



Erdheim-Chester Disease Global Alliance

A Nonprofit 501(c)(3) Organization
P.O. Box 775, DeRidder, LA 70634 USA
www.Erdheim-Chester.org

"Supporting those affected by Erdheim-Chester Disease"

ECDGA Fun Run – Fundraising Guide

November 2016

*A kind gesture can reach a wound that only
compassion can heal." - Steve Maraboli*

Fun Run/Walk Fundraiser Tips

Follow this quick checklist throughout your planning to stay on track.

Hosting a fun run/walk fundraiser can be fun, challenging and rewarding. The key to a successful event is promotion and organization. The following is a roadmap to help you coordinate a successful fun run/walk. Each event will be different and the following steps can certainly be modified to fit your needs. You can lengthen or shorten the timeline, depending on the amount of time available for planning. Generally, 4-6 months of planning will allow you plenty of time to organize a successful run/walk.

4-6 Months in Advance

- Solicit help
- Select a location
- Select a date
- Select a name
- Decide on length(s) of run/walk
- Attend or volunteer at another run/walk

3-5 Months in Advance

- Select a route
- Gain approval and needed support for route
- Create registration form
- Create sponsorship form
- Notify area run clubs
- Place on community calendars
- Begin soliciting sponsors
- Design T-shirt
- Hire or borrow a timer device to track participant time
- Set a budget & begin tracking costs/donations/registrants

2-3 Months in Advance

- Solicit run day volunteers
- Place articles in newspapers, get TV interviews, get radio interviews
- Distribute registration forms
- Select T-shirt vendor and determine required order time

1 Month in Advance

- Ensure supplies needed for run are available
- Ensure restrooms are available for participants
- Complete sponsorship solicitation
- Run packet material
- Order winner medals/prizes
- Order runner bib numbers
- Contact volunteers

2-3 Weeks in Advance

- Order T-shirts

1 Week in Advance

- Create Signs
- Assemble Participant Packets

Day Before

- Walk/Travel Route
- Obtain Snacks, Drinks and Ice
- Verify all Materials will be at Race on Time

Day of Race

- Place signs
- Set up registration tables
- Ensure volunteers are set
- Set up snacks
- Set up finish line

After Race

- Send Out Thank You Notes
- Notify Media of Event Success

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Advanced Tips

Need more help with your event? Take it a step further with these extra tips.

4 – 6 Months in Advance

Solicit Help

Having family members, friends or other interested parties help you coordinate the event will make it easier and more fun. Ask around for help. If you can find someone who has hosted a fun run in the past, ask them to be your mentor. For anyone you ask to help you, be specific in the type of help you need. Some people may want to help coordinate the entire event. Others may want to help with a quick and easy task. Some ideas of tasks that you might want help with include, but are not limited to: (1) creating the registration and sponsorship forms; (2) designing the t-shirt; (3) helping on the actual day of the run/walk; (4) raising awareness of the run/walk; (5) announcing at the race; (6) soliciting sponsors for the run/walk, etc.

Decide on Length(s) of Run/Walk

The longer the run, the more serious runners you will have attend. Most people begin by coordinating a 5K Run or 1 Mile Walk. This combination will appeal to many different levels of athletes and non-athletes. Adding in the 1 mile walk option will encourage those who are interested in the cause, but are not athletes, to participate.

Select a Location

Most people who host a run/walk will do so in their local communities. There are many advantages to this, the most obvious being that people usually know more people in their local community than elsewhere. However, it is also possible to host an event in a nearby location that offers other benefits such as beauty, an interesting course, an affiliation with another scheduled event, etc. You will need to decide early where you will host your event.

Select a Date

In selecting a date, consider the following:

- Weather at that time of year.
- Other activities happening in the community on that day. You may want to select a date when not much else is happening in the community. You may also want to consider selecting a date when a compatible event is happening and work with the coordinator of the other event for potentially marketing the events together. You can contact your local city official, Chamber of Commerce and/or Tourist Commission who will be able to advise you on events planned for your community.
- Sunrise/sunset times in relation to your proposed start time. Running in the dark will result in some additional safety issues that you may not want to face.
- Your schedule. When will you have time to do the things you will need to do before the event?

Select a Name

You will want to select a name for your event. Something catchy or something with meaning to your community will be a plus. If you want, you might name the event in honor/memory of someone. You might also want to tie the name into a holiday that will coincide with the event (e.g. Jingle Bell Run or a costume run at Halloween).

Attend or Volunteer at Another Run/Walk

A really good way to get a handle on what happens at a run/walk is to become a volunteer at one. You can look in your newspaper or search online for a run in your area. Call the coordinator and ask if you can volunteer. Explain that you are planning a future event and would like to do something that will allow you to gain a good understanding of what is required to host such an event. Most coordinators will welcome the help and be more than willing to show you the ropes.

You Can Make a Difference



Advanced Tips (cont.)

3 – 5 Months in Advance

Select a Route

An easy way to select a route is to talk to others in your community who have hosted a run or participated in a run. Ask them about the route used. What was good about it, what didn't work so well? You may want to use the same route; you may want to try another. You can use a GPS to ensure the length of the route is correct or use an online website (e.g. www.mapmyrun.com). You can use one of the online map programs (e.g., to print out maps that you will need to provide to support personnel and volunteers. Determine if you will need a water station at an intermediate location along your route. Be sure it will be possible to clearly mark the route with signs and/or volunteers to ensure the runners will not get lost.

Gain Approval for Route

You will need to contact the local official wherever you have decided to hold your run/walk. If it is within the city limits, this will usually be the local police. If it is not in the city limits, this might be your sheriff. If you are lucky enough to have a nearby state or national park in your area where you would like to host your event, you will need to contact the officials in the Park Office. You will most likely need to provide the official in charge with a letter containing a request for approval for the event. The letter should include the name of the event, the date, the route, what the proceeds will be used for, and what you are requesting as far as road closures and safety measures. Things you might want to consider are police force and/or barricades at intersections and an ambulance on standby.

Create Registration Form

A sample registration form can be found in Attachment 1.

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Create Sponsorship Form

A sample sponsorship form can be found in Attachment 2.

Notify Area Run Clubs

A google search will find run clubs in your area. Most have web sites with a contact email. Run clubs are usually happy to post information about upcoming runs on their website. Simply send them an email with all the particulars of the run (who, what, where, when, why), along with a copy of your registration form.

Place on Community Calendars

Each community uses different media for communicating community events. Most communities use several. Contact as many as you can find and ask them to including information about your run. Media outlets to consider are local newspapers, churches, community signs, local TV stations, swap-shop type publications, "What's Happening?" type publications, etc. Don't fall into the trap thinking that you need to only notify one media outlet. The more you can contact, the more people who will hear about your event. The more people who hear, the more people who will be interested and attend.

Begin Soliciting Sponsors

Asking people for money is never easy. When asking for a sponsorship, think of it as providing a business an opportunity to present their face to the community in a positive and caring way. Most businesses have included in their budgets money for donations. They are happy to make these donations in a visible manner. Be sure to let the business know you will make their sponsorship visible. It is advisable to set two or more levels of sponsorship, with a donation at the higher level and providing the business more visibility with your participants. Some businesses might prefer to donate goods or supplies. You might want to consider this and request your grocery stores to donate fruit, drinks, and/or ice. You might want to ask restaurants to donate food or portable restroom businesses to donate a port-a-potty.

Advanced Tips (cont.)

Design T-Shirt

Participants of a run/walk are usually interested in the t-shirt given at the event. You might want to design your own t-shirt or you may want to use the design of the ECD Global Alliance. You can design t-shirts on-line (e.g., www.uberprints.com), using a commercially available software package, or with the help of a local t-shirt company. Those businesses that sponsored your run at a particular level or higher will expect their logo to go on the t-shirt.

Set a Budget & Begin Tracking Costs/Donations/Registrants

As with any endeavor, it is important to look at your run/walk in a financially responsible manner. You need to determine what you believe you will raise through sponsorships and registration fees. You will need to determine the costs of hosting the race. Attachment 3 is a spreadsheet you can use for your event. You will also need a method to closely track all donations made and all costs incurred. Keep receipts and careful records of all money, including registration fees and forms. The ECD Global Alliance will find it helpful to have a complete list of participants, along with their physical and email addresses. These can then be used by the organization to keep interested parties up-to-date on the state of ECD research and organizational activities.

Hire or Borrow a Timer Device to Track Participant Time

The more serious runners will be interested in knowing how fast they ran the course. There are various ways to capture runner's times. A simple method is to use a group of volunteers with stopwatches to record times. However, this can quickly become unmanageable if the crowd is great. There are more sophisticated machines that can be rented, or borrowed from another organization that might host multiple races.

2 -3 Months in Advance

Solicit Run Day Volunteers

Pre-run

- Posting signs
- Setting up tables (registration, finish line, snacks)
- Handing out packets to participants who pre-registered
- Registering participants who did not pre-register
- Snack/drink preparation (including intermediate water location along the route if needed)
- Announcer / race kick off
- Photographer

Run

- Race course guides to ensure participants know correct route, place volunteers at turns
- Photographer

Post Run

- Finish line (2 to keep track of runners and their times)
- Recorder (person to record finish times for each runner)
- Poster (person to post winners in visible manner)
- Announcer & medal presenter for winners
- Clean up
- Photographer

Don't forget to thank your volunteers!

Place Articles in Newspapers, Get TV Interviews, Get Radio Interviews

Write up information about the event. Explain how any proceeds will be used, why the event is taking place, the racecourse and anything about the event that might encourage people to participate. Contact all media sources you know about and ask for articles to be published and/or interviews to be conducted. The idea is to make as many people aware of the event as possible.

Distribute Registration Forms

Place registration forms in as many locations where people will see them as possible. Places to consider: schools, gyms, libraries, churches, hospitals, doctor offices, sporting goods stores, restaurants, banks, pharmacies, and general businesses.

Select T-Shirt Vendor and Determine Required Order Time

You want to make certain the t-shirts arrive in time to create participant packets. Contact your t-shirt vendor to determine when they will need the order to get you the shirts in the time frame you need.

Advanced Tips (cont.)

1 Month in Advance

Ensure Supplies Needed for Run are Available

See attached list for the supplies that will be needed.

Complete Sponsorship Solicitation

You will need to have all your sponsors identified in time to assemble their logos and do the final design work for the t-shirt.

Order Runner Bib Numbers

Bib numbers can be purchased online or at a local store that provides sport trophies and t-shirt printing.



Ensure Restrooms are Available for Participants

If your race starting and ending points have restroom facilities you are lucky. However, if none are available you probably want to consider having portable restrooms available. You can find someone who provides this service and call them. They might just donate the use of the facility.

Create Run Packet Material

Decide what you want to include in the participant packet. This might include, but not be limited to: a brochure on ECD, a flyer thanking all the sponsors of your event, bibs along with method for securing bib to clothes (4 safety pins will do the trick), t-shirt, information about upcoming runs, and/or any trinkets you want to provide.

Order Winner Medals/Prizes

Medals can be purchased online or at a local store that provides sport trophies. You will need medals for your winners in each age category for both men and women. You can decide whether you will provide medals for first place winners only, first and second place, or first, second and third place. You can also decide if you want to provide an overall male/female winner trophy. (Prizes can also be socks, hats, drawstring bags, water bottles, coffee mugs, small gift certificates donated by businesses, etc.)

Contact Volunteers

You will want to touch base with your volunteers to verify they will be available to help and explain to them their duties. You might want to meet with them to go over how the race will function and explain in detail how they will do their tasks. Be sure to let them know where they need to be at what time on the day of the race. You might also want to call the local officials supporting the race to ensure everything is still a go as far as their support.

2 – 3 Weeks in Advance

Order T-shirts

Order your t-shirts in time to create your participant packets. Be sure to include the logos of your sponsors. Order enough shirts to cover all your pre-registered participants, your volunteers and your sponsors. You will also want to order some extras to cover those who will register on the day of the event. It is difficult to predict the number you will need to order, but it is recommended that you order about 25% extra. If your supplier requires more time, you may need to order the t-shirts earlier.

1 Week in Advance

Create Signs

Signs you might want to consider include, but are not limited to, registration, racecourse directions, winner boards, and sponsor promotions. You can have these signs created professionally; you can use white boards or even create your own signs on poster board. Be aware that in good weather the later will work fine. However, should the weather be less than desirable, the professionally created signs will be of benefit.

Assemble Participant Packets

Place all the material you want to give participants in a giant envelope. For runners, include their bib number. If you are using tear off bib numbers, you will want to fill out the bottom of the bib prior to putting it in the envelope. Place the participant's name on the outside of the envelope and file them alphabetically. This will allow participants to pick up their material quickly on the morning of the event.

Advanced Tips (cont.)

Day Before

Walk/Travel Route

You probably want to travel your race route in the day(s) before the race to ensure there will be no surprises on the day of the race. Be sure to give yourself time to get something resolved if you see a potential problem.

Obtain Snacks, Drinks and Ice

Possible snacks for the race include apples, bananas (cut in half), oranges (cut in fourths), donuts (cut in half), pizza, cupcakes, cookies, or just about anything that can be eaten with your hands. Drinks should include water and sports drinks such as Gatorade. Many grocery stores will donate these items or at least provide them at cost. Ask before you pay!

Verify all Materials will be at the Race on Time

Make a list of everything you will need on the race day and who will be bringing it. You don't want to find yourself needing something you left at home.

Day of Race

Place Signs

Place signs where appropriate at the beginning of the race route, along the race route and at the finish line. Make sure they are easily visible.

Setup Registration Tables

Set the tables up with ease of flow in mind. Make certain that people can approach and leave the table area even if there is a crowd.

Ensure Volunteers are Set

Check to ensure all your volunteers have arrived on time and are aware of their responsibilities.

Setup Snacks

Make your snacks available in a pleasing and sanitary manner. Make certain that it will be possible for people to reach the snacks without difficulty and without creating a bottleneck.

Setup Finish Line

After Race

Send Out Thank You Notes

Send your sponsors and/or volunteers thank you notes. You may want to provide Certificates of Appreciation to businesses. Include statistics about the event's success, a t-shirt, and the other information you included in the participant's packets. Don't forget those who donated their time or material (i.e., police force, grocery stores, etc.)

Notify Media of Event Success

Begin thinking about your next event. What do you want the public to know? Let them know how much their support meant and how many funds raised will be used.

fundECD.org

To donate, please send a check to ECD Global Alliance, P.O. Box 775, DeRidder, LA 70634. Make an online donation at www.fundECD.org. Thank you for your support!

The ECD Global Alliance | P.O. Box 775, DeRidder, LA 70634 USA
Support@Erdheim-Chester.org | (337) 515-6987 | www.Erdheim-Chester.org
The ECD Global Alliance is a 501 (c)(3) non-profit organization.





[ECD Patient] Honor Run

Supporting Erdheim-Chester Disease Global Alliance
www.erdheim-chester.org | support@erdheim-chester.org

5k Run/ 1 mile Walk

March 6, 2011 at 8:00 am

Location: List race starting location (address and landmark description).

Time: Registration Time-; Run/Walk Starting Time

Course: Attach map if available and/or list street names. (Explain the type terrain for the race and whether it is a loop course or if there will be transportation available back to the starting point.)

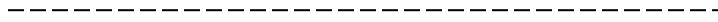
Register: Please register by mail by March 6 to: ECD Global Alliance, P.O. Box 775, DeRidder, LA 70634 or drop off at Greater Beauregard Chamber of Commerce, 111 N. Washington St, DeRidder, LA 70634

Entry Fee: Pre-registration \$20 (includes t-shirt); Day-of registration \$25 (includes t-shirt as long as they last). Checks should be made payable to ECD Global Alliance. Deadline for pre-registration rate is March 6.

Runner Age Divisions: 13 & under; 14-19; 20-29; 30-39; 40-49; 50 & over

Medals will be awarded to 1st & 2nd place 5k winners in each division.

Cut here



Entry Form ECD 5k Run / 1 Mile Walk [March 6, 2011]

CHECK ONE:

Before **March 6:** (\$20) 5K Run _____ 1 Mile Walk _____

After **March 6:** (\$25) 5K Run _____ 1 Mile Walk _____

PRE-REGISTRATION REQUIRED:

T-shirt Sizes (Circle One): **Adult:** 3X-Large 2X-Large X-Large Large Medium Small
Youth: Large Medium

Name: _____ **Age:** _____ **Sex:** _____

Address: _____ **City:** _____ **State:** _____ **Zip:** _____

Phone: _____ **E-mail:** _____

WAIVER

I know that running a road race is a potentially hazardous activity. I should not enter unless I am medically able and properly trained. I agree to abide by any decision of race officials relative to my ability to safely complete the run. I assume all risks associated with running in the event, including, but not limited to, falls, contact with any participants, the effect of the weather including high heat and humidity, traffic and the condition of the road with all such risks being known and appreciated by me. In consideration of the foregoing, I, for myself, or heirs, executors and administrators, waive and release any and all rights and claims for damages I may have against the ECD Global Alliance, volunteers, organizers, and any individuals of organizations otherwise involved with the operation of this event for any and all claims or damages, demands, actions whatsoever which may arise as a result of my participation in this event. I grant all foregoing to use any photographs or any records of this event for any legitimate purpose. Because of the nature of this event, registration fees are non-refundable.

I have carefully read this Waiver and Release and fully understand its contents. If I am under 18 years of age at the time of registration, my parent or legal guardian has completely reviewed this Waiver and Release and understands and consents to its terms, and authorizes my participation by his/her signature below. I am aware that this is a RELEASE OF LIABILITY, a contract between me and the persons and entities mentioned above, and I sign of my own free will.

Participant Signature

Parent/Guardian Signature if under 18

Date



**ERDHEIM-CHESTER DISEASE
GLOBAL ALLIANCE**

ECD Global Alliance
P.O. Box 775
DeRidder, LA 70634 USA
337.515.6987
www.erdheim-chester.org

ECD AWARENESS ACTIVITY

Raising Awareness & Research
Funds for ERDHEIM-CHESTER
DISEASE GLOBAL ALLIANCE

Date: Saturday, March 24, 2012

Time: Run/walk will begin 8:00 a.m.

Location: XXX

Sponsorship Opportunities:

- ✓ \$250 or Greater Donation – Logo on run t-shirt
- ✓ Other Donations – Listing in registration packet

Checks Payable To:

ECD Global Alliance
P.O. Box 775
DeRidder, LA 70634



Donation accepted online at www.fundECD.org.

All funds raised will go to the ECD Global Alliance, a 501(c)(3) organization, EIN # 27-0759192. The ECD Global Alliance is an international organization based in DeRidder, LA with a mission to serve all people affected by an extremely rare and serious disorder called Erdheim-Chester Disease.

Our mission can only be accomplished with the help of donors such as yourself. On behalf of the organization, its board of directors, and those it serves, we thank you for making it possible to support those affected by Erdheim-Chester Disease. We pray that someday these efforts will translate into a cure for ECD.

**ECD GLOBAL ALLIANCE
A NONPROFIT 501 (C)(3) ORG.**

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**SUPPORTING THOSE
AFFECTED BY
ERDHEIM-CHESTER
DISEASE**



What is Erdheim-Chester Disease (ECD)?

www.erdheim-chester.org

MEDICAL FACTS

- Extremely rare, debilitating and life threatening disease with less than 550 cases documented in the world. The cause is unknown.
- Affects different organs in different people, but can affect almost all organs; unless successful treatment is found, organ failure can result.
- More common symptoms/signs can include bone pain in legs & knees (More than 50% of ECD patients share this symptom.), bulging eyes, balance issues, excessive thirst/urination, shortness of breath, excessive fatigue, weight loss, cardiac issues, vision problems, and/or reduced kidney function.
- To date, there is no “cure” for ECD, although more effective treatments are being discovered. The best treatments available today control and sometimes shrink the growths associated with the disease.

The World Health Organization has reclassified Erdheim-Chester Disease as a **histiocytic neoplasm**. This means the rare disease is now considered a slow-growing blood cancer that may originate in the bone marrow or a precursor cell.

WHAT IS IT LIKE TO HAVE ECD?

You are so tired and sick feeling all you want to do is sleep. You have difficulty eating. You are getting sicker every day.

Your pain level sends you to the ER periodically. New and more serious health issues continue to occur.

You find it difficult to walk only a few steps because of breathing issues and you have no balance. You find it difficult to walk only a few steps because of breathing issues and you have no balance.

Your medical team may be unfamiliar with the disease, making it likely that you will have to travel a long distance to reach an ECD Care Center that will be able to help you.



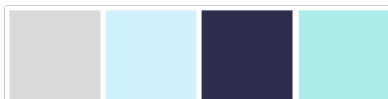
ERDHEIM-CHESTER DISEASE GLOBAL ALLIANCE

501(C)3 ORGANIZATION

The ECDGA is an international patient advocacy group based in DeRidder, LA, providing support to patients and research funds to find treatments.

Founded in 2009 in Memory of F. Gary Brewer

fundECD.org





Fun Run Budget Spreadsheet

www.erdheim-chester.org

Expense Description	Estimated Cost	Actual Cost	Explanation/Notes
Printing Flyers			
Printing Registration			
Printing Sponsorship			
Printing Brochures			
Postage			
Runner Bibs			
Winner Medals			
T-shirts			
Equipment Rental			
Facility Fee			
Insurance Fee			
Food for Runners			
Drinks for Runners			
Signs			
Misc.			
EXPENSE TOTAL	\$	\$	

Income Description	Estimated Income	Actual Income	Explanation/Notes
Sponsorships			
Registration Fees			
Donations			
Misc.			
INCOME TOTAL	\$	\$	

Funds Raised	Estimated Funds Raised	Actual Funds Raised
GRAND TOTAL	\$	\$





Fun Run Tracker for Supplies, Volunteers & Sponsors

www.erdheim-chester.org

Supplies

Supply	Who Providing	Who Picking Up	Date to Pick Up	Status	Returned by/Date
Runner shoot (finish line), timer, clock					
Sound system					
Tables <ul style="list-style-type: none"> • Registration • Pre-registration • Water/snacks at start, end and midway • Finish line recording / posting 					
Ice chests					
Ice					
Water, Gatorade					
Fruit <ul style="list-style-type: none"> • Bananas, cut in half • Oranges, cut in quarter • Apples, whole 					
Donuts, pizza, cookies, cupcakes or other					

Supply	Who Providing	Who Picking Up	Date to Pick Up	Status	Returned by/Date
Signs (directional, registration tables)					
Registration Packets (including, bib number, 4 safety pins, sponsor sheet, t-shirt, ECD pamphlet, announcement for other area events) all in an envelope with the participant's name					
Leader Boards for posting winners					
Markers for leader boards					
Bibs & extra safety pins					
Pens, pencils, markers					
First-aid kit					
Registration forms					
Pens					
Tape					
Staple Gun					

To Do

Activity	Who doing?	Status

Sponsorships Obtained

Sponsoring Organization / Person	Amount	Thank You Note Written?

