

CCDS Fundraising Toolkit



A CCDS Fundraising Guide

To help you plan your next fundraising event

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Overview



How am I helping the Association for Creatine Deficiencies?

Thank you for your interest in raising funds to support the Association for Creatine Deficiencies (ACD). We are so grateful for people like you who want to partner in our mission to better the lives of those impacted by Cerebral Creatine Deficiency Syndromes (CCDS). Raising funds is crucial to our organization as we continue to provide patient, family, and public education, to advocate for early diagnoses, and to promote and fund medical research for treatments and cures for CCDS.

What does the ACD do with the donations they receive?

All donations go into PatientStrong, our general fund, which drives the following ACD initiatives:

PATIENT AND COMMUNITY

- Patient and family travel grants to attend the biannual CCDS Symposium
- CCDS Family and Physician Symposium costs

EDUCATION AND ADVOCACY

- ACD attendance of medical conferences and rare disease seminars
- Speaking at FDA public forums
- Providing up-to-date online CCDS resources
- Producing educational videos and materials for the public and allied healthcare professionals
- Partnering with other rare disease advocacy groups like the National Organization for Rare Disorders (NORD), and Global Genes to increase CCDS visibility
- Advocating for newborn screening at the state and national levels

MEDICAL RESEARCH

- Building a secure and comprehensive international patient registry
- Funding research grants
- Collaborating with medical professionals, drug developers, the Advisory Committee for Heritable Disorders in Newborns and Children, the National Institutes of Health (NIH), the Centers for Disease Control (CDC), and several others on research efforts related to early detection and potential therapeutics

How will this toolkit help me?

In this toolkit you will find several ideas and suggestions for planning fundraising events. These can be adapted to meet the needs of your specific context. Maybe you're ready to dive into the deep end and plan a large-scale fundraiser, or perhaps you'd rather get your toes wet first. No matter where you're at, this toolkit will have something for you!

Getting Started!



Choosing the right fundraiser for you is the first step in getting started. In choosing a fundraising event, consider your own strengths, your audience, and any circumstances that can impact your success. No matter how big or small, the right fundraiser for you is manageable, easy to communicate and execute...and, most importantly, **FUN!**

Private fundraiser vs. sponsored fundraiser

PRIVATE FUNDRAISER

The event host will be responsible for all fundraising expenses. The host will be responsible for the planning of the event, marketing materials, etc. Event materials can feature the ACD as the charity being supported, but should not indicate that the event is sponsored by the ACD. Donations received directly from donors via the ACD website or check will receive a receipt for their tax-deductible donation. If the private fundraising individual accepts cash, the ACD will not be able to recognize the individuals that contributed the cash.

SPONSORED FUNDRAISER

The ACD will collaborate with the event host on marketing materials (i.e. branding to promote the event, sponsorship packages, pricing structure, etc.). Expenses incurred by the host will only be reimbursed based on a budget that is agreed upon during the planning of the fundraiser. The ACD will limit the budget of fundraising expenses to the industry norm of 20% or less of income from the event.



Planning Your Fundraiser



Taking the ACD Challenge by choosing to plan a fundraiser is a huge advocacy effort. The ACD depends on funds generated through fundraising efforts to run our organization and mission-driven initiatives.

Here are 10 easy steps to get you started!

- 1. Put together a planning committee.** Gathering a group of enthusiastic, like-minded people to help you support the mission of the ACD will increase the chance that your event will be effective.
- 2. Brainstorm.** Meet together with your committee to brainstorm fundraiser ideas. Be creative!
- 3. Choose your event type.** Discern what type of event will be the best fit for your group. The type of fundraiser you put together will depend on the size, interests, talents, goals, and time availability of participants.
- 4. Identify your audience.** Who will be there? Who will be supporting the ACD's cause?
- 5. Develop a budget.** It's important to consider all of the costs associated with your event, as well as to brainstorm ways to keep costs low.
- 6. Develop a timeline.** This is important for keeping everything on track!
- 7. Schedule the event.** Choose a time that is convenient for participants. Be sure to check for conflicting events taking place in the community.
- 8. Tell us about it!** Let the ACD know about your event. We will list your event on our website and provide you with the link so you can share it with your contacts and through any social media platforms.
- 9. Submit Funds.** Please forward all funds to the ACD within 30 days following the event.
Address: 6965 El Camino Real, Suite 105-598, Carlsbad, CA 92009 USA.
- 10. Say thank you!** Send thank you letters, cards, emails or give a quick call to everyone who attended or supported your event. The ACD will also do their part to acknowledge and thank donors.

Fundraising Ideas



The best way to set up an effective fundraiser is by doing something that you enjoy!

IDEAS TO GET YOU STARTED

- › Dinner party
- › Car wash
- › Casual dress tickets
- › Pie smash
- › Bake off
- › Cake auction
- › Pot luck
- › Game night
- › Craft sale
- › Facebook birthday fundraiser
- › Backyard movie night
- › Lemonade stand
- › Pictures with Santa

INVOLVE THIRD PARTIES

- › Corporate match programs
- › Employer volunteer incentive programs
- › Volunteer grant programs
- › Charitable giving fund
- › Tax-deductible giving

FOR THOSE WHO FEEL MORE AMBITIOUS

- › Walk for Strength team/event
- › Bike-A-Thon
- › Garage sale
- › Luncheon
- › Women's goods/vendors party
- › Holiday Heroes fundraising event
- › Read-A-Thon
- › Flea market
- › Fashion show
- › Auction
- › Music concert
- › Scavenger hunt
- › Walk-A-Thon
- › Talent competition
- › School fundraiser
- › Football watch party

- › Sports tournament
- › Boat racing
- › Church fundraiser
- › Golf outing
- › Black-tie event
- › Dance-A-Thon
- › Dine out for a cause
- › Restaurant or retail promotion

Promoting Your Event

How and when to promote your event

It is helpful to establish an event timeline to maximize the publicity of your fundraiser.

3-4 months before the event - Identify your audience and let the ACD know about your fundraiser.

4-6 weeks before the event - Send out any media materials (i.e. emails, social media posts, posters, etc.)

2 weeks before the event - Follow up with any media contacts who received your information.

1-2 days before the event - Notify any TV news assignment desks/newspapers, giving them the basic details about your event.

Suggested language - It is important to use consistent messaging that accurately defines your mission and objectives. You are free to use the following description of the ACD in your communications. For more helpful descriptions, visit: <https://creatineinfo.org/about-acd/>

ABOUT ACD:

The Association for Creatine Deficiencies' mission is to eliminate the challenges of CCDS. ACD is committed to providing patient, family, and public education, to advocate for early intervention through newborn screening, and to promote and fund medical research for treatments and cures for Cerebral Creatine Deficiency Syndromes. Because CCDS mimic symptoms of other medical conditions, patients are often first diagnosed with autism, cerebral palsy, epilepsy, and other disorders. Proper diagnosis and early intervention are critical to establishing screening and treatments needed to improve life quality and longevity for the CCDS patient. To learn more about creatine deficiencies please visit: <http://www.creatineinfo.org>.

OUR MISSION:

To provide patient, family, and public education, to advocate for early intervention through newborn screening, and to promote and fund medical research for treatments and cures for Cerebral Creatine Deficiency Syndromes (CCDS).

ABOUT CCDS:

Cerebral Creatine Deficiency Syndromes are inborn errors of metabolism, which interrupt the formation or transportation of creatine. Creatine is necessary to increase adenosine triphosphate (ATP) which provides energy to all cells in the body. Creatine is essential to sustain the high energy levels needed for muscle and brain development. The most common symptom of CCDS is a global delay. Speech delay may be particularly severe, and intellectual disability of variable severity is typically present in older children and adults. Other additional symptoms may include seizure disorders, muscle weakness, autistic-like behaviors, movement disorders, gastrointestinal problems, and failure to thrive.

Share Success Take Pictures!



Social media is a really great tool for fundraising.

REMEMBER THE FOLLOWING WHEN POSTING ABOUT YOUR EVENT TO SOCIAL MEDIA:

- Tell your followers why you created the event, and share the event details, your goal, and the difference it makes for the ACD
- If you have a fundraising page, include the link if possible
- Share consistent posts before, during, and after your fundraiser
- Tag us in your photos on Facebook, Twitter, and Instagram

Photos are a great way to tell the story of your fundraiser.

HERE ARE SOME SUGGESTIONS FOR HOW TO TELL THE STORY WELL:

- Write out a list of photo opportunities you want to capture at your event
- Prioritize candid and close-up shots
- Include children in the photos, but be sure to ask permission from their parent/guardian
- If applicable, take photos of your corporate sponsors
- Know that photos featuring 1-3 people are most effective
- Post the photos to your social media accounts
- Send out photos as thank-you's to your supporters
- After the event, please email the best 3-5 photos to fundraising@creatineinfo.org with the names of the people in the photos



The Finishing Touches



The funds you raised will make a big difference for the patients and families served by the ACD. Thank you for your support!

After your fundraiser, be sure to:

SEND IN YOUR DONATIONS/PROCEEDS

Checks should be made out to **Association for Creatine Deficiencies**, and mailed to:
6965 El Camino Real, Suite 105-598
Carlsbad, CA 92009 USA

Please do not mail cash. Instead, get your local bank to convert the cash into a check, made out to the **Association for Creatine Deficiencies**, and mail it to the address above. Include a short summary description of your fundraiser

SEND A LIST OF DONORS

We would like to thank donors personally and keep them informed of future initiatives they might want to participate in. Email the list to **fundraising@creatineinfo.org**

SEND SOME PHOTOS FROM YOUR EVENT

Email the best 3-5 photos from your event to **fundraising@creatineinfo.org**

SAY "THANK YOU!"

Thanking those who participated in your fundraiser by sending them a card, letter, email or note is a great way to show your appreciation.

START THINKING ABOUT YOUR NEXT FUNDRAISING EVENT!

The best time to begin thinking about your next fundraiser is right after your event has concluded. You can take what you learned about what worked and what didn't to make your next event a success!

FAQ



Have questions? Luckily, we have answers to your fundraising FAQs.

CAN I USE THE ASSOCIATION FOR CREATINE DEFICIENCIES' TAX EXEMPTION NUMBER?

Because the ACD is not hosting your event, it is considered a third-party event. For this reason, you will not be able to use the 501(c)(3) charitable classification, federal tax ID number, or tax-exempt certificate. However, you may use the tax ID number for donation purposes.

OUR TAX EIN# IS: 46-2133007

CAN YOU HELP ME GET A PERMIT FOR MY EVENT?

The organizer is responsible for obtaining all necessary permits or licenses.

WHO WILL PROVIDE INSURANCE FOR MY EVENT?

The ACD cannot provide insurance for third-party events. If it is needed, the event organizer will be responsible for securing insurance.

WHAT CAN I PROVIDE TO PEOPLE WHO MADE DONATIONS FOR TAX PURPOSES?

Event organizers cannot use the ACD's tax exemption status in connection with the event. The ACD can provide an authorization letter confirming that the organizer is raising funds for the ACD. In addition, we will send them a letter acknowledging their donations.

WILL MY DONORS GET A RECEIPT?

Provide the ACD with names and addresses, or email addresses for donors or sponsors. The ACD will send them a personal thank you, and this will act as their receipt.

CAN SOMEONE FROM THE ACD ATTEND OR ASSIST IN PLANNING THE EVENT?

Staff members are generally unable to attend or plan events. We will offer guidance for your event, but we do not have the staff to handle the organizational and administrative tasks connected with this.

Fundraiser Guidelines

The Association for Creatine Deficiencies builds solid fundraising practices that uphold the highest ethical standards.

Below are guidelines for all fundraising initiatives.

ACD SPONSORED FUNDRAISER GUIDELINES

- The fundraiser host submits a **Fundraiser Support Request Form** to the ACD before announcing the event. This form details the plans for the event and what support is requested from the ACD. Please allow 14 days for review and approval.
- Once the request form has been approved, a **Fundraiser Host Agreement** is to be signed and submitted to the ACD. This form confirms the host's understanding of the use of the ACD logo, adherence to the approved budget for the event, and agreement to conform with the rules of an ACD sponsored fundraiser as outlined in the contract.
- If the event consists of a sporting component, participants must sign an ACD liability waiver form. If funds are collected directly by the event host, payment must be submitted by check within 30 days following the conclusion of the event.
- Reimbursement of hosting expenses, in accordance with the **Fundraising Host Agreement**, will be made after all funds have been given to ACD.
- The event host is responsible for obtaining any necessary permits and clearances required by local and state government and complying with all applicable laws, and also obtaining appropriate insurance coverage as necessary.
- All Sponsored Fundraising applications must state a specific budget for expenses based on a minimum income. Any expenses in excess of this budget are the responsibility of the fundraising host. Additionally, if the funds raised do not meet with the budget, the ACD will pay only the "Minimal Fundraising Budget" percentage listed in the contract.
- ACD retains the right to decline any event if it conflicts with its mission, fundraising efforts, or event calendar.

PRIVATE FUNDRAISER IN SUPPORT OF ACD GUIDELINES

- Any use of the ACD logo must be approved by the ACD. Examples include, banners, giveaways, invitations, etc.
- While keeping the event a "Private Fundraiser" the host may ask for social media support and/or a creatineinfo.org landing page. These may be provided at the discretion of the ACD board of directors.
- Donors making payments directly to ACD via our website or check will receive a receipt for their tax records.

Fundraiser Guidelines

PRIVATE FUNDRAISER IN SUPPORT OF ACD GUIDELINES CONTINUED...

- The fundraising host can be informed of donations made on the ACD website only if the donor makes their donation through a fundraiser specific landing page stating: "Your fundraiser host will be notified of your name and donation amount in order to acknowledge all event sponsors and donors. To make a private donation, please visit creatineinfo.org/make-a-donation." We are unable to disclose donors under any other circumstance.

For questions or more information on ACD Sponsored Fundraising Events and Private Fundraising Events, please contact fundraising@creatineinfo.org. Thank you for your interest in supporting the ACD!

ORGANIZER RESPONSIBILITIES

- All expenses are the responsibility of the event organizer. ACD is not responsible for any expenses incurred for a private fundraising activity, and will not advance funds or reimburse expenses unless approved in advance by the Board of Directors. We recommend finding event sponsors or charging an event fee to help cover expenses. You may not purchase goods or services under ACD's name, and ACD's sales tax-exemption (on purchase) cannot be extended to any third-party private fundraising effort.
- The event organizer is responsible for the planning and execution of the event including safety precautions and adherence to applicable laws. As the beneficiary of a fundraising event, ACD does not accept or assume any liability associated with the event, including, but not limited to, any injuries sustained by event volunteers or participants during the event. The event organizer will indemnify, defend, and hold harmless ACD, its directors, officers, and employees from any and all claims that may arise out of or relate to such event.
- The event organizer is responsible for obtaining all applicable permits or licenses, including, but not limited to, alcohol, solicitation, and sales tax licenses.

PROMOTION AND PUBLICITY

All third-party private events must be publicized and conducted in a manner that makes it clear that ACD is the beneficiary, not the sponsor or host of the event. Promotional materials must clearly state that the event is raising funds that will benefit ACD (e.g. "proceeds benefit ACD") Event names may not incorporate the name of ACD, as in "The ACD Walk-a-thon." ACD's name may be used in a second clause identifying the relationship of the event with the Association, such as "John Doe Walk-a-thon, benefiting ACD."

All event materials that include ACD's logo, including, but not limited to, advertising, press releases, posters, fliers, t-shirts, and public service announcements, must be reviewed and approved prior to distribution.

FINANCIAL POLICIES

The event organizer may not keep any portion of the proceeds (beyond real expenses) as profit or compensation. The event organizer may not set up a temporary bank account in ACD's name, as this is illegal. Donors must be informed that the tax deductible amount of a donation is only the amount that is over and above the value of any goods or services received in exchange for the donation. If a donor pays less than the value of an item, then they will not receive a tax deduction. If goods are sold to raise money as part of a fundraising event, it must be made clear to the event participants what percentage of the sale price benefits ACD.