



## Do It Yourself (DIY) Event Policies and Guidelines

Thank you for your interest in supporting Cure SMA! Cure SMA depends on generous support from our community of donors, supporters, sponsors, and volunteers to fuel our mission to cure SMA. Funds raised through by your DIY event will directly impact our work by increasing investment in research, care, and direct support services for the SMA community.

### About Cure SMA

Cure SMA is dedicated to the treatment and care of spinal muscular atrophy (SMA)—a disease that takes away a person's ability to walk, eat, or breathe. SMA is the number one genetic cause of death for infants. Since 1984, Cure SMA has grown to be the largest network of individuals, families, clinicians, and research scientists working together to advance SMA research, support the full SMA community, and educate the public and professional communities about SMA. The organization has directed and invested in comprehensive research that has shaped the scientific community's understanding of SMA, led to breakthroughs in treatment and care, and provides individuals and families the support they need today. We are currently on the verge of breakthroughs that will strengthen bodies, extend life, and lead to a cure.

Learn more about Cure SMA and its programs at [www.cureSMA.org](http://www.cureSMA.org).

### Overview

Cure SMA defines a Do It Yourself (DIY) event as any fundraising activity by a non-affiliated group or individual (third party), where Cure SMA has limited fiduciary or oversight responsibilities. Cure SMA is not liable or responsible, under any circumstance, for the promotion and/or staging of a DIY event. The event organizer shall sign a waiver and indemnification agreement detailing that the organizer assumes all risk for expenses and liabilities.

All funds received from a Do It Yourself (DIY) event are considered unrestricted unless stated otherwise in writing by the check writer(s). Expenses may not be offset against gross revenue without the written consent of Cure SMA in advance of the event. If expenses are being taken out from the gross revenue, the organizer should indicate in advance of the event either the guaranteed donation or the percentage of gross proceeds that will be donated to Cure SMA. If the organizer takes out expenses from the gross, Cure SMA may reserve the right to review event financial statements at any time. Unless the organizer is registered as a 501(c)(3) organization, donations made payable to the organizer do not qualify as charitable, tax deductible contributions. Donations made payable directly to Cure SMA, are tax deductible to the full extent of the law.

To be classified as a Do It Yourself (DIY) event, it must be demonstrated that Cure SMA is not involved in raising the money; that is, the event is not managed by Cure SMA staff. Cure SMA staff is not involved in planning, income and expense accounting, or event execution, and Cure SMA does not incur any expense because of the event other than minimal amounts such as mileage reimbursement for attending the event. Do It Yourself (DIY) event organizers must comply with all local laws relating to fundraising, and Cure SMA staff should remind Do It Yourself (DIY) organizers to check local law. Organizers should not utilize Cure SMA's name in securing any relevant permits or licenses. Accordingly, Cure SMA shall have no obligation to report to the state or local government the activities of the DIY organizer.

## **COVID-19 Event Regulations and Procedures**

Do It Yourself (DIY) event organizers should be aware of and are required to comply with local, state, or federal regulations and CDC guidance governing gatherings and events. The event organizer agrees to implement the appropriate precautions, including limiting event size, encouraging mask use, and implementing social distancing to limit exposure to COVID-19.

## **How Cure SMA Can Help with Your Approved Promotional Activity or Event**

1. List your event/promotion on Cure SMA's website and local social media if 100% of the event's proceeds are being directed to Cure SMA.
2. Provide information and quotes for your press release.
3. Provide standard promotional materials.
4. Provide acknowledgement letters for donors who make checks payable to "Cure SMA."

Consult with the DIY event organizer and provide guidance and fundraising resources for your event to the best of our ability.

## **Limitations**

1. Due to the volume of events and promotions, we cannot guarantee that a representative will be available to attend your event or events associated with your promotion.
2. Cure SMA will not supply any funding to finance a DIY event/promotion, nor will we be responsible for any debts incurred.
3. Cure SMA does not share or sell its internal list of donors or supporters, nor does it solicit these contacts for DIY events/promotions.
4. Cure SMA does not provide volunteers to run DIY events unless discussed and agreed upon when event/promotion proposal is approved.

## **Criteria to Use When Entering Third-Party Relationships**

The following criteria will apply to all DIY events/promotions conducted on behalf of Cure SMA:

1. Sponsoring organization/individual is responsible for all sales, marketing, and promotion of the event.
2. All publicity and/or promotional materials released to the mass media referencing Cure SMA's involvement require advance approval from Cure SMA.
3. Hazardous events will not be considered. These include:
  - a. Base jumping
  - b. Bull riding
  - c. Extreme skiing (adaptive skiing is permitted)
  - d. Gliding
  - e. Hang Gliding
  - f. Hot air ballooning
  - g. Motocross
  - h. Private aircraft travel
  - i. Rappelling
  - j. Rock climbing
  - k. Scuba diving
  - l. Skateboarding with stunts involved
  - m. Ski jumping
  - n. Skydiving
  - o. White water rafting/kayaking

4. If only a portion of the proceeds will go directly to Cure SMA, the sponsoring organization must clearly disclose to donors/participants the approximate amount or percent that will go to it.
5. Cure SMA and its mission must always be represented in a positive light by the sponsoring organization.
6. All marketing materials must be approved by Cure SMA in advance and comply with existing style guidelines regarding the use of the Cure SMA's logo and/or name.
7. Checks from participants of DIY events must be made out to sponsoring organization, unless otherwise approved by Cure SMA. Use of Cure SMA's tax ID number is strictly prohibited.
8. Sponsoring organization should provide Cure SMA with a list of targeted corporate sponsors. Cure SMA reserves the right to exclude solicitation of specific sponsors.
9. Cure SMA policies do not permit a DIY event to establish a bank account in the name of the organization. If a bank account is being established, it must be opened in the third-party's name.
10. The third-party will tender the percentage of net proceeds from the event due to Cure SMA within forty-five (45) days of the event.

### **Liability**

1. The DIY event organizer agrees to indemnify, defend, and hold harmless Cure SMA for any liability associated with the serving of alcohol at the event.
2. Local municipalities and property owners will often require third-party organizers to provide evidence of insurance particularly when the activity involves a specific number of participants/attendees. DIY event organizer activities shall not rely on Cure SMA's insurance for the event. We recommend organizers comply with insurance requirements as you assume ALL risk associated with the activity.
3. DIY event organizers are also responsible for obtaining applicable permits and licensing in use of all public facilities and/or properties through the appropriate municipality. Cure SMA has no responsibility for obtaining applicable licenses and permits.

### **Accessibility**

All DIY event activities should be accessible to people with disabilities. The activity should take place at a location that meets ADA regulations. DIY event organizers should promote and make arrangements for any special accommodation needs of participants, volunteers, and/or staff.

### **Indemnification**

By signing these guidelines, you agree to defend, indemnify, and hold harmless Cure SMA and its respective officers, directors, chapters, agents, volunteers, and employees, from and against any and all claims, demands, suits, judgments, losses, or expenses of any nature whatsoever (including reasonable attorneys' fees) arising from, or relating to the DIY/third-party activity or your breach of these guidelines.

### **Tax Issues**

Cure SMA is a charitable organization as defined under 501(c) (3) of the Internal Revenue Code. Any contribution to Cure SMA qualifies as a deduction under Section 170 of the Internal Revenue Code.

Difficulty could arise when an independent, outside organization wishes to raise money for Cure SMA. If the payments are made to this independent organization and it is not a qualified organization, the payments will not be deductible for income tax purposes. If the payments are made directly to Cure SMA then such payments are tax deductible.

**Policy Review**

Cure SMA may make changes from time to time to improve the effectiveness of its operation. Please contact Cure SMA staff should you have any questions regarding these guidelines.

If you have any questions or wish to comment about the Do It Yourself (DIY) Event Guidelines, please contact the Vice President, Finance & Operations by one of the following methods:

1. Email: [marline@curesma.org](mailto:marline@curesma.org)
2. Phone: 847.709.6318

**Approval**

A Cure SMA staff member will send a written approval or decline for your event within 7 business days of submission.

I certify that I have read and understand the intent of these guidelines and release.

Name (Please Print): \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_ Email: \_\_\_\_\_