



P.O. Box 39
Pacific Palisades, CA 90272
310-459-1071
Tax ID: 52-1545992
www.myelin.org
info@myelin.org

Fundraising Packet

The Myelin Project is incredibly grateful to you for your commitment to our cause and desire to help us in our mission to improve the quality of life for those living with all forms of adrenoleukodystrophy (ALD). Enclosed you will find information to help you fundraise for our organization. This packet includes:

- Information about The Myelin Project
- Fundraising strategy (to help you reach your goal)
- Fundraising ideas (list of fundraisers and tips to make them successful)
- Fundraising letter template (to make it easier to send to you family/friends to ask for support)
- Corporate matching gift processes and payroll deduction information
- Sample Fundraiser Sponsorship form

Most importantly, we hope that you have fun while you fundraise! If you have any questions, please contact us at info@myelin.org. We are here to help you!

About Us

We are a 501(c) 3 non-profit organization focused on improving the quality of life for those living with all forms of [adrenoleukodystrophy \(ALD\)](#) through research, advocacy, and family support. We believe we can accomplish our mission by pursuing the following initiatives to:

- Fund Scientific and Clinical Research to Find a Cure
- Advocate for Newborn Screening of ALD
- Provide Family Support to Low-Income ALD Families
- Raise Awareness and Promote Education of ALD



Board Member Jean Kelley with her husband, and son, Brian, who has ALD.

Myelin is an insulating layer, or sheath, that forms around nerves, including those in the brain and spinal cord. It is made up of protein and fatty substances. The purpose of the myelin sheath is to allow electrical impulses to transmit quickly and efficiently along the nerve cells. If myelin is damaged, the impulses slow down which is what occurs in [adrenoleukodystrophy \(ALD\)](#). [Adrenoleukodystrophy \(ALD\)](#) is a rare x-linked genetic brain disease that affects roughly 1 in 17,000 people. It destroys the myelin and has four different forms, or phenotypes. The most devastating appears in childhood, generally between the ages of four and ten years old. Normal, healthy boys suddenly regress rapidly. Symptoms begin with hyperactivity, withdrawal, and/or difficulty concentrating. As the disease continues to destroy myelin in the brain and nervous system, symptoms grow worse including blindness, deafness, seizures, loss of muscle control, and progressive dementia. Often this leads to either death or permanent disability usually within 2 to five years of diagnosis.

The Myelin Project was established in 1989 by Augusto and Michaela Odone for their son Lorenzo who suffered from [adrenoleukodystrophy \(ALD\)](#), a rare genetic myelin disease that deteriorates myelin in the brain and central nervous system. Although not medical doctors, the Odones developed a treatment, "Lorenzo's Oil" now adopted throughout the world. The story of the Odones' struggle was dramatized in George Miller's 1992 film "[Lorenzo's Oil](#)" starring Nick Nolte and Susan Sarandon.

Fundraising Strategy

I. Learn about The Myelin Project

The Myelin Project was established in 1989 by Augusto and Michaela Odone for their son Lorenzo who suffered from [adrenoleukodystrophy \(ALD\)](#), a rare genetic myelin disease that deteriorates myelin in the brain and central nervous system. Although not medical doctors, the Odones developed a treatment, "Lorenzo's Oil" now adopted throughout the world. The story of the Odones' struggle was dramatized in George Miller's 1992 film "[Lorenzo's Oil](#)" starring Nick Nolte and Susan Sarandon.



The 1992 film "Lorenzo's Oil" starring Nick Nolte and Susan Sarandon

II. Assemble your Team

For those starting a fundraising team, assemble it. Think of everyone you know, including your friends, family, colleagues, neighbors, and anyone else you feel comfortable reaching out to be on your team. Your team should contain people with multiple connections and relevant expertise. Choose a team captain to keep the team on task and to help create your fundraising plan and implementation strategy.

III. Plan your Fundraiser

Fundraising events are a popular form of fundraising. While they can be great money makers for an organization, they can also be time consuming and expensive. The success of events depends on careful planning. (Yes, you should have a written event plan for every event you hold!) To help you ensure that your fundraising event is a winner, here are ten major components that you must incorporate into your event plan:



1. Purpose: Before doing anything else, you must decide what the purpose of your event is. Is this truly a fundraising event? Or does it have other goals? Perhaps your organization may be hoping to raise money at the event, but the main function of the event is to gain publicity, or reach out to a new network. Many charitable events have more than one goal. Figuring out the details for your event will depend on knowing what goals you are trying to achieve.



2. Fundraising Goal: In conjunction with the event host committee, organization staff, and key fundraisers, you must decide what amount of money you plan to raise at the event. If this is truly a fundraising event, then everything in the event plan will be geared to raising this specific amount of money. The amount you choose should be what you hope to net, that is, the amount you plan to raise after expenses are deducted.



3. Budget: Every fundraising event plan should contain a complete budget listing all of the expenses that will be required to hold the event. Your budget should include staff, invitations, space rental, catering, entertainment, transportation, security, utilities, and anything else that will be required to make the event a success. Your budget should take into account your fundraising goal, ensuring that you raise that amount above and beyond all expenses. Be sure to leave a little extra room in your budget for unforeseen costs.



4. Leadership & Sponsorship: As part of your fundraising efforts, your event will most likely have a "host committee" and one or more "host committee chairpersons." These people are responsible for contributing substantial amounts of time and effort to the event and encouraging others to do the same. The host committee is generally composed of wealthy donors, business leaders, or local celebrities. The host committee and chairpersons are not responsible for actually running the event, but are integral to ensuring that you reach your fundraising goals.

Sponsorship: If you are affiliated with a company, high school, university, and/or church, approach them to ask if they

are interested in sponsoring your event. Local religious organizations can be key sources of funding. Call the minister/priest/rabbi and explain who you are and ask for help. Go to local businesses and ask for their assistance. Be sure to let the manager know if it is a place that you frequent.



5. Target Audience: Who is the target audience for your event? Is this a general fundraiser where everyone will be invited? Or is this event geared towards a specific group like business people, parents, or young professionals? In short, you must decide whom you will invite to your event.



6. Timetable & Event Set Up: Fundraising requires careful planning and hard work. Draw up a timetable, have a meeting with your team, and be sure to schedule future meetings going forward. Make tangible goals for each day/week/month. Your event staff should plan the event set-up well in advance. The set-up includes all of the particulars of the actual event: Where will it be? Will food be served? Will there be entertainment? What kind of attire will be required? What is the itinerary for the event?



7. Marketing: Just like a new product, your event needs to be aggressively marketed to your target audience. You need to convince your supporters that your organization and event are worthy of their time and money. Draw up an entire marketing plan for the event. Possible methods of “getting the word out” include: using your non-profit’s fundraising network, mailed invitations, social media, direct mail, phone banks, word of mouth, and the event host committee.

- **Send out Emails and Letters:** Think of everyone you know, including your friends, family, colleagues, neighbors, and anyone else you feel comfortable reaching out to for support. Reach those who don’t have email by customizing the fundraiser letter template included in this packet. Feel free to contact us for letterhead upon which to print your letters. This will give your letter a professional look and show organizational backing. We can also provide you with self-addressed envelopes to remove one step that a donor has to take in order to support you.
- **Contact your local media:** they are always looking for interesting articles about community members. Contact your local media and ask them if they would like to run a story about you and/or your fundraiser. Try local newspapers, radio shows, talk shows, etc. Ask if they would like to interview you.



8. Sales: Once you market your event, there must be a procedure in place for making the actual ticket sales, or accepting donations for the event. You must decide whether there will be different contribution levels for the event (such as a flat ticket charge, an extra charge to be invited to a V.I.P. reception in addition to the event, etc.). You must decide who will sell the tickets, how they will be shipped or delivered, and who will be responsible for organizing the incoming information.



9. Practice: While you probably won’t need a full run-through of your event, it is essential that everyone who is working the event know, ahead of time, what their responsibilities are, where they should be during the event, and how the event is going to “flow.” If you are having a large or unusual event, the key event staff may want to have a practice run to make sure that your operation is running smoothly.



10. Thank Your Donors and Volunteers: One of the most common complaints from contributors to charitable fundraising events is, “They never even said ‘thank-you.’” Ditto for your event volunteers. Make sure that the organization takes the time to send thank-you notes to everyone who is involved in your event, including contributors, volunteers, staff and vendors. Keep your donors happy... you’re probably going to be asking them for another donation sometime down the road.



50 Fundraising Ideas

1. **Baby and/or Kids Resale** - It's no secret that babies and young children can quickly outgrow their clothing and toys, usually way before these items are worn out. Take advantage of this by hosting a baby and kids' resale for your next fundraising event.
2. **Bingo Is Its Name-O** – Get prizes donated and charge an entrance fee for a night of Bingo.
3. **Party Like It's 1999** – Get entertainment and food donated and charge a ticket fee for each guest.
4. **Spell S-U-C-C-E-S-S** – Hold a spell-a-thon with each contestant collecting donations for the number of words they spell correctly. The top winners receive donated prizes.
5. **Smoothie Stand** – A healthy and yummy twist on the tired ol' lemonade stand.
6. **Strike Gold** – Participants ask friends and family to donate old jewelry they no longer wear and turn the gold in for cash.
7. **50/50 Raffle** – Sell raffle tickets and offer half of the proceeds as prizes.
8. **Going Once, Going Twice** – Seek out service and product donations. Hold an online or live silent auction.
9. **Buy a Meal** – Volunteers donate homemade meals to sell.
10. **Karaoke Style** – Have participants raise pledges for their commitment to lip-sync and sell tickets to the performance.
11. **Working at the Car Wash** – Coordinate group members to wash cars in a high traffic location for donations.
12. **Cook Off** – Solicit local celebrities to enter their best dishes and have people pay to vote on the winners.
13. **It's a Wrap** – Coordinate with a store to offer gift wrap services during the holidays.
14. **It Tastes so Sweet** – Get baked goods donated to sell at a large event like a dance or basketball game.
15. **Trendy Bracelets** – Sell silicone bracelets that promote your cause.
16. **Scratch Cards** – Donors receive a sheet of coupons for a small donation of a few dollars.
17. **For the Birds** – Deliver a group of fake pink flamingos to a donor's yard and leave a note explaining the cause and asking for a donation to "replant" the flamingos in the yard of the next "victim" the first donor designates.
18. **Another Man's Treasure** – Collect gently used items from group members to be sold at a yard sale.
19. **Text It** – Use a service that allows your organization to receive donations of \$5-10 by text messages.
20. **Bail Me Out** – Handcuff two willing fundraisers and let them lose when they raise "bail".
21. **Sticky Fly** – Sell pieces of duct tape for donors to stick your group's leader to a wall suspended above the floor for a portion of an event.
22. **Sit-a-thon** – Offer babysitting services for a designated evening or two.
23. **Make it Up** – Send out invitations to a made up event and offer invitees tickets to support the cause without having to leave home.
24. **It's a Bust** – Sell balloons for \$10 each and insert a number in each that corresponds to a raffle ticket given to the purchaser. Pop a balloon for each available prize and read off the winning number.
25. **Nacho Dough** – Sell a lunch or dinner of nachos and a cookie at a church or school when participants already need to stay through a meal.
26. **Go Hairless** – Volunteers commit to shaving their heads if a specified amount is raised by a deadline.
27. **Make the Grade** – Have students get pledges for "A's" and "B's" at the beginning of a quarter and collect the donations after report card time.
28. **Change It** – Start a competition between classes, families or individuals by giving them each a coin jar to



collect change for a designated amount of time. The one with the most collected wins a prize.

29. **Skip a Meal** – Sponsors commit to giving up a meal together and give the money saved to the designated cause.
30. **Holiday Shop** – Collect new and gently used items from your volunteers and resell them in gift baskets at a holiday shop.
31. **Rent-a-Worker** - Volunteers commit to working for an afternoon doing any odd jobs sponsors “hire” them to do.
32. **Egg ‘Em On** – Go door to door negotiating with each neighbor for how much they will pay to see you do a crazy stunt with a raw egg (i.e. juggle, crack it on your head, throw it up and catch it).
33. **Go Casual** – In schools or offices with specific uniforms, everyone gets to dress down if they raise enough money to meet a goal.
34. **Pay it Forward** – Give each person in your organization \$10 and a specific amount of time to use the funds to raise as much as they can for the cause.
35. **Reverse Raffle** – All potential sponsors get a raffle ticket and sell it back for \$10 to avoid getting their name drawn to do something embarrassing.
36. **Cookbook** – Group members offer their best family recipes for a cookbook.
37. **Fore!** – Hold a tournament at a golf course that will offer reduced greens fees and get prizes donated. Getting local celebrities to participate will draw more participants.
38. **Diva it Up** – Design and sell t-shirts advertising your group’s cause.
39. **Work of Art** – The younger members in your organization create a drawing that is transferred onto note cards, t-shirts, mouse pads or coffee mugs for purchase.
40. **Spa Night** – Offer to have female volunteers give manis, pedis and 5 minute massages at a Women’s Night Out for donations.
41. **Halloween Collection** – Use this door-to-door holiday to collect coats, candy, or change for your charity.
42. **Give it Up** – Sponsors commit to give up a regular activity for a month and donate the money they save to the designated cause.
43. **Capital Campaign** – Set a goal, make the direct ask, and avoid an endless slew of small fundraisers.
44. **Social Media Call** – Let potential donors know about your fundraising need through Facebook and Twitter.
45. **X Marks the Spot** – Sell golf balls for \$10 each and send them all down a hill with the “tossers” blindfolded. The 3 that get closest to the center of a taped “X” below win cash prizes.
46. **Eat for a Cause** – Ask a local restaurant to donate 10% of their profits on a designated night for your cause in exchange for encouraging supporters to eat there.
47. **Matching Gift** – Ask a corporation or individual to match any donations your organization collects in a specified amount of time. Then, contact potential donors about giving to match the gift.
48. **Birthday Pledge** – Ask for donations to a favorite cause instead of birthday gifts.
49. **Who’s Got Talent** – Hold a talent show with an entry fee for each act and sell tickets.
50. **Pump it Up** – Coordinate with a local gas station to have volunteers serve as gas station attendants who pump gas and clean windshields for donations for a day.



 **Sample Fundraiser Solicitation Letter**

March 18, 2016

Mr. John Doe
123 Maple Street
San Francisco, CA 94122

Re: Fundraiser Event

Dear Mr. Doe,

You are cordially invited to join us at the _____ to support The Myelin Project. The event will begin at _____ in _____. The Myelin Project is a 501(c) 3 non-profit organization focused on improving the quality of life for those living with adrenoleukodystrophy (ALD) through research, advocacy and family support to low-income patients and their families. As you may know, I have a personal connection with this disease (_____).

Adrenoleukodystrophy, or ALD, is a deadly genetic disease that affects roughly 1 in 17,000 people most severely affecting boys and men. It destroys myelin, the protective sheath that surrounds the brain's neurons - the nerve cells that allow us to think and to control our muscles causing relentless progressive deterioration to a vegetative state or death, usually within five years. Every 36 hours, a child is born with ALD in the United States yet parents will not know that their children have it because currently only two states screen for the disease at birth. Last year, The Myelin Project successfully sponsored and passed legislation adding ALD to California's newborn screening program, to be implemented on January 1st, 2016.

Without newborn screening, children born with ALD are at high risk to be misdiagnosed, and when left untreated, most children will die before they reach the age of seven years old. The lack of ongoing research and accurate diagnosis have proven to be deadly. Therefore, the research, advocacy, and family support services provided by The Myelin Project are crucial to the health and well-being of thousands of ALD patients and their families throughout the United States.

Your helpful donations are truly something to celebrate. If you are unable to attend but would like to contribute, you may do so by mail. You may also pass the invitation to someone else to represent you at the event. We want very much to help these children so one day they, too, may dance.

Your response by _____ will be appreciated.

Sincerely,

Your Name
Your Title/Company



Corporate Matching Gift Process

There is an easy way to possibly double your support through a corporate matching gift program. Many companies will match their employee's charitable gifts. Sometimes, employers will even match a contribution made by a friend to support you in fundraising for an event.

Here's how to take advantage of a **Corporate Matching Gift Program**:

1. Contact your Human Resources department and ask if your employer has a matching gift program.
2. If so, ask for a matching gift program form to complete and submit a copy to your company and one copy to us. This way we know that you are providing a matching gift.
3. If your company does not have a corporate matching gift program but is interested in making a matching gift, please provide them with the following information:

The Myelin Project
P.O. Box 39
Pacific Palisades, CA 90272
(Tax ID #: 52-1545992)

The matching gift check will go directly to The Myelin Project and the donation will be credited to your personal fundraising account.

4. If your company uses an online matching gift process, access your company's website and submit a matching gifts request. Print a copy of your request for your records.



Automatic Payroll Deductions

For employees who wish to effortlessly donate to a worthy cause, automatic payroll deductions are one of the easiest ways to regularly contribute to a nonprofit organization. However, companies usually limit the type of nonprofit their employees can contribute to. For instance, if a company has a specific interest in sustainability and the environment, it might restrict employees' donations to nonprofits whose missions most closely aligns with theirs. However, once a nonprofit is on a company's list of approved organizations, automatic payroll deductions are a great way to receive ongoing, predictable donations.

If you have any questions or your company needs more information, please contact us:

Greg Benton
1-800-869-3546
info@myelin.org
www.myelin.org

Fundraiser Sponsorship Form

Date, Time, & Event Location

\$10,000 – *Angel Sponsor*

- 20 event tickets, 20 raffle tickets, 20 drink tickets
- Recognition at the event
- Company logo/Family name prominently displayed on our flyers, banner and evening program
- **2 months of food and care for a low-income ALD/AMN patient and their family**

\$5,000 – *Helping Hand Sponsor*

- 10 event tickets, 10 raffle tickets, 10 drink tickets
- Recognition at the event
- Company logo/Family name displayed on our flyers, banner and evening program
- **Cell preparation for hematopoietic stem cell gene therapy treatment experiment**

\$2,500 – *Caring Heart Sponsor*

- 6 event tickets, 6 raffle ticket, 6 drink tickets
- Recognition at the event
- Company/Family name displayed on our banner and evening program
- **1 month salary for lab research assistant**

\$1,000 – *Friend Sponsor*

- 4 event tickets, 4 raffle tickets, 4 drink tickets
- Recognition at the event
- Company/Family name displayed on our banner and evening program
- **3 – 4 months of utility bill payments for a low-income ALD/AMN patient and their family**

\$125 – *Individual Ticket*

I would like to purchase _____ (please enter amount) Individual Ticket(s).
 1 event ticket includes a three course meal, open bar, and live entertainment

Donate your home-away-from home, a round of golf at your country club, tickets to a sporting event, jewelry, travel opportunities, family and couple packages are just a few ideas!

Name(s): _____

Address: _____ City: _____ ST: _____

Phone: _____ Email address: _____

Sponsorship Level/Donation amount/description of item: _____

Credit card type _____ Credit card #: _____ - _____ - _____ CCV _____ Exp: _____

Signature: X _____

Your thoughtful generosity is greatly appreciated.