countries to date.



~90% of our expenditures are invested in our mission.

MORE AMERICANS HAVE THAN EVER BEFORE, YET EPILEPSY **RESEARCH REMAINS UNDERFUNDED EPILEPSY IMPACTS 3.4 MILLIO** PEOPLE IN THE U.S. in will develop epilepsy in their lifetimes. Of the top 5 chronic EPILEPSY IS conditions among MORE COMMON children and adults. than autism spectrum **EPILEPSY IS** disorder, cerebral palsy, THE COSTLIEST multiple sclerosis AND SECOND and Parkinson's MOST COMMON. disease combined. CITIZENS UNITED FOR CURE **RESEARCH IN EPILEPSY** ww.cdc.gov/media/releases/2017/p0810-epilepsy-prevalence.htm 5) Madicine. 2012. Epilepsy Across the Specthum: Promoting nd Understanding, Washington, DC: The National Academies Press of cont/10.1292/12930 d Undessansung, Hys. Lorg/10.17226/13379. and Mortality Weekly Report (MMWR), 2017, August 10. ww.odr. cov/mmwr/volumes/66/wt/mm6631a1.htm.

GETTING STARTED

STEP 1: CONNECT WITH CURE

Our team is here to help! Set up an appointment with a member of the CURE Outreach Team by emailing <u>EVENTS@cureepilepsy.org</u>.

Once we receive your email, we'll set up a time to discuss, either by phone or in person, your event and all the logistics. During this discussion, our team will also walk you through our CURE Champion Event Agreement, which we ask all our event hosts to review and sign.

We'll help solidify your plan and review the documents in the "Helpful Documents" section (found at the end of the Toolkit) with you to ensure you are supported throughout the planning process.

STEP 2: GATHER HELP

It's important to always ask for help! While the CURE Outreach Team will assist you with event planning, logistics, and implementation, it's always helpful to enlist the assistance of those closest to you. Family members, friends, co-workers, neighbors, and classmates can make the best CURE Champion Team for your event. Every Team looks different. Feel free to shape it to the needs of your specific event.

STEP 3: SELECT YOUR EVENT

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.

Past CURE Champion events include lemonade stands, bake sales, fun runs/walks, dance classes, sporting events, and birthday or tribute campaigns. Please feel free to contact CURE for more examples of successful past CURE Champion events or for help setting up a new type of event.

STEP 4: FUNDRAISE

Many people find this to be the most daunting task in setting up an event, but it can also be the easiest. To help guide you through this step, follow the process below:

Choose Your Fundraising Platform

TeamRaiser

Your CURE contact can set you up with your own fundraising page. This can be used for ticket sales, registration, and general donations. On the fundraising page, you can share your story, event details, have a running list of donors, a blog, and a thermometer showing progress towards your goal. You can also receive donation alerts through your donor page.

Facebook Giving

Facebook Fundraisers have raised over \$1 billion in three years and do not charge any credit card processing fees – meaning 100% donations received go toward CURE's mission. Your Facebook Fundraiser is easy to start, and your CURE contact can provide a setup guide and fundraising tips. You can share your fundraising page with friends, create posts, and track your goals.

Share Your Story

Share with your potential donors why funding epilepsy research is so important to you. Be sure to share the compelling epilepsy statistics found in this packet. You can also set up a Personal Story page on the CURE website which can help get your story out to the public:

Make the First Donation

The size doesn't matter. It is much easier to ask others to do something you have already done it 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 now. Plus, 100% of all donations are taxdeductible and contribute to CURE's 4-star organizational rating by Charity Navigator. *

Helpful steps for more detailed events

Solicit Sponsorships

Depending on the size of your event, you may choose to get local sponsors to cover extraneous costs and raise your total donation level. The best place to start in identifying potential sponsors will always be with your own personal contacts and those of your Committee. Sponsors may donate monetarily or with goods and services. Before reaching out to sponsors, contact the CURE Outreach Team to ensure there are no duplicative asks. Also, it is important to determine sponsorship levels, as well as a Benefits Package offering sponsor recognition (including logos) on social media, webpages, printed materials, t-shirts, promotional materials, etc.

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 will help you turn a profit. A good formula to consider is taking the cost per person and doubling it. Designate a number of tickets to ask each of your volunteers to be responsible for selling. Remember to share the cost per person or fair market value with CURE staff.

Auctions

Silent auctions can be very profitable to your fundraising endeavors. The key here is to get goods and services donated. Follow the same strategy we advise above for soliciting sponsorships—utilize your personal contacts to generate leads and ask! Ask stores you frequent: electronics, sporting goods, salons, restaurants, and more. While we cannot provide you with our tax-exempt letters, your CURE contact will be more than happy to provide you with a letter attesting to the fact that you are hosting an event to benefit CURE. This letter will provide the business with all the necessary tax information.

* Citizens United for Research in Epilepsy (CURE) is a non-profit 501(c)(3) tax-exempt organization. Our tax identification number is 36-4253176. As no goods or services were provided in exchange for this contribution, your donation is 100% tax deductible.

STEP 5: LOGISTICS

You are now ready for the fun part – setting up the details of the event itself! If you have chosen to plan an event with little startup cost, your venue may simply be your home, workplace, or school campus. If your event involves a larger number of people, there are a number of questions to consider:

1. Does the venue require a rental fee?

2. Does the venue have enough space, or do I have to limit the capacity?

3. Does the venue provide enough food or beverage, or do I need to have the event catered?

4. Does the venue meet the audio/visual needs of my event?

5. Does the venue carry adequate insurance, or do I need to purchase my own event insurance?

6. Is the venue accessible for individuals with disabilities?

7. Do I provide decorations for the event or does the venue come decorated?

When 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' to potential guests and participants. Then follow up with a formal invitation once the event details are finalized. Utilize email lists and Facebook event pages to send information electronically to avoid printing costs. Alternatively, find a printer who will donate at least a portion of their services for formal invitations.

An Event Timeline document will help you keep track of important dates leading up to the event, as well as deposit and payment dates and deadlines. An Event Budget spreadsheet will help manage all event financials and ensure you limit the overall costs incurred for the event logistics. See samples of both documents and a complete Event Management Checklist in the Helpful Documents section at the end of the Toolkit.

SPREAD THE WORD

There are many ways to help spread the word about your event. Your communications should always include **date**, **time**, **location**, **price**, **a short description of the event**, **and a mention of CURE and the need for further research**. Don't forget: the easiest way is for you and your Committee to tell **everyone** within your social networks. Other ways include:

Printed Materials

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 CURE Champion Team members are involved with. Submit event details to your local newspaper calendar editor. Post to any online local calendars as well. If you post your event on a calendar, be sure to post the link to any social media pages you might have for further exposure!

Electronic Communications

Utilize electronic communication as much as you can. It's simple and far reaching. The best way to start is by changing the signature in your email. You can add a simple Save the Date and link to your event or fundraising page to grab attention. You can also send electronic invitations, updates, and thank you's once your event is over.

Social Media

Enlist the help of your CURE Champion Team, friends, family, and volunteers to share information about your event on social media! Provide them with any links, images, or logos they should include.

<u>Facebook:</u> If you make a Facebook event page, share it with your CURE contact so the CURE Facebook can share photos and updates pertaining to your event. Your fundraising page can also have a link to the Facebook event page and vice versa.

<u>Twitter:</u> Consider creating an event-specific hashtag to use on your personal Twitter account. Be sure to share this with all your committee, attendees, friends, family, etc. and encourage them to tweet from the event.

Instagram: Encourage event participants, sponsors, and entertainers to post Instagram Stories leading up to your event. They can also share the event page link in their bios. If you create a catchy hashtag to use for your event, make sure your CURE Champion Team, attendees, friends, family, etc. know about it and use it as well.







@CUREforepilepsy

@cureepilepsy

@cureepilepsy

WRAP-UP

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

CURE will issue thank you letters which double as tax-receipts for your donors. These receipts will go out as gifts are received, meaning if gifts are submitted before your event the acknowledgement letters will go out before the event as well. 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 want to consider sending your own hand-written thank-you notes to your supporters. Your CURE contact can assist you with this by pulling a donor list after your event is closed. You may choose to incorporate your story to show donors how critical their help is to you and to those living with epilepsy. You may also want to include your grand total to show how successful your event was because of your attendees' and supporters' help.

Contact the CURE office so we may include a write-up on your event on our website, social media posts, and in future CURE communications. Don't forget to send any and all photos of your event to the CURE Outreach Team at EVENTS@cureepilepsy.org.

For larger events, follow-up with any press coverage your event received. 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.

Finally, set up a conference call or in-person meeting with the CURE Outreach Team for final wrap-up and a review of the event proceedings. We will ask you to complete a questionnaire about your experience working with the CURE Outreach Team and with hosting an event. If you created a fundraising page for your event, be sure to discuss when the page should be deactivated with your CURE contact.

We are so grateful you devoted your time and efforts to raising critical funds for epilepsy research. We thank you for serving as a CURE Champion and hope you remain a member of the CURE family.



HELPFUL DOCUMENTS

SAMPLE BUDGET

EVENT NAME:

EVENT DATE:	BUDGET	ACTUAL
EVENT REVENUE		
Sponsorships		
Individual Ticket Sales		
Table Sales		
Silent Auction		
Raffle		
Other:		
Total Revenue		

EVENT EXPENSES

Audio Visual and Lighting	
Awards/Gifts	
Equipment Rental	
Food and Beverage	
Insurance	
Licenses and Permits	
Merchant Fees	
Music and Entertainment	
Parking and Transportation	
Photography/Video	
Promo Materials: Postage	
Promo Materials: Printing	
Promo Materials: Other	
Public Relations	
Silent Auction/Raffle	
Subcontracted Labor	
Supplies and Decorations	
Travel	
Venue Fee and Deposit	
Other:	
Total Expenses	
NET EVENT INCOME	
OPERATING MARGIN (Tip: Keep at or below 20%)	

TASK SUMMARY

To get started, here is a basic list and description of tasks which may be helpful in setting up any type of event. Keep in mind this does not serve as a specific checklist, as every event is different and will follow a different timeline, so you'll want to personalize this information into a worksheet tailored to your specific event. For an event that involves less planning, you may only utilize a few sections of this task list. For more detailed events, you may need to additional help than this task list can provide, and a member of the CURE Outreach Team can assist you further.

You can create your own checklist template in a Microsoft Word document or ask CURE for a sample template to help you. Once you have a checklist, you can plan the event from start to finish and create a timeline of tasks and schedule of deadlines, which assures that every single detail gets covered.

ESTABLISH EVENT SPECIFICS

The first step is to contact CURE Outreach Team at <u>events@CUREepilepsy.org</u> or 312-255-1801 to discuss event ideas and begin brainstorming. There are many preliminary details that are vital to a successful event that need to be established — event goal, event profile, and your CURE Champion Team members.

Event Goal

The event goal is the overall reason for hosting an event. It could be anything from fundraising or celebrating employee success to imparting information or launching a new product.

Establish your Event Profile

The profile of the event includes all the necessary information required for successful execution – including date, time, location, and your intended audience. For an event to be successful, you have to know your audience and clearly understand what expectations they have of the event. If you don't meet their needs, then the desired guest action is less likely to happen. Profile your audience; then, take it a step further. Determine what you want them to feel, think, and do both during and after the event. And make sure to incorporate components in your event design that will provoke those responses.

Build your CURE Champion Team

Determine what individuals within your community would be valuable assets in assisting you with the event logistics, financials, hospitality, outreach, and other components. These are generally people who you trust and share your passion for a cure for epilepsy.

BUILD YOUR EVENT BUDGET

When you contemplate recording every anticipated event expense, creating an event budget seems daunting. With a Microsoft Excel spreadsheet, it's not that complicated. Start with the major categories, such as catering, décor, and rentals. Then, breakdown all the expenses under each category and let Excel do the work for you!

Under this section of your list, you can add details such as research about cost of rentals or negotiated discounts with vendors. The event budget isn't a checklist line item that can simply be marked off. Your checklist is a living, breathing document, and this format encourages you to keep revisiting all aspects of the event until it is as costeffective as possible.

CREATE THE EVENT DESIGN

This is the heart of the pre-planning because it covers the range of event components that impact guests the most.

Program

The program relays the story of the event goal and objectives. Each story element leads to the next story element, which builds anticipation during the event. The peak of that anticipation should be dramatic. It is what you want your guests to remember the most. An event checklist helps layout the story by breaking down the timeline of the event.

Layout

How you're using your space — all the way down to the seating arrangements — can make all the difference. A visual layout of your event space can make sure everything goes smoothly the day of the event.

Theme

Choosing an event theme isn't just for fun. The theme represents the event message and serves other essential purposes, such as:

- Themes create buzz. The guests' event experience begins long before the event. A themed invitation and social media post creates anticipation and sets the tone for the future event.
- Most importantly, an event theme connects the individual event components (such as décor, catering, and entertainment), thereby layering the event message into a cohesive guest event experience.

Listing considerations for how each themed event component can convey the event message will lead to a carefully-crafted strategy for a lively, purposeful event.

Decorations and Promotional Items

Décor can run from simple to elegant depending on the event. Determining a list of items as you create a virtual "walk-through" of the event can make for a successful event. For example, if you are conducting a race, you'll need to plan for everything including t-shirts, bibs, medals, as well as all the resources needed

at the start and finish lines. Your CURE Outreach representative can help you with creating this list.

Food and Drink

Choosing a menu or bar package is also a detailed task. There are MANY vendors out there to choose from. Plus, you have to consider guests' cultural sensitivities and the array of their dietary preferences and restrictions. Then, there is the question of how food and drink choices will impact the environment. A detailed checklist can be created with the help of your CURE Outreach representative to ensure all specifics are detailed and documented.

Entertainment and Audio/Video Needs

You will definitely need some space on your checklist for booking the entertainment that may be associated with the event. This can include arranging speakers, closing streets for a race/walk, microphones and displays for presentations, etc. There are contracts and invoices, permits and insurances, volunteer and security needs, as well as many other tasks to consider depending on the type of event.

Your CURE Outreach representative can help you with a checklist that acts like a blueprint for EVERY aspect of the design or layout of the event, helping you to see the big picture, while you are ensuring every component that affects the guest experience at the event is well though-out.

CREATE YOUR MARKETING PLAN

Event marketing creates buzz, builds anticipation and guarantees a good turnout. It can also involve a variety of channels (from printed flyers to dedicated event emails) and multiple teams (from graphic designers to social media managers). Plus, running a digital marketing campaign in a channel like Facebook comes with its own web of dates, analytics, and budget. CURE is happy to provide resources to assist you with your marketing plan. This includes social media outreach, 'Save The Date' and Invitations, and CURE promotional materials (giveaways).

CREATE A FUNDRAISING PLAN

Choose your fundraising platform and follow the chart laid out with you in the accompanying Toolkit. Your fundraising plan should include your event goal, how you will market the event, and a list of potential donors. It is also important to create a list of milestones that will ensure you stay on track to meet your fundraising goals.

CREATE A LOGISTICAL PLAN

Plan to create a logistics timeline or a detailed event agenda: a minute-by-minute schedule of EVERYTHING from vendor arrival and set-up to run-through and post-event breakdown. There are many moving parts on event day, as well as unexpected situations that arise. This can include:

- CURE Champion Team and Volunteer individual task list
- Vendor contact information and time/date information
- Food and Beverage information
- Audio/Video information
- Supplies and Materials

Please contact CURE for assistance with creating a logistics document.

PLAN FOR THE UNEXPECTED

It's the little details that make a big difference. That's why you'll want to keep track of every minute thing that can affect the guest experience.

An event can be ruined before it even begins by poor directions or long lines at the registration table. What about guest <u>access to Wi-Fi</u>? If you force your guests to unplug, you might have a riot on your hands! And what if someone has a medical emergency? Those are the small, but very important details that need to be added to an event planning checklist. Include everything from signage and promotional materials to photography and contingency plans.

Be sure to utilize your CURE Outreach Team to ensure all the little details are planned for in advance.

POST-EVENT FOLLOW UP

After your guests leave the event feeling all warm and fuzzy, touch base with them. This is an opportunity to reinforce the event message and get feedback, as well as prompt guests to take action to meet event objectives.

When putting together your list, contemplate a variety of post-event communication methods that will achieve those results, such as sharing event photos, sending a thank you note, posting on social media, or linking to event materials. The checklist will not only help you manage the tasks but track the results.

DEBRIEF

Shortly after the event, you will want to sit down with your CURE Champion Team, talk about what went right, and what can be improved. On an event planning checklist, you can list criteria to consider that will map back to your event goals.

You can then schedule a debrief with your CURE Outreach Team and discuss this list of criteria, as it will help you as you plan your next CURE Champion event. You will also want to ensure that with the help of your CURE Outreach team, you ensure all funds are distributed to CURE, all tax-exempt letters are sent, and all pictures and event summaries have been submitted to CURE.

Finally, you should celebrate your success and feel good knowing that all of your hard work is helping fund critical research to find a cure for epilepsy.



CURE CITIZENS UNITED FOR RESEARCH IN EPILEPSY



CITIZENS UNITED FOR Research in Epilepsy



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CHAMPIONS