



FUNDRAISING TOOLKIT

www.clovessyndrome.org



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OVERVIEW

How am I helping CLOVES Syndrome Community?

Thank you for your interest in raising funds to support CLOVES Syndrome Community (CSC). Our success depends on the initiative of supporters like YOU. Each dollar that you raise will allow CSC to support our community and make donations that will help further scientific and medical discoveries around CLOVES Syndrome.

What does CLOVES Syndrome Community do with the donations we receive?

Science & Research

Since 2014, CSC has donated \$73,000 to four research facilities focused on CLOVES and PIK3CA related conditions, around the world.

Family Services

CLOVES Syndrome Community provides support to people with CLOVES Syndrome and their families through social media, newsletters, our website, and our private Facebook group, providing emotional support, guidance, and information about CLOVES Syndrome. Our annual CLOVES Family Camp named Betsy's Camp is a no-staring zone, where families connect, relax and have fun lakeside.

Education

Our biennial CLOVES Family Conference brings together families and affected individuals with scientists and clinicians working with and researching CLOVES Syndrome. We have also created, printed and dispersed two books for children and youth with CLOVES.

Awareness

We work continuously to raise public awareness and generate additional support among individuals, community organizations, and the medical



community. Up-to-date information on CLOVES Syndrome--from medical issues to daily living issues--is available online.

How will this toolkit help me?

Feel free to use a few of our ideas and suggestions, or all of them – whatever works best for you and your event! For your first event, you may want to start with something simple and easy to plan. But whether you've hosted fundraising events in the past or are new to fundraising, the toolkit's aim is to make planning your fundraiser as easy as possible. From creating a timeline and a budget, to organizing and publicizing your event, this is a complete planning guide that will allow anyone to become a successful fundraiser for CSC.

LET'S GET STARTED!

Are you thinking of hosting a fundraiser to raise money for CLOVES Syndrome Community? The possibilities are endless!

Once you've come up with your fundraiser idea, email info@clovessyndrome.org--we're here to help!

How can CLOVES Syndrome Community help with my event?

- Consultation on fundraisers and events – we can help you brainstorm ideas and put you in touch with anyone who may have already organized an event like the one you're planning
- Approved use of our logo, when appropriate
- CSC branded literature and wristbands
- A letter of authorization to validate the authenticity of the event and its organizers
- Tax ID number for donation purposes only



- Help with writing letters, emails, press releases, and other promotional material
- Your own personalized fundraising page on Mighty Cause - <https://www.mightycause.com/organization/Cloves-Syndrome-Community>
- Regular reports of the donors who give to CSC through your fundraising efforts

Services we are unable to provide

- Our sales tax exemption number
- Insurance or liability coverage
- Mailing list of donors and/or vendors
- CLOVES Syndrome Community stationery
- Funding or reimbursement of your expenses
- Celebrities or professional athletes for your event
- Publicity (e.g. newspaper, radio, television)
- Guaranteed attendance of CSC staff

LET THE PLANNING BEGIN

Deciding to host a community fundraiser for CLOVES Syndrome Community is a huge accomplishment in itself – thank you!

Here are 10 suggested steps to help you get started:

1. **Form a planning committee.** Depending on the size of your event, bringing together a group of enthusiastic and dedicated people who share an interest in raising money for a great cause will increase the probability of a successful event. This could just be you and a few friends.
2. **Brainstorm.** Gather members of your planning committee, or just family and friends, to brainstorm ideas for your fundraiser. Give free rein to your imagination – several heads are better than one!



3. **Choose the “right” event.** The type of event you choose should fit the size, interests, talents, goals, and time availability of everyone involved.
4. **Identify your audience.** Consider who is most likely to attend and support the type of event you have selected.
5. **Develop a budget.** Try to identify expenses and possible sources of funds, including securing in-kind products and services. This will help keep your costs down, which is something everyone will appreciate.
6. **Develop an event timeline.** A timeline is important in planning for your event.
7. **Schedule the event.** Select a time that is appropriate and convenient for those who will be attending. Be sure to check local community calendars for conflicting events.
8. **Let CSC know.** Let us know about your event so we can publish the information on our website.
9. **Collect all funds.** We ask that all funds be forwarded to CLOVES Syndrome Community within 30 days following the event. This can be done via Paypal (clovessyndrome@gmail.com; use the friends and family option to avoid fees), or USPS (PO Box 406, West Kennebunk, ME 04094)
10. **Say thank you!** Sending thank you letters, notes, emails, or best of all, a personal phone call, to everyone who participated in or supported your event shows your appreciation and reinforces their goodwill in supporting CSC. CSC will also send an acknowledgement letter to all donors.



FUNDRAISING IDEAS

What activities do you enjoy? Whether it's cooking, crafting, or exercising, simply add a fundraising component to it. It's the perfect way to give back to a great cause while doing something you love.

Ideas to get you started:

There are so many simple ways to make a big difference to people affected by CLOVES Syndrome and their families. Here are some ways you and your friends can make an impact:

- Office Jeans Day
- Pie Smash
- Potluck
- Game Night
- Bake Sale
- Craft Sales
- Wishing Well
- Cook Off
- Coin Drive
- Movie Night
- Lemonade Stand
- Car Wash

If you're feeling a bit more ambitious

Why not open up your fundraising efforts to a larger crowd? Organize a fun event with a truly meaningful mission. Here are some great ways to engage friends, neighborhood residents, co-workers, and more:

- Bike-A-Thon
- Variety Show
- Car Show
- Fashion Show
- Auction
- Music Concert
- Boat Racing
- Church Fundraiser
- Golf Outing



- Luncheon
- Garage Sale
- Holiday Gatherings
- Fun Run
- Read-A-Thon
- Flea Market
- Scavenger Hunt
- Walk-A-Thon
- Talent Competition
- School Fundraiser
- Super Bowl Party
- Sports Tournament
- Black-Tie Event
- Dance-A-Thon
- Dine Out for a Cause
- Restaurant or Retail Promotion

PUBLICIZING YOUR EVENT

These tips and tools will help maximize publicity of your event at very little cost. Apply some, or all of them, depending on the size of your event.

Create a timeline to maximize publicity

A timeline is important in planning a publicity strategy for your event. Keep this timeline in mind as you put together a publicity plan:

3-4 months before the event

Identify your target audience based on age-group, interests, and location, develop a targeted media list. Let CSC know about your fundraiser.

4-6 weeks before the event

Distribute media materials (i.e. posters in your neighborhood, a media alert, Facebook posts, emails etc.).

2 weeks before the event



Make follow-up calls and send emails to the media who received the information from you.

1-2 days before the event

Email and/or fax a media alert with the basic information about your event (who, what, when, where, and why) to the TV news assignment desks and daily newspapers.

Suggested language

The following is a simple description of CLOVES Syndrome, which you can use in your communications:

CLOVES Syndrome stands for Congenital, Lipomatous, Overgrowth, Vascular Malformations, Epidermal Nevi and Spinal/Skeletal Anomalies and/or Scoliosis. CLOVES syndrome is rare, progressive, complex and non-hereditary. The degree of severity can range from mild to severe and can cause pain, difficulty with mobility, loss of function in body systems and an array of neurological complications. There is no cure for CLOVES and there are limited effective treatment options. CLOVES is caused by a somatic genetic mutation in a gene called PIK3CA that increases the activity of the gene. CLOVES belongs to a category of diseases known as PIK3CA-overgrowth spectrum or PROS.

DAY OF THE EVENT

Social Media

Whether you're promoting your event or celebrating its success, social media can play an important role in your fundraising. Remember these tips when spreading the word through your social media accounts.

- Tell your friends and followers why you have created this event.
- Be specific about event details, your goal, and the difference it makes for CSC.
- Be sure to include a link to your fundraising page, if applicable.
- Post consistently! Share updates before, during, and after your event.
- Tag us in your photos on Facebook, Twitter, and Instagram (@clovessyndromecommunity)



Create Lasting Memories

Photos are a great way to document your event, whether for publicity or simply to share with family and friends. Here are some tips on capturing special moments at your fundraiser:

- Write out a photo wish list in advance to make sure you get photos of everything and everyone you want.
- Take candid and close-up shots that capture the different aspects of your fundraiser.
- Include kids in the photos, if applicable. It's essential to always ask permission from a parent or guardian first.
- Take pictures of your corporate sponsors, if applicable.
- Photos with 1-3 people only are the best for publicity.
- Post the photos to your social media accounts that are the most appropriate for the event.
- Use these photos as a way to thank your supporters.
- After the event, please email the best 3-5 photos to info@clovessyndrome.org, with the names of the people featured.

WRAP UP

The proceeds from your fundraiser will leave a lasting impact on people affected by CLOVES Syndrome, and their families. Thank you for your support! After your fundraiser, all you need to do is:

- ❑ **Send in your donation/proceeds**
 - Checks should be made out to CLOVES Syndrome Community, and mailed to: CLOVES Syndrome Community PO Box 406, West Kennebunk, ME 04094
 - Please do not mail cash. Instead, get your local bank to convert the cash into a check, made out to CLOVES Syndrome Community, and mail it to the address above.
 - Include a short note explaining your fundraiser.



- ❑ **Send us a list of those who donated**
 - We would love to thank your donors ourselves and keep them in the loop about all the work their donation will support.
 - Email the list to info@clovessyndrome.org

- ❑ **Send some photos from the event**
 - Email the best 3-5 photos from your event to info@clovessyndrome.com

- ❑ **Say thank you!**
 - Sending thank you letters, notes, emails, or make a phone call, to everyone who participated in or supported your event shows your appreciation and reinforces their goodwill in supporting CSC.

- ❑ **Start thinking of your next fundraiser**
 - The best time to think of a new idea is right after the event or fundraiser.
 - Think of what parts went well and what could be changed to make the next one even more successful.

FREQUENTLY ASKED QUESTIONS

Can I use CLOVES Syndrome Community's tax exemption number?

Because CLOVES Syndrome Community is not hosting your event, it is considered a third-party event. For this reason, you will not be able to use CSC's IRS 501(c)(3) charitable classification, federal tax ID number or tax-exempt certificate. However, you may use the tax ID number for donation purposes only. Please email info@clovessyndrome.org.

Can you help me get a permit for my event?

The organization and execution of the event is the responsibility of its event organizer. You must obtain all necessary permits or licenses.

Who will provide insurance for my event?

CLOVES Syndrome Community cannot provide insurance for third-party events. The event organizer is responsible for obtaining insurance for the event, if needed.



What can I give people who made donations for tax purposes?

CLOVES Syndrome Community third-party event organizers cannot use CSC's tax exemption status in conjunction with the event. However, CLOVES Syndrome Community can provide an authorization letter confirming the organizer's intent to raise funds for CSC. In addition, we will send an acknowledgement letter.

Will each of my donors get a receipt?

If you provide the name and address, or email address, for donors or sponsors, CLOVES Syndrome Community will send them a personal thank you, which will serve as a receipt.

Can someone from CLOVES Syndrome Community attend or help me plan our event?

Because of the large number of events and the small number of staff, staff members are generally unable to attend and plan third-party events. We are happy to provide guidance for your event, but we do not have the staff to handle the organizational and administrative tasks associated with third-party events.

FUNDRAISER GUIDELINES

A "Third-Party Event" is defined as any fundraising activity conducted by a group or individual that is not employed by CLOVES Syndrome Community, where CSC has no fiduciary responsibility and little or no staff involvement in its execution. These policies pertain to all events or activities benefiting CSC that are organized and executed by third parties.

Organizer Responsibilities

- All expenses are the responsibility of the event organizer. CSC is not responsible for any expenses incurred for a third-party 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 a registration fee to help cover expenses. You may not purchase goods or services under CSC's name, and CSC's sales tax-exemption (on purchase) cannot be extended to any third-party event of 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, CSC 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 CSC, 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 events must be publicized and conducted in a manner that makes it clear that CSC 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 CSC (e.g. “proceeds benefit CLOVES Syndrome Community”)
- Event names may not incorporate the name of CSC, as in “The CSC Walk-a-thon.” CSC’s name may be used in a second clause identifying the relationship of the event with the Foundation, such as “John Doe Walk-a-thon, benefitting CSC.”
- All event materials that include CSC’s logo, including, but not limited to, advertising, press releases, posters, flyers, 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 CSC’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. For example, if a participant pays \$200 to participate in a golf outing, and the value of the outing is \$50, the donation amount is \$150. 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 CSC.



Support - Research - Education

THANK YOU!

