

SUDC FOUNDATION FUNDRAISER HOST AMBASSADOR PROGRAM

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If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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I. Introduction

Thank you for your participation in the SUDC Foundation Fundraiser Host Ambassador Program. The Foundation truly could not do its work without you.

The SUDC Foundation currently receives no public funding. All of the work it does is supported through private donations and revenue generated by event planners like you. In fact, approximately 85 percent of the Foundation's revenue comes from fundraising events.

Fundraiser Host Ambassadors are essential to the work of the Foundation. Hosting a fundraiser positions you to be a representative of the Foundation in your community.

Those who host an event are considered **Fundraiser Host Ambassadors**. Every event should have one or two people to oversee the event. Oftentimes, parents of an SUDC child serve as the Fundraiser Host Ambassadors but they do not have to. To ensure you have all the information and resources you need, we ask all those interested in hosting a benefit event to become SUDC Fundraiser Host Ambassadors. This will include:

- Being a registered member of the SUDC Foundation and completing the training process to be a Fundraiser Host Ambassador
- Understanding the mission and work of the SUDC Foundation
- Understanding and showing a willingness to speak using the SUDC Foundation's Key Messages
- Coordinating with the SUDC Foundation to ensure you have the most accurate and current information regarding SUDC and the work of the Foundation

This kit provides requirements, Foundation resources and extensive tips to prepare you and help you plan your fundraiser. Our staff will guide you through the event planning process to help ensure your success. If you have any questions please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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II. CATEGORIES OF EVENTS

The SUDC Foundation classifies events in one of three ways:

- SUDC Foundation Event;
- Private Foundation Event; and
- Community Event

Before planning an event that benefits the SUDC Foundation in some way, you should consider the event category you may want to host, depending on the resources you have available to you and what support you would like from the Foundation. No matter which category your event falls under, SUDC Foundation staff will work with you every step of the way.

A. SUDC Foundation Event

An SUDC Foundation event is one where the finances are managed by the Foundation. The event is also covered under the SUDC Foundation's liability insurance. As with all events hosted by a Host of a Fundraiser Ambassador, SUDC staff will provide guidance, access to administrative support and any of the event planning resources the Foundation has.

The Fundraiser Host Ambassador for an SUDC Foundation Event will:

- Clearly identify the SUDC Foundation as the sole beneficiary.
- Submit a proposed budget to the Foundation for approval. Fundraising costs should not exceed 20 percent of the total revenue. This is based on the General Accounting Principles standards for 501c3 nonprofit organizations.
- **Not** sign contracts or enter into agreements on behalf of the SUDC Foundation. (i.e. venue applications, vendor sales, etc.) All appropriate contracts will be submitted to the Foundation to be reviewed and signed by a Director of the Foundation.
- Provide a tax receipt from the SUDC Foundation to those who donate directly to the Foundation, either by credit card, cash or check payable to "The SUDC Foundation," or by making an online donation through the Foundation's website or fundraising page.

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B. Private Foundation Event

A Private Foundation Event is hosted by a private foundation, sometimes established in memory of an SUDC child but separate from the SUDC Foundation, with at least a portion of the funds being raised donated to the SUDC Foundation.

Private Foundation Event finances and planning logistics are managed by that foundation's directors or trustees. Events are covered under their own liability insurance, although the SUDC Foundation requires the SUDC Foundation be listed as an additional insured party. A Private Foundation trustee, or its representative who is registered with the SUDC Foundation, can access any of the event planning resources the SUDC Foundation offers.

C. Community Event

A Community Event is one that benefits the SUDC Foundation, but the Fundraiser Host Ambassador plans and organizes the event on his or her own, sometimes in conjunction with local community organizations.

The Fundraiser Host Ambassador is responsible for managing the finances of the Community Event as well as acquiring liability insurance, although the SUDC Foundation requires the SUDC Foundation be listed as an additional insured party. A Community Event Fundraiser Host Ambassador can access any of the event planning resources the SUDC Foundation offers.

To help guide you in choosing your best type of event, an overview and comparison chart for these categories can be found in **Appendix A**.

Fundraiser Host Ambassadors for both Private Foundation and Community Events will:

- Assume all liability for hosting the event and agrees to hold harmless the SUDC Foundation, its directors, servants, agents, employees and volunteers from any claims as a result of this event.
- Identify the SUDC Foundation as the beneficiary. For example, your fundraiser can not be called "The SUDC Concert for Timmy."

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- Ensure the event aligns with the SUDC Foundation branding principles and mission as stated in the MOU agreement.
- State the percentage amount directed toward the SUDC Foundation on all donor communications.
- Provide receipts from the SUDC Foundation to anyone who donates directly to the SUDC Foundation.

III. SUDC FOUNDATION EVENT PLANNING RESOURCES

This kit is full of resources to help you plan your event. Our staff is available to help guide you through the planning process and further explain these resources. If you have any questions or need any guidance, please contact our Director of Development, Elizabeth Milliken at elizabeth@sudc.org or the Ambassador Program Assistant at ambassadorprogram@sudc.org

Depending on your event, you may utilize all of the resources below or just a few. The most important thing is to know they are available, and whenever in doubt, contact the Foundation staff to any questions you have. Specifically, SUDC Foundation staff will help you by providing:

Administrative and Event Planning Support:

- SUDC staff assistance and/or guidance through regular and as-needed event support calls. Support calls often include an initial planning and brainstorming call with the Director of Development, monthly check-in calls and weekly check-in calls the month prior to the event.
- SUDC Foundation's IRS Determination Letter. As you are requesting donations or sponsorships, you may be asked to share the Foundation's IRS Determination Letter. This letter is proof of the SUDC Foundation's 501c3 status, which is a designation from the United States Internal Revenue Service that the Foundation is a not-for-profit organization and is tax-exempt. Your donors or sponsors may need this letter for filing their taxes and for record-keeping purposes. You can access this letter through the events page on the SUDC Foundation's [website](#). The link is also included in **Appendix B**. **Please be sure to speak with a representative of the SUDC Foundation before you use this letter.**

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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- SUDC Foundation Financial Information. You may also be asked to share financial information on the SUDC Foundation as you are requesting sponsorships and donations. The SUDC Foundation believes in complete transparency with respect to its financial information. The Foundation will provide past and present financial documentation, free of charge, for anyone who would like to see it. Please follow the link in **Appendix C** to access the [SUDC Foundation's most current financial statement](#).
- Guidance navigating local fundraising laws. If you plan to use raffles as part of fundraising for your events, there may be different laws or regulations they are subject to depending on where you live. No matter where you live, SUDC Foundation staff can assist you in researching and helping you adhere to local raffle regulations.
- Assistance with the creation of online registration site for your event.
- Credit card processing. The Foundation also has access to mobile credit card readers you can borrow for your event. In the event a mobile card reader is not available, the Foundation's event team will instruct you how to process credit card payments directly to the SUDC Foundation.

Marketing and Communications Resources:

- Inclusion of your event in SUDC Foundation communication channels including the Foundation's website (sudc.org), monthly e-news, Facebook page, Twitter and Instagram accounts and other printed materials.
- Free memorial websites for any registered family to remember a child lost to SUDC. The site is hosted on the SUDC Foundation's website and features an optional page to publicize any event you host in support of the SUDC Foundation's mission. To request a memorial website, please fill out a [Memorial Site Request Form](#) on the SUDC Foundation's website (you must be logged in as a registered member to view this section of the website.)
- Event planning email group for open communication with other SUDC Foundation supporters
- Press releases written specifically for your event

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Visual and Promotional Materials

- Digital files of the SUDC Foundation logo, photos and first names of children lost to SUDC whose parents/guardians gave permission for their use in fundraising and memorial activities (Please note that in order to obtain permission to use digital files, the Fundraiser Host Ambassador must sign a Memorandum of Understanding provided by the SUDC Foundation.)
- Copies of [SUDC Literature](#) including flyers outlining SUDC and the work of the SUDC Foundation for general or medical audiences, newsletters and Frequently Asked Questions brochures
- SUDC Foundation promotional materials including bags, pens, event banner and quilt, if available
- SUDC Foundation videos including:
 - [Explaining the Unexplained](#): A short and poignant video that captures facts on SUDC and its raw, emotional cost.
 - [The Faces of SUDC](#): A video featuring children taken far too soon from SUDC.
 - [Love Beyond Reason](#): An 8-minute documentary depicting the challenges the medical community faces as it tries to understand this classification of death and the heartache of parents and families who have experienced the sudden loss of a thriving child with no medical cause or explanation. Scenes from the documentary were filmed at the first-ever conference for this rare phenomenon, hosted by the SUDC Foundation and the NYU Post-Graduate Medical School.
- Additional event planning toolkits including branded artwork and more resources for specific types of fundraising events
 - [Run for a Reason Planning Guide](#)
 - [Pins for a Purpose Planning Guide](#)

To access any of these additional resources when links are not provided, please contact the SUDC Foundation.

IV. [PLANNING YOUR EVENT](#)

So you are ready to plan your event! Read through the following sections for guidance and also to help you brainstorm what your event vision is. What you want and what you don't want are

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equally important. Then, plan a call with the Foundation Director of Development to answer any questions you have and map out a successful event plan!

Hosting an event can be emotional and may seem overwhelming at times, so you may want to consider adding an additional Co-Fundraiser Host Ambassador, such as another family member or relative, to help share the work and provide you with emotional support along the way.

Every event will be different, and will require a different level of commitment from you. Depending on your event, you may need to:

- Develop and maintain a timeline to ensure deadlines are met
- Manage and oversee all finances including bank account, invoices, incoming and outgoing dollars
- Be a liaison with the SUDC Foundation to ensure materials, plans, etc. are approved and meet event standards
- Collect and manage all monetary and in-kind (goods and services) donations
- Sign a Memorandum of Understanding (MOU) provided by the SUDC Foundation if you wish use the SUDC Foundation's name, logo, pictures and names of SUDC children the Foundation has permission from families to use to ensure your event closely aligns with the Foundation's brand, vision, mission and value proposition
- Communicate with the SUDC Foundation prior to and after your event and help to improve our fundraising efforts
- Educate, motivate and manage a team of volunteers

A. Choose an Event Type, Date and Location

The first, and most important, step in planning your event is to decide what type of event you wish to host. Events come in all shapes and sizes. Event hosts have planned events including memorial races, bowling events, golf outings, fishing events, spaghetti dinners, concerts and black-tie galas in honor of children lost to SUDC. Each type of event requires a different time commitment to plan. The larger the event, the more planning is needed. SUDC staff is available to help you brainstorm the type of event that is right for you.

Next, you will need to select a date and location.

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When choosing a **date and time** for your event, here are some important things to consider:

- Is there a significant date or time of year that is special to you or the child you are honoring? A birthday or an anniversary? Difficult timeframes you might want to avoid?
- What type of event do you want to hold? Does it need to be outdoors? If so, warmer months might be best. Would it be better to have it indoors? If so, then any time of year would work.
- Who will be interested in coming to your event? If you are expecting it to be family-oriented, daytime, weekend events tend to be best. If you are hoping for it to be for adults, perhaps a weekend evening might be best.

When choosing a **location**, here are some important things to consider and items to discuss with the manager of the potential venue:

- Adequate space. How many people do you hope to attend? Do you have enough space for everything you want to do? Registration? Refreshments? Seating? Raffles? Entertainment?
- Parking
- Restrooms
- Wheelchair accessibility
- Public permits needed. Does the location you are considering require you to have any specific permits to hold your event there?
- Proof of insurance. Does the venue require you to have and be able to provide proof of insurance?
- Equipment included. What do you need for your event and will the venue be able to help provide it? For example, tables, chairs, audio/visual equipment, dishes and/or utensils, bowling shoes for a bowling event, golf carts for a golf event, etc.
- Food and beverages. Are you able to bring food/beverages/alcohol to the venue? Or do you have to use the food it provides or one of its preferred vendors?
- Signage. How and where will they allow you to hang signage for your event?
- Booking the venue. Do you need to sign a contract or provide a deposit?

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B. Create a Timeline

Creating a timeline will help to keep you on track with planning your event, help you stay organized and prevent you from forgetting any important elements. It will be helpful to create a timeline for the months leading up to your event to help with planning it as well as a timeline for day-of logistics and follow-up timeline for after your event concludes.

To see a sample(s) timeline, please refer to the link in **Appendix D**.

C. Create an Event Budget

Creating an event budget is essential to ensure your event meets its fundraising goals. Your budget should include any costs you will likely incur in planning the event, but it should also outline your revenue streams and fundraising goals. As a general rule, your total expenses should equal no more than 20 to 25 percent of your fundraising goal. This may seem daunting, especially if you have not hosted an event before. Feel free to work with the Foundation Director of Development to plan a budget that works for your vision and provides you peace of mind. The first year you plan your event, it may be necessary to cover some one-time start-up costs. For example, you may want to order a banner for your first event that you can reuse for future events if you choose to. For a sample budget, please refer to the link in **Appendix E**.

If you choose to host an SUDC Foundation Event, your budget will be submitted to the SUDC Foundation for prior approval.

As you establish your budget, here are some things to consider:

- What will your expected costs be? This can and should include
 - Any costs associated with your venue
 - Renting equipment (tents, tables, chairs, audio/visual equipment, etc.)
 - Food and beverages
 - Publicity (signs, flyers, postcards, advertisements, website, etc.)
 - Giveaways and/or items available for purchase (T-shirts, bags, souvenir cups, pens, etc.)
 - Entertainment

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- How will your event raise funds?
 - **Will there be a cost associated with attending the event?** If so, how much?
 - **Will you raffle items off?** Will those items be donated? Please see **Appendix F and Appendix G** for sample in-kind donation request letters. A raffle can feature items, often donated by family, friends or local businesses to the event, as an additional fundraiser. Items to be raffled off can include anything from themed baskets, larger items or tickets to sporting events or guest packages to resorts or hotels. Patrons attending your event usually purchase a set of tickets and enter to win each prize in a drawing at the event. There may be specific laws and regulations that govern the use of raffle fundraisers in the area you are hosting the fundraiser. The staff at the SUDC Foundation would be happy to assist in helping you to adhere to those.
 - **Will you hold a 50/50 raffle?** Patrons typically purchase tickets in a 50/50 raffle for a chance to win half of the proceeds raised by the raffle. The other half of the proceeds go directly to the fundraiser.
 - **Will you host a silent or live auction?** Will the items to be auctioned off be donated? Auctions usually feature higher-priced items donated to the event to raise additional funds. Your auction can be “silent” by putting a bid sheet next to an item while it is displayed, and patrons can put their name and the amount they are willing to pay for the item on the bid sheet. Please see **Appendix H** for sample silent auction bid sheets. An auction can be “live” by having someone announce items available for auction and asking bidders to shout out the amount they wish to pay for the item. In both types of auction, the items goes to the highest bidder.
 - **Will you solicit sponsors for the event?** Creating a sponsorship program for your event can help bring in large donations, typically from businesses, but possibly from individuals as well. You can offer the opportunity to be the “Event Sponsor,” in which the sponsoring entity is mentioned each time the name of your event is mentioned. For example, your event could be called “Baseball for Benjamin sponsored by Smith & Co.” You can also create various levels of sponsorship packages (Platinum, Gold, Silver, Bronze, etc.) that include different incentives for each level. Some suggestions can include featuring company logos on publicity in advance of the event, mailed invitations or postcards, placement on the event website, signage at the event, T-shirts, placement in the program,

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etc. Please contact Elizabeth Milliken, SUDC Foundation Director of Development at elizabeth@sudc.org as you develop your sponsorship program to see if the Foundation has existing relationships with business in your area. Please also see **Appendix I** for a link to sample sponsorship levels, **Appendix J** for a sample sponsorship application and **Appendix K and L** for sample sponsorship letters.

Tips for Soliciting Sponsors:

- You may want to ask to sell tickets or offer registration opportunities at a sponsoring company's location. It will help drive business to the company and help to publicize your event further.
- As you solicit sponsors, try to find a connection between your cause/event and the business you are soliciting. You may be able to make a personal connection through friends or family, or connect with the owners as a parent or grandparent. You may choose to emphasize the benefits to their business in contributing to the event. Approximately 81 percent of consumers report switching to brands that support a good cause (<https://www.mobilecause.com/fundraising-event-planning/>).
- Start early! Many companies, especially larger ones, schedule their charitable donations well in advance. The further along they are in their financial reporting cycle, the less likely it is they will have room in their budget to be able to contribute to your event.
- Instead of or in addition to asking a business to be a sponsor of your event, you may want to ask it to donate goods or services to your event to help offset costs. Your event venue, local grocery stores, rental companies, catering companies, restaurants/bakeries and artists/entertainers may be willing to donate their time, services and products to your event.
- **Will you solicit and accept monetary donations?** Please ensure any checks intended to go directly to the SUDC Foundation are made payable to the SUDC Foundation.
- **Will your event include other ways to raise money?** Do you want to incorporate a bake sale? Sell novelty items, such as T-shirts, souvenir cups, pens, bags, etc.?

As you are researching the best value for items you may need to buy, please see **Appendix M** for a list of suggested vendors provided by the SUDC Foundation. The SUDC Foundation receives no financial incentives from any of the vendors on the list. It is simply a list of vendors

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compiled with suggestions and experiences from people who have planned events with the Foundation in the past.

D. Recruit and Manage Volunteers

Depending on the size and scale of your event, you may want to consider recruiting some dedicated volunteers to help you pull it all off. This section offers suggestions on managing volunteers as well as ways to break them into committees to help ensure you have assistance with all aspects of planning your event.

If you choose to recruit volunteers, you will likely want them to be involved starting early so they can help you throughout the planning process as well as involving additional volunteers to help you in the days leading up to and the day of the event.

As you build your timeline, be sure to include regular meetings or virtual check-ins with your team of volunteers. Your first planning meeting should be no later than approximately three months before your event, but it could take place as soon as you have your date and location confirmed. Consider crafting and utilizing agendas to run your meetings and ensure you don't miss any details.

Please see **Appendix N** for a link to a Sample Volunteer Management Template.

You may want to divide your volunteers into groups, or committees, to ensure all of the essential elements of your event have adequate coverage and to allow volunteers to contribute to an area of interest to them.

Even if you take a “committee approach” to dividing up the work, the Fundraiser Host Ambassador will ensure that groups communicate, cooperate and collaborate with each other.

Below are some examples of the types of committees you may wish to form as well as the suggested skill set and responsibilities for each.

Marketing and Public Relations Committee

Important skills and interests:

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- Marketing/publicity skills for advertising your event
- Graphic design skills for helping to create promotional materials
- Copy writing skills
- Knowledge of printing on a large scale
- Public relations and media outreach experience
- Direct mail experience for promoting your event through mailing campaigns

Responsibilities:

- Managing the design and execution of materials including brochures, invitations, flyers, posters, banners website and social media platforms (Facebook, Twitter, Instagram, etc.)
- Posting local advertising including hanging posters, mailing promotional materials, distributing flyers and brochures, etc.
- Working with the Fundraising Host Ambassador to obtain any necessary permissions and approvals from the SUDC Foundation
- Contacting local media if the event is newsworthy. The SUDC Foundation can provide any interested media with a [Media Kit](#). The link is also available in **Appendix O**. **Please note that anyone who speaking *on behalf of the SUDC Foundation* must also be a registered member of the SUDC Foundation and have gone through the appropriate application and training process to be a Media Spokesperson Ambassador.**
- Making arrangements for the event to have a photographer and videographer
- Managing mailing of postcards and/or invitations

Sponsorship Committee

Important skills and interests:

- Comfortable with speaking to people they don't know and soliciting donations
- Well-organized

Responsibilities:

- Help create sponsorship levels
- Solicit sponsors

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- Maintain database of potential sponsors (including contact information), track progress and monitor what each will be donating as well as what incentives they have been promised
- Coordinate with fundraising committee to prevent duplicating efforts
- Maintain communication with committed sponsors

Operations and Logistics Committee

Important skills and interests:

- Well-organized
- Event planning and/or running experience

Responsibilities:

- Planning set-up and clean-up of event
- Managing registration, ticket sales or check-in
- Safety (Ensuring proper safety measures are organized including contacting local police or emergency personnel. Please see **Appendix P** for a link to an Emergency Planning Protocol guidance)
- Helping create and maintain a checklist of day-of equipment and supplies needed. Please see **Appendix Q** for a list of equipment and supplies to consider having on the day of your event.
- Planning and executing decorations
- Helping create and maintain day-of event timeline
- Helping create and manage contingency plan. No event, no matter how well-planned, is exempt from mistakes or unexpected circumstances. What could go wrong with your event? List out any potential problems as well as a way you might be able to deal with those challenges if they come up. Having a backup plan will help ease stress the day of your event.

Fundraising Committee

Important skills and interests:

- Comfortable with sales/solicitation
- Well-organized

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Responsibilities:

- Organizing and managing fundraising activities at the event (raffles, bake or novelty sales, auctions)
- Maintaining database of potential donors (including contact information), track progress and monitor what each will be donating as well as what incentives they have been promised
- Coordinating with sponsorship team to prevent duplicating efforts

Food & Beverage Committee

Important skills and interests:

- Well-organized
- Comfortable with soliciting donations

Responsibilities:

- Making arrangements for food to be available at event
- Soliciting local vendors and businesses to donate food and beverage items for the event
- Managing the delivery/pick up, on-site locale, distribution, clean-up and donation of leftovers to food pantries
- Maintaining database of potential donors (including contact information), track progress and monitor what each will be donating as well as what incentives they have been promised
- Coordinating with sponsorship team to prevent duplicating efforts

Entertainment and Activities Committee

If your event will feature a formal program, entertainment or activities, you may want to consider adding an Entertainment and Activities Committee.

Important skills and interests:

- Well-organized
- Experience planning activities
- Knowledge of operating audio/visual equipment

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

Note: Material in this Ambassador Kit is subject to change at any time. With any updates, we will post the latest version the SUDC Ambassador website and that will, by default, replace the previous version.



The SUDC Foundation
800-620-SUDC (973-239-4849)
www.sudc.org

Updated 2.1.1

Responsibilities:

- Coordinating activities, supplies and prizes
- Planning and coordinating any memorial activities. The SUDC Foundation can provide pictures and names of children lost to SUDC whose parents and/or guardians have given the proper permission for their use in events. The Fundraiser Host Ambassador must coordinate with the SUDC Foundation to access those.
- Scheduling and tracking entertainment plan including the schedule for any formal program and where and when any music will be played
- Testing all audio/visual equipment the day of the event

V. PUBLICIZING YOUR EVENT

Publicizing your event is a terrific opportunity to share the story of your loved one as well as raise awareness of SUDC and the SUDC Foundation.

Publicity Requirements from the SUDC Foundation

- It is essential that anyone promoting and publicizing your event use consistent language when describing SUDC and the SUDC Foundation. Please see **Appendix R** for the Key Messages and **Appendix S** for Difficult Questions to Answer Messaging Guidance that will provide helpful guidance with approved language and accurate information on SUDC and the Foundation.
- When mentioning the leadership of the SUDC Foundation, please refer to Laura Crandall, Co-Founder, and President and Executive Director and Lorri Caffrey, Co-Founder and Assistant Executive Director.
- Please refer to the SUDC Foundation as such, not The SUDC Foundation, especially in written materials.
- When posting information on social media, please include a link to the www.sudc.org and tag the SUDC Foundation's social media platforms

Tips for publicizing your event

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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www.sudc.org

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- Create a website for your event. The SUDC Foundation offers free memorial websites for any registered family to remember a child lost to SUDC. The site is hosted on the SUDC Foundation’s website. Registered families may work with a member of the SUDC Foundation staff to create a loving tribute to their child. The site contains about 4 pages with sections for you to share pictures of your loved one, tells site visitors about him or her, make donations in his or her memory and an optional page to publicize any event you host in support of the SUDC Foundation’s mission. You will also receive your own web address to share with family and friends. To request a memorial website, please fill out a [Memorial Site Request Form](#) on the SUDC Foundation’s website.
- Create a Facebook profile and/or event to help promote your event via social media and garner extra interest when patrons interact with and RSVP to the page. If you are hosting an SUDC Foundation Event, Foundation staff can help you create this page.
- Invite family and friends to distribute event flyers and post and share event updates on social media

Earned Media

“Earned media” is when a member of the media (radio, print, television or web) covers your event. It is called “earned” media because the outlet is covering your event because of its newsworthiness, not because anyone paid it to be there, as it would be with paid advertising.

The SUDC Foundation has a [Media Kit](#) available to be given to any members of the media who wish to cover your event. The Foundation can also provide some tips and resources for assessing the “newsworthiness” of your event, conducting strategic media outreach, producing press materials for your event and being interviewed by the media. **Please note that anyone who speaking on behalf of the SUDC Foundation must also be a registered member of the SUDC Foundation and have gone through the appropriate application and training process to be a Media Spokesperson Ambassador.**

Please follow up with the SUDC Foundation following any media coverage of your event.

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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VI. AFTER YOUR EVENT

In order to maximize the success of your event and improve the chances of continuing that success into subsequent events you may wish to plan, after your event, consider taking these additional steps:

- ✓ Celebrate and thank your volunteers for all their hard work
- ✓ Clean up and catalogue/store any materials that can be used again
- ✓ Manage your donations. Any donations designated for the SUDC Foundation must:
 - Be sent to the SUDC Foundation, 549 Pompton Avenue, Suite 197, Cedar Grove, NJ 07009.
 - Be made payable to The SUDC Foundation if in check form.
- ✓ The SUDC Foundation encourages that all participants, donors and sponsors receive a formal thank-you letter. All donors contributing over \$250 must receive a tax receipt by law. SUDC Foundation staff would be happy to help you coordinate any thank-you letters if you wish to provide necessary contact information. Please see **Appendix T** for sample monetary and **Appendix U** and **Appendix V** for sample in-kind thank-you letters.
- ✓ Update event website and social media platforms with photographs and thank-yous from the event. Please share any photos with the SUDC Foundation if you are willing.
- ✓ Host a post-event evaluation meeting with volunteers to discuss successes, opportunities for improvement and room for growth for the event to help plan future events. You may want to consider asking some of your participants to fill out a post-event evaluation to help inform your discussion. You can find a sample in **Appendix W**.
- ✓ Contact the SUDC Foundation and let staff know the date for next year's event!

If your event is considered an SUDC Foundation event, please follow the additional instructions:

- ✓ Upon completion of the event, all forms, receipts and a formal accounting shall be mailed to The SUDC Foundation (549 Pompton Avenue, Suite 197, Cedar Grove, NJ 07009) for proper file storage.
- ✓ Whenever possible, expenses associated with the event should be submitted to the SUDC Foundation for review and payment through the SUDC Foundation.
- ✓ Cash received at the event may be used to pay expenses, however, no item can be paid for without a proper receipt. All receipts should be marked accordingly as being "paid using cash from event."

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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- ✓ Often companies provide matching funds for monetary donations as well as for volunteer hours. If you receive an application for a company match from an event participant, please send promptly to the SUDC Foundation together with a copy of proof that the employee made the underlying donation. The Foundation will submit the completed application to the appropriate business in a timely manner.
- ✓ Checks should all be made payable to the SUDC Foundation and forwarded by mail to the SUDC Foundation, 549 Pompton Avenue, Suite 197, Cedar Grove, NJ 07009. This should be completed within 15 days of your event as a courtesy to participants and donors.

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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Appendix A: Categories of Events Quick Guide

	SUDC FOUNDATION EVENT	PRIVATE FOUNDATION EVENT	COMMUNITY EVENT
Event Beneficiary	All proceeds benefit the SUDC Foundation	All proceeds benefit the Private Foundation, with a portion of or all proceeds donated to the SUDC Foundation	A portion of or all proceeds benefit the SUDC Foundation
Event Organizers	Registered SUDC family in direct collaboration with SUDC Foundation staff	Private Foundation Foundation's board of directors and fundraising committee	Registered SUDC family or friend; often organized with other community groups, neighbors or businesses
Financial and Legal Oversight	Provided by the SUDC Foundation	Private Foundation's trustees and directors	Registered SUDC family or friend and/or community group
Event Liability	Covered by SUDC Foundation	Private Foundation assumes all liability for hosting the event and agrees to hold	The Fundraiser Host Ambassador will assume all liability for hosting the event and

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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		harmless the SUDC Foundation, its directors, servants, agents, employees and volunteers from any claims as a result of event	agrees to hold harmless the SUDC Foundation, its directors, servants, agents, employees and volunteers from any claims as a result of event
Access to Event Planning Resources from the SUDC Foundation	Any registered SUDC family can access any of the event planning resources the SUDC Foundation offers	Any registered SUDC family can access any of the event planning resources the SUDC Foundation offers	Any registered SUDC family can access any of the event planning resources the SUDC Foundation offers

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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Appendix B: IRS Determination Letter

The IRS Determination Letter can be found on the SUDC Foundation's website at:
<https://sudc.org/family-services/member-services-access/event-planning>

Appendix C: Current SUDC Foundation Financial Statement

Please visit the website and to read the SUDC Foundation's most current financial statement:
<https://sudc.org/about-us/financial-overview>

Appendix D: Sample Timeline

Please visit the event planning section of the website for a sample timeline:
<https://sudc.org/family-services/member-services-access/event-planning>

Appendix E: Sample Budget

Please visit the event planning section of the website for a sample budget:
<https://sudc.org/family-services/member-services-access/event-planning>

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The SUDC Foundation
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Appendix F: Sample New In-kind Donation Request Letter

[DATE]

Dear [NAME],

[CHILD'S NAME] was a happy and healthy child. At the age of [AGE], [CHILD'S NAME] went to sleep and never woke up. We still do not know why.

Sudden Unexplained Death in Childhood (SUDC) is a category of death in children between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy. Most often, a seemingly healthy child goes to sleep and never wakes up. At this time, we do not know what causes SUDC, how to predict it or how to prevent it.

Soon after our loss, we learned of the SUDC Foundation. The SUDC Foundation is the only organization worldwide whose purpose is to promote awareness, advocate for research and support those affected by SUDC. Being part of a community of others who have experienced SUDC helped us not feel so alone. And the SUDC Foundation provides all services at no cost to the people it serves. While the SUDC Foundation is making progress, much work remains ahead.

We have created this event in memory of [CHILD'S NAME] to raise awareness of SUDC and help bring about a world without SUDC so no family must go through what we have. The (first..second..third..etc.) annual [NAME OF EVENT] will take place on [DATE] at [TIME] at [LOCATION]. It will include [BRIEF DESCRIPTION OF EVENT].

We're now asking for assistance from organizations such as yours. Your generosity will play an instrumental role in minimizing this tragedy. Any gift you make is greatly appreciated and is tax-deductible to the extent allowable by law. In particular, we are hoping you might be willing to donate [GOOD OR SERVICE NEEDED].

Thank you in advance for your gift. Please feel free to contact me at [CONTACT INFORMATION] to learn more about getting involved. You can also visit our website at [WEBSITE] or the SUDC Foundation at www.sudc.org for more information.

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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www.sudc.org

Updated 2.1.1

Sincerely,
Family Name
In Memory of our angel [CHILD'S NAME]

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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www.sudc.org

Updated 2.1.1

Appendix G: Sample Repeat In-kind Donation Request Letter

[DATE]

Dear [NAME],

Your generosity last year had an immediate impact on the Sudden Unexplained Death in Childhood (SUDC) Foundation. Thanks to donations such as yours during [EVENT], we were able to raise more than [TOTAL MONEY RAISED] from [NUMBER] participants.

These funds were put to excellent use. For example, [DETAILS ON WHERE PREVIOUS FUNDING WENT TO SUPPORT].

But much remains ahead. As the [NUMBER] anniversary of [CHILD'S NAME] tragic death approaches, his/her parents are still living without knowing what caused their unfathomable loss. Countless other parents across the country and throughout the world share a similar struggle.

To continue our pursuit of this heartbreaking phenomenon, we're looking for your assistance again.

The second (third, fourth, etc.) annual [NAME OF EVENT] will take place on [DATE] at [TIME] at [LOCATION]. It will include [BRIEF DESCRIPTION OF EVENT]. Any gift you make is greatly appreciated and is tax-deductible to the extent allowable by law. In particular, we are hoping you might be willing to donate [GOOD OR SERVICE NEEDED].

Thank you in advance for your gift. Please feel free to contact me at [CONTACT INFORMATION] to learn more about getting involved. You can also visit our website at [WEBSITE] or the SUDC Foundation at www.sudc.org for more information.

Sincerely,
Family Name
In Memory of our angel [CHILD'S NAME]

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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The SUDC Foundation
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www.sudc.org

Updated 2.1.1

Appendix H: Sample Silent Auction Bid Sheets

To see sample silent auction bid sheets, please refer to the event planning section of the SUDC Foundation's website:

<https://sudc.org/family-services/member-services-access/event-planning>

Appendix I: Sample Sponsorship Levels

To see sample sponsorship levels, please refer to the event planning section of the SUDC Foundation's website:

<https://sudc.org/family-services/member-services-access/event-planning>

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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Appendix J: Sample Sponsorship Application

Name: [PERSON and/ or BUSINESS]

Address: (Please print)

Phone:

Email:

Sponsorship Options (please circle one)

Option 1: Platinum Sponsor

This option will be for sponsors contributing \$1,000 or more to the event and the SUDC Foundation. Sponsor's logo will be most prominent on all printed materials including advertising, promotions and T-shirts. Company signage (provided by you) will be visible at event.

Option 2: Gold Sponsor

This option is for sponsors contributing \$500. Sponsor's logo will be visible on all printed materials including advertising, promotions and T-shirts. Company signage (provided by you) will be visible at event.

Option 3: Silver Sponsor

This option is for sponsors contributing \$250. Sponsor's logo will be on T-shirts and on event day signage.

Option 4: Bronze Sponsor

This is if you do not wish to sponsor but would like to make a donation. Please indicate dollar amount (\$)

Option 5: Donation of materials or service to [EVENT NAME]

Item: Estimated Value: \$

Please make checks payable to: The SUDC Foundation

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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www.sudc.org

Updated 2.1.1

Appendix K: Sample New Sponsorship Request Letter

[DATE]

Dear [NAME],

[CHILD'S NAME] was a happy and healthy child. At the age of [AGE], [CHILD'S NAME] went to sleep and never woke up. We still do not know why.

Sudden Unexplained Death in Childhood (SUDC) is a category of death in children between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy. Most often, a seemingly healthy child goes to sleep and never wakes up. At this time, we do not know what causes SUDC, how to predict it or how to prevent it.

Soon after our loss, we learned of the SUDC Foundation. The SUDC Foundation is the only organization worldwide whose purpose is to promote awareness, advocate for research and support those affected by SUDC. Being part of a community of others who have experienced SUDC helped us not feel so alone. And the SUDC Foundation provides all services at no cost to the people it serves. While the SUDC Foundation is making progress, much work remains ahead.

We have created this event in memory of [CHILD'S NAME] to raise awareness of SUDC and help bring about a world without SUDC so no family must go through what we have. The (first..second..third..etc.) annual [NAME OF EVENT] will take place on [DATE] at [TIME] at [LOCATION]. It will include [BRIEF DESCRIPTION OF EVENT].

We're now asking for assistance in the form of sponsorships from organizations such as yours. Your generosity will play an instrumental role in minimizing this tragedy. Any gift you make is greatly appreciate and is tax-deductible to the extent allowable by law. I have enclosed information on sponsorship opportunities with this letter.

Thank you in advance for your gift. Please feel free to contact me at [CONTACT INFORMATION] to learn more about getting involved. You can also visit our website at [WEBSITE] or the SUDC Foundation at www.sudc.org for more information.

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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www.sudc.org

Updated 2.1.1

Sincerely,
Family Name
In Memory of our angel [CHILD'S NAME]

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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www.sudc.org

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Appendix L: Sample Repeat Sponsorship Letter

[DATE]

Dear [NAME],

Your generosity last year had an immediate impact on the Sudden Unexplained Death in Childhood (SUDC) Foundation. Thanks to donations such as yours during [EVENT], we were able to raise more than [TOTAL MONEY RAISED] from [NUMBER] participants.

These funds were put to excellent use. For example, [DETAILS ON WHERE PREVIOUS FUNDING WENT TO SUPPORT].

But much remains ahead. As the [NUMBER] anniversary of [CHILD'S NAME] tragic death approaches, his/her parents are still living without knowing what caused their unfathomable loss. Countless other parents across the country and throughout the world share a similar struggle.

To continue our pursuit of this heartbreaking phenomenon, we're looking for your assistance again.

The second (third, fourth, etc.) annual [NAME OF EVENT] will take place on [DATE] at [TIME] at [LOCATION]. It will include [BRIEF DESCRIPTION OF EVENT] and we would love if you would consider being one of our sponsors again. Any gift you make is greatly appreciated and is tax-deductible to the extent allowable by law. I have enclosed information on sponsorship opportunities with this letter.

Thank you in advance for your gift. Please feel free to contact me at [CONTACT INFORMATION] to learn more about getting involved. You can also visit our website at [WEBSITE] or the SUDC Foundation at www.sudc.org for more information.

Sincerely,
Family Name
In Memory of our angel [CHILD'S NAME]

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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Appendix M: Suggested Vendors

Below is a list of suggested vendors provided by the SUDC Foundation. The SUDC Foundation receives no financial incentives from any of the vendors on the list. It is simply a list of vendors compiled with suggestions and experiences from people who have planned events for the Foundation in the past.

Printing/Supplies

[PaperMart](#): Vast selection of party and gift supplies with a low-price guarantee

[Staples](#): Copy and printing services, raffle tickets, name tags, other office supplies; SUDC Foundation has an account you may be able to access

[VistaPrint](#): Graphic design services, marketing materials, invitations, signs, posters; SUDC Foundation has an account you may be able to access

[CustomInk](#): Design lab for quality T-shirts and novelties at a reasonable price with free shipping

[IronMark USA](#)

[DesignCrowd](#): Graphic design services including logo development

Crowdfunding

Crowdfunding is any online fundraising campaign that builds support for your cause through the collective efforts of family and friends, primarily via social media. Some sites that you can use to crowdfund include:

[Network for Good](#)

[JustGiving / FirstGiving](#)

[RunSignUp](#)

[Booster](#): T-shirts

[Bonfire](#): variety of T-shirts

[Facebook](#)

[SUDC Foundation Memorial Website](#)

Promotional Products

[4Imprint](#)

[Vistaprint](#)

[CustomInk](#)

[IronMark USA](#)

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Appendix N: Sample Volunteer Management Template

To access a sample volunteer management template, please visit the event planning section of the SUDC Foundation's website:

<https://sudc.org/family-services/member-services-access/event-planning>

Appendix O: Media Kit

To access the SUDC Foundation's Media Kit to give to members of the media who might cover your event, please visit the SUDC Foundation's website:

<https://sudc.org/media>

Appendix P: Sample Emergency Management Protocol

To access a sample emergency management protocol, please visit the event planning section of the SUDC Foundation's website:

<https://sudc.org/family-services/member-services-access/event-planning>

Appendix Q: Sample Equipment and Supplies list

- ✓ Tents
- ✓ Tables
- ✓ Chairs
- ✓ Alphabetized copies of pre-registered participants to check in
- ✓ Signage including banners, table top signs, easels
- ✓ Envelopes/cash boxes for cash/checks
- ✓ Pens
- ✓ Registration forms or additional tickets
- ✓ First Aid (bandages, ice bags, ace bandages, athletic tape, etc.)
- ✓ All appropriate paperwork including permits, contracts and insurance information
- ✓ Refreshments for volunteers
- ✓ Silent auction bid sheets
- ✓ Audio-visual equipment

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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- ✓ Raffle items
- ✓ Raffle tickets
- ✓ Trash bags
- ✓ Duct and masking tape
- ✓ Scissors
- ✓ Containers for leftover food

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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Appendix R: Key Messages

These Key Messages provide an **overarching communications guide for the SUDC Foundation**. They provide the groundwork for all Foundation communications. Message consistency is essential to the success of any organization. All future communications about and for the Foundation should include these messages in some manner.

These messages are **not a script and do not need to be memorized verbatim**. Instead, they should serve as a **guide outlining key concepts for all future communications**. Key words or phrases are bolded to emphasize those key concepts as well as accurate terminology preferred by the Foundation. But each communicator should use them in a manner that is most comfortable for him/her and best suited for the audience s/he is communicating with.

These messages are also **not intended to be limiting**. Each message point serves a specific and strategic purpose for the Foundation and are written succinctly and concisely for ease of communication. Each message point has additional data points to be incorporated when additional support is needed. Additional support can be added or expanded upon as needed as well.

These Key Messages have four main points:

- **The Need:** This message point explains the need that exists, the challenge that has to be overcome or a problem that must be solved.
- **Why We Do What We Do:** This message point clarifies why the Foundation exists and the void it fills.
- **How We Do It:** This message point describes how the organization works in its unique way to address the need, challenge or problem.
- **Vision:** This message point describes the world the organization hopes to create once it has accomplished its mission and the end result of its efforts after the needs are met, the challenges are overcome and the problem is solved.

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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SUDC Foundation's Key Messages

The Need: Every year, **at least 400 children** die for no known reason. Even after a **thorough investigation and autopsy**, families, medical professionals and death investigators have no answers on why a healthy and thriving child passes away suddenly and unexpectedly. The only answer we have currently is Sudden Unexplained Death in Childhood (SUDC).

- **Sudden Unexplained Death in Childhood (SUDC) is a category of death in children between the ages of 1 and 18 which remains unexplained after a thorough investigation and autopsy.**
- Most often, SUDC occurs in seemingly healthy children during sleep.
- At this time, **we do not know what causes SUDC, how to predict it or how to prevent it.**
- SUDC is believed to be rare; occurring in about **one in every 100,000 children.**
- **We do not know exactly how often SUDC occurs.** Because of inconsistencies in death certification practices and because the World Health Organization (WHO) lacks a specific way to record sudden and unexplained deaths in children that have been thoroughly investigated, it is impossible to know how widespread the problem is.

Why We Do It: **SUDC is one of the most under-recognized medical tragedies of our time.** The medical community and our society have failed these children and their families. **We have done far too little for far too long, and we have to change that.** Research is crucial to uncovering cause(s) of and ways to prevent SUDC deaths. Families not only need emotional support, but also medical guidance, assistance navigating the difficult and often confusing process of searching for what may have happened to their child and how to live their lives after loss.

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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Medical professionals need help providing the best medical care and emotional support for the families they care for.

- **While it is the fifth leading category of death among children ages 1 to 4, SUDC has received no public funding to date.**
- SUDC families often grieve in isolation, without information, resources or awareness that other families exist with a similar loss.
- Due to a lack of consistency and standards in death investigations, coroners and medical examiners don't always have the resources to perform all the testing needed to thoroughly investigate each child's death or give the support families need.
- The lack of consistency and standards leads to a lack of data, further exhausting the medical community's ability to find overarching connections and trends in SUDC deaths.

How We Do It: The SUDC Foundation is the only organization worldwide whose purpose is to promote awareness, advocate for research and support those affected by SUDC. The SUDC Foundation provides all services at no cost to the people it serves.

- The SUDC Foundation currently supports **over 800 families in 18 countries.**
- The SUDC Foundation provides personalized, comprehensive care from licensed clinical social workers with a variety of programs and cultivates a community of support for bereaved families so no one grieves alone.
- The SUDC Foundation helps families navigate the difficult and often confusing investigation into their child's death by being a liaison between families and the medical examiner or coroner.
- The Foundation assists families in accessing DNA banking services and SUDC research, including the Sudden Unexplained Death in Childhood Registry and Research Collaborative (SUDCRRC), at New York University. The SUDCRRC provides families with a thorough case review of a child's medical history and death, as well as additional

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testing to examine possible causes and ways to diagnose and prevent SUDC.

- The SUDC Foundation helps doctors, medical examiners and coroners to care for and communicate with families experiencing the sudden, unexpected and/or unexplained loss of a child.
- The SUDC Foundation supports efforts, including legislative, to ensure comprehensive and standardized death investigations, fair treatment of and appropriate medical care for families and thorough data collection to improve our understanding of SUDC.

Vision: **The SUDC Foundation envisions a world where no more children are lost to Sudden Unexplained Death in Childhood.**

Appendix S: Difficult Questions to Answer Messaging Guidance

[Question: What is the cause of SUDC?

Answer: *At this time, we do not know what causes SUDC. Sudden Unexplained Death in Childhood (SUDC) is a category of death, **not a cause of death**, in children between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy. It is likely that SUDC does not have a single cause, but many causes, and is an umbrella term to describe these deaths that have not been specifically determined.*

Question: Is SUDC like SIDS (Sudden Infant Death Syndrome) and/or SUID (Sudden Unexplained Infant Death)?

Answer:

*SUDC is **similar** to SIDS/SUID in that it occurs in otherwise healthy children most often during sleep and has no known explanation. There may be other similarities, but research on SUDC is in its early stages and more is needed to better understand how similar or different the underlying causes are.*

*The biggest **difference** we know is that a child's death may be certified SIDS/SUID only before he or she is 12 months old. A child's death may be certified as SUDC if he or she is over 1 year old, but under the age of 18.*

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More background information: A death is “certified” based on how the cause and manner of death is described on the death certificate. In most areas, this is performed by a medical examiner or coroner, although some exceptions do exist. One challenge to answering this question, and to research on this subject in general, is the lack of standardized autopsies on infants and children who die suddenly, resulting in data that is inconsistent and incomplete. Consistent and complete data is essential for sound research. The SUDCRRC is collecting the largest registry of SUDC victims and is poised to better explain the similarities and differences of sudden infant versus child death in the future.

To learn more about the differences between SUDC and SIDS/SUID, please refer to the SIDS/SUDC message guidance on the Ambassador website. Of note, there are two meanings to the acronym SUID. Sudden Unexpected Infant Death (SUID) is used to describe the death rate of the three most frequent types of sudden unexpected deaths, which are SIDS, undetermined deaths and accidental asphyxia. Sudden Unexplained Infant Death, SUID, as used in this document refers to the terminology used for a final cause of death sometimes used by pathologists.

Question: Is SUDC caused by brain abnormalities that have been reported in some cases of SIDS/SUID?

Answer: Research into the possible causes of SIDS/SUID and sudden unexpected infant deaths has received over \$500 million in public funding to date. SUDC has received no public funding for research, so SUDC research has been far less extensive. We do not yet know if there is a correlation between brain abnormalities and SUDC.

More background information: Research involving brain abnormalities in some cases of infants who have passed from SIDS/SUID studied abnormalities in the autonomic nervous system which may have affected an infant’s ability to react to some life-threatening situations, such as increasing levels of carbon dioxide. Similar studies have not yet occurred to date in SUDC cases due to lack of funding, as well as difficulties accessing appropriate biospecimens from suspected SUDC victims. The SUDC Registry and Research Collaborative (SUDCRRC) is currently performing comprehensive brain analyses of children affected by SUDC to better understand potential brain mechanisms that may exist.

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Question: Do vaccines cause SUDC?

Answer: *There is no scientific evidence that vaccinations increase the risk for SUDC. However, it is important to understand that the purpose of a vaccine is to cause an immune response to build immunity for that disease if/when exposed in the future. Immune responses vary from individual to individual, whether that response is from an exposure to a virus, bacteria or vaccine.*

Significant research in this area has occurred. A study published in 2015 examined over 2,000 deaths reported to the U.S. Vaccine Adverse Event Reporting System (VAERS) database between 1997-2003. This study found no relationship between vaccinations and death despite an estimated 2 billion doses of vaccines administered during the same time period.

The SUDC Foundation recommends all families follow guidelines provided by the American Academy of Pediatrics in regard to maintaining current vaccinations. These vaccinations protect children from significant diseases that have a higher incidence of death than SUDC and lead to disability and mortality.

The SUDC Foundation works tirelessly to find the most accurate answers for sudden, unexpected and/or unexplained child deaths, whatever they may be. Through funding the most highly-qualified research to date on SUDC, we endeavor to not just find “an” answer for our children’s deaths, but “the” irrefutable answers to ensure a brighter future for all children.

You can read more at:

<https://academic.oup.com/cid/article/61/6/980/451431>

<https://www.cdc.gov/vaccinesafety/concerns/febrile-seizures.html>

Question: How often does SUDC occur and why don’t we know exactly how often SUDC occurs?

Answer: *SUDC is believed to be rare; occurring in about one in every 100,000 children. We do not know exactly how widespread SUDC is. Unlike with SIDS/SUID and known causes of death, the World Health Organization (WHO) does not have a specific classification code for sudden, unexplained deaths in children over 364 days old when a comprehensive investigation has taken place. This makes tracking deaths determined to be unexplained after a thorough investigation impossible at present. We are only able to estimate SUDC deaths by examining the*

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statistics of deaths with “undetermined” causes (R99), which is most likely an underestimation of the true incidence of SUDC.

Every year, at least 400 children are lost to undetermined causes. It is most common in young children and is the fifth leading category of death among children ages 1 to 4 years.

Question: Why haven't I heard of SUDC before?

Answer: The term SUDC was first used in 2005. It has received no focus from public health officials, no public research funding and no major awareness campaigns devoted to it. Currently, awareness efforts are limited to the vital work of the SUDC Foundation and its community. Unfortunately, most people first learn of it after a tragedy in their own child or someone they know. Raising awareness of SUDC is at the core of the work of the SUDC Foundation.

Question: Why has SUDC not received public funding for research?

Answer: It is difficult to know for sure. SUDC-related deaths are rare, and a lack of consistency in reporting them makes it difficult to recognize trends on a national or international level. As with the study of any rare medical phenomenon, it is vital to collect information to study enough children lost to SUDC to evaluate trends, identify risk factors and gain insight into its causes and eventual prevention. The SUDCRRC is a centralized registry to collect this vital information for the access of multiple researchers who would otherwise not be able to identify enough cases to study.

Question: Do febrile seizures cause SUDC?

Answer: At this time, we do not know. Febrile seizures are seizures provoked by fever and/or illness. They are believed to be harmless, and more than 95 percent occur in around two to four percent of all children 6 months to 6 years. They commonly run in families. In some patients, prolonged febrile seizures can cause scar tissue in the brain and predispose the child to subsequent epilepsy. Among families registered with the SUDC Foundation, more than 25 percent report a history of at least one febrile seizure in their child who died. We know the incidence of febrile seizures among families registered with the SUDC Foundation, but we do not know how this relates to all families affected by SUDC in the general population. The data collected by the SUDC Foundation is based on families registered with us. It does not represent all families affected by SUDC and it is not population-based. This could lead to biased data. The SUDC Registry and Research Collaborative is examining the potential link between febrile seizures and some instances of SUDC.

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Additionally, Sudden Unexpected Death in Epilepsy (SUDEP) refers to the sudden and unexpected death of a person with epilepsy that is unexplained after a thorough investigation. Children with febrile seizures are not diagnosed with epilepsy, however SUDEP research may also aid SUDC research in better understanding possible causes of death.

Question: Is SUDC genetic? Can it happen more than once in the same family?

Answer: *Although rare, we know that there are some genetic causes of sudden death that are not discovered by standard autopsy investigations. This is one of the many reasons that we advocate for comprehensive investigations, including genetic testing, for all sudden unexplained deaths, as well as screening of family members. Research will improve our understanding of the specific genetic variations that may contribute to some cases of sudden death that currently fall under SUDC. This could lead to the ability to screen at-risk children and help them receive appropriate medical care.*

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Appendix T: Sample Monetary Donation Thank-You Letter

[DATE]

[NAME]

[ADDRESS]

Dear [NAME],

Thank you so much sponsoring the (first, second, third, etc.) annual [NAME OF EVENT] and for your generous donation to the Sudden Unexplained Death in Childhood (SUDC) Foundation. The event was an overwhelming success on all accounts! Thanks to people like you and your organization, we raised more than [DOLLAR AMOUNT] and spent the day with [NUMBER] friends and family members. It was a beautiful tribute to our precious (son/daughter) [CHILD'S NAME] on the weekend of what would have been (birthday, anniversary, other special occasion).

In honor of [CHILD'S NAME], proceeds will help support the SUDC Foundation's mission. Please remember that contributions are fully tax-deductible to the extent allowable by law. The SUDC Foundation can be referenced under federal tax ID 46- 5008779. Please retain this letter as a receipt for your files with the amount of your donation as [AMOUNT OF DONATION].

On behalf of our family and the SUDC Foundation, thanks again for your involvement with this year's [EVENT]. We are deeply touched by your support and we hope to see you at next year's event!

Sincerely,
[NAME OF FAMILY]

If you have any questions or need any help planning your event, please contact the Ambassador Program Assistant at ambassadorprogram@sudc.org.

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Appendix U: Sample New In-Kind Donation Thank-You Letter

[DATE]

[NAME]

[ADDRESS]

Dear [NAME],

Thank you so much for your wonderful donation of [GOOD OR SERVICE] at a value of [ENTER AMOUNT IF KNOWN] to [EVENT] and for your generous donation to the Sudden Unexplained Death in Childhood (SUDC) Foundation. We are so grateful. There are no words to express how much we appreciate the love and support from our community. While the pain of losing [CHILD'S NAME] is still so strong, his/her spirit shines so bright and it is evident through the love and generosity of people like you.

Your donation will directly benefit the Sudden Unexplained Death in Childhood (SUDC) Foundation. Our hope is that in honor of [CHILD'S NAME], the money raised this year will help the SUDC Foundation continue its mission to promote awareness, advocate for research and support those affected by sudden unexpected or unexplained death in childhood.

Please remember that the value of your contribution and/or gift is tax-deductible to the extent allowable by law. The SUDC Foundation can be referenced under federal tax ID number 46-5008779. Please retain this letter for your files as your receipt for the charitable donation.

Thank you again, on behalf of our family and the SUDC Foundation, it is truly appreciated.

Please consider joining us again next year.

Sincerely,

[FAMILY NAME]

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Appendix V: Sample Repeat In-Kind Donation Thank-You Letter

[DATE]

[NAME]

[ADDRESS]

Dear [NAME],

Thank you so much contributing to the (second, third, fourth, etc.) annual [NAME OF EVENT] and for your generous donation to the Sudden Unexplained Death in Childhood (SUDC) Foundation. The event was an overwhelming success on all accounts!

Thanks to people like you and your organization, we raised more than [DOLLAR AMOUNT] and spent the day with [NUMBER] friends and family members. It was a beautiful tribute to our precious (son/daughter), [NAME], on the weekend of what would have been his/her (birthday, anniversary, other special occasion).

Please remember that contributions are fully tax-deductible to the extent allowable by law. The SUDC Foundation can be referenced under federal tax ID 46-5008779. Please retain this letter as a receipt for your files of your contribution of [NAME OF GOOD OR SERVICE PROVIDED] with the value of [DOLLAR AMOUNT IF KNOWN].

On behalf of our family and the SUDC Foundation, thanks again for your involvement with this year's [EVENT]. We are deeply touched by your support and we hope to see you at next year's event!

Sincerely,
[FAMILY NAME]

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Appendix W: Sample Post-event Evaluation Questions

To access a list of sample post-event evaluation questions, please visit the events planning section of the SUDC Foundation's website:

<https://sudc.org/family-services/member-services-access/event-planning>

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