

# X OUT ALD FUNDRAISING TOOLKIT





## X out ALD Fundraising Toolkit

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## Introduction by Dr. Troy Lund

On behalf of the Leukodystrophy Center at the University of Minnesota, I would like to thank you for joining X out ALD in raising funds to support our adrenoleukodystrophy research. I always look forward to seeing how families bring the mission to life in their own way – with bake sales, bean bag tournaments, BBQs, block parties, cookies, lemonade stands, motorcycle runs, Pampered Chef parties, relay races, and more. I hope this resource helps inspire your creativity and makes fundraising easier. My favorite part about the Outrun ALD event is seeing families from across the country unite in September, during Leukodystrophy Awareness month. There's something about grassroots fundraising that feels so personal and profound.

Anyone who runs an academic lab will tell you that it is challenging, exhausting, and frustrating. That said, even on the hardest days, the patients and families keep us going. My goal is to provide every ALD patient with effective treatment options. Anything less is not acceptable. Thank you for joining us in this effort.

With gratitude,

Troy Lund, MD, PhD



**Dr. Troy Lund**



## A Note from the Board of Directors

### Making a Difference

ALD is considered a rare disease and as such there is very little in the way of funding support. Every dollar raised for ALD research helps to ensure that projects and ideas that might otherwise not come to fruition can be translated to care provided at the bedside. This will allow physicians and specialists to move forward and have a greater impact on care options for the ALD community.

X out ALD wants to stop this disease in its tracks and we have chosen to support the research efforts of Dr. Troy Lund at the University of Minnesota Leukodystrophy Center. Dr. Lund manages the world's largest biorepository for ALD and is working tirelessly on improving transplant outcomes and in providing treatment options for those who come later to diagnosis. With your help, we can ensure the University of Minnesota Leukodystrophy Center has the ability to move forward in their research to save the lives of ALD boys. When you support this life saving research, you are giving ALD boys a fighting chance against a disease that could potentially rob them of every functional ability and possibly take their life.

Currently, X out ALD organizes the annual Outrun ALD 5K event. We hope to see our success continue so research efforts can proceed effectively and efficiently. We run for many reasons as articulated on the following page. Having a virtual event format has served to widen our reach and give families and supporters the freedom to use their creativity to develop their own fundraising methods and host their own local events.

We are grateful to each and every one of you for your support and commitment for improving outcomes for ALD boys regardless of their stage of diagnosis. This toolkit provides ideas on how you might contribute to achieving our mission.

Thank you for helping us to X out ALD!

With gratitude,

*Amanda, Cassie, Dan, Jamie, & Marie*

The X out ALD Board of Directors





## Today we walk for...

The young boy who is going through a bone marrow transplant in order to save his life

The mom with ALD who quietly manages her own symptoms while worrying about her children

The man with AMN who has lost the ability to walk a 5K

The mom and dad anxiously awaiting MRI results so they can breathe again

The boy who is told he can no longer play the sport he loves because of the possibility of a head injury

The parents who know the feeling of loss from a failed IVF cycle

The doctors and researchers who work tirelessly to develop better treatment options

The boy who is dealing with late effects of treatment

The family of a newly diagnosed baby trying to comprehend this new reality

The boy who is diagnosed too late for life saving treatment

The families who are living in the dark because they have not yet received a diagnosis

The mom who grapples with guilt for passing this disease to her child

The young boy who has lost his ability to walk, see, hear or play

The young woman who may have to make difficult family planning decisions in her future

The dad who silently struggles with his fears while trying to be strong for his family

The boy who has to worry about having an adrenal crisis and can't leave home without having pills and shots nearby

The loved ones who aren't with us today because of this disease

The parents who have buried their child

The thousands of people who are greatly impacted by this disease on a daily basis

We walk in memory of the boys who lost their battle with ALD and in honor of their loved ones. We will continue fighting.



## Let's get started!

You want to help raise funds for ALD research. What's next? We're here to help.

Thank you for joining us in fundraising to support the groundbreaking research efforts of the University of Minnesota Leukodystrophy Center. We are excited to have you join us in our mission to X out ALD and we are here to support you in your efforts.

## Talking Points

Chances are your supporters want to know a little something about who and what they are supporting. Below is some information about our organization's mission as well as basic facts about adrenoleukodystrophy that can be shared throughout your fundraising efforts.

### Mission Statement

X out ALD is a 501(c)(3) organization dedicated to increasing awareness of adrenoleukodystrophy and supporting research of the disease at the University of Minnesota Leukodystrophy Center. We raise funds for medical research that will lead to more effective treatments and improve outcomes for children with ALD.

### What is ALD?

Below are some resources and basic information about ALD as we know it today to get started on educating your potential supporters. Consider using them in social media stories/posts or post them along your event route.

### What is ALD? – ALD Connect

[X-Linked Adrenoleukodystrophy - Symptoms, Causes, Treatment | NORD \(rarediseases.org\)](#)

**ALD is caused by an underlying genetic mutation in the *ABCD1* gene.**

**Individuals with ALD are unable to create enough of the protein that helps the process of breaking down very long-chain fatty acids (VLCFAs).**

**A buildup of VLCFAs can cause adrenal problems and can potentially lead to brain damage. ALD is an x-linked inherited genetic disease, but it can also occur as a result of a spontaneous mutation.**





Based on best estimates, ALD affects approximately 1 in 16,000 people.

Adrenoleukodystrophy occurs all over the world and is observed across all ethnicities and geographies.

There is no known correlation between genotype and phenotype in ALD meaning even two brothers with the same *ABCD1* mutation can develop different symptoms.

There is no way to predict the way that ALD will affect an individual.

ALD symptoms can vary depending on age, gender, and the body tissues affected. The primary phenotypes that can occur in males with the ALD gene: asymptomatic (newborn screening), adrenal insufficiency, cerebral ALD, adrenomyeloneuropathy (AMN).

Cerebral ALD is the most severe form of ALD.

The riskiest time for a boy with ALD is from the ages of four to 10, when they are most likely to develop cerebral disease. After 10, the risk of cerebral lesions decreases, but never disappears.

35% of boys will develop cerebral disease, most commonly between the ages of four and 10.

It is recommended that boys diagnosed with ALD through newborn screening follow a protocol to monitor for cerebral ALD development, allowing for any brain lesions to be caught early enough for treatment.

Cerebral ALD is ALD that progresses to affect the brain. Boys can start to show symptoms that include vision changes, hyperactivity and learning difficulties. The condition progresses very quickly, so early diagnosis is essential. If left undiagnosed or unmanaged, cerebral ALD can have severe effects and lead to significant disabilities or even death.

With the advent of newborn screening, we now have the ability to monitor boys from birth to ensure they have access to timely, specialized treatment. However, some jurisdictions do not offer this and many boys will continue to be identified at a later stage of progression making their treatment more complex and challenging.

Many boys with cerebral ALD undergo a bone marrow transplant, which uses healthy stem cells to halt the progression of brain lesions.



Patients with adrenoleukodystrophy do not display any symptoms at birth. Without knowledge of a family history of ALD or identification via newborn screening, the disease will likely go undetected until symptoms appear. Early diagnosis of adrenoleukodystrophy is the key to saving lives, because newborn screening allows prospective monitoring for adrenal function and the onset of cerebral ALD.

The only known treatments for the cerebral form of the disease are hematopoietic stem cell transplantation and gene therapy. Both of these treatments are complex and carry many risks affecting quality of life and outcome.

Adrenal insufficiency is often the first detected symptom for boys with ALD.

Adrenal insufficiency is also known as Addison's disease.

Common symptoms of adrenal insufficiency include fatigue, loss of appetite, darkening of the skin (hyperpigmentation) and abdominal pain. Although adrenal insufficiency is manageable, it can become life-threatening if it is not detected early.

Because the ALD gene is on the X chromosome, women with ALD have a 50% chance of passing the gene to any children they have. Men with ALD have a 100% chance of passing their ALD gene to any daughter and a 0% chance of passing the gene to any son.

More than 850 different mutations in the *ABCD1* gene have been identified and are cataloged in the ALD mutation database at [www.adrenoleukodystrophy.info](http://www.adrenoleukodystrophy.info).

If someone with ALD is asymptomatic, it means they do not show signs or symptoms of ALD. Babies identified by newborn screening have this phenotype. Most individuals with the ALD gene are free of clinical symptoms for at least the first three years of life. Some individuals have no symptoms for many years.

Adrenoleukodystrophy is diagnosed by a simple blood test, which measures the very long-chain fatty acids levels. This test is widely accepted as a highly accurate means of diagnosing males of all ages. However, in about 15% of females with ALD the VLCFA test shows normal levels and thus provides the individual with a "false negative" result.

Most men with ALD will develop adrenal insufficiency at some point in their lives, which can be life threatening if not properly managed.





Originally, ALD was thought to only be a disease of boys and men; we now know this is not true and women with a mutated *ABCD1* gene can also have symptoms of ALD.

Most women with ALD will not develop adrenal insufficiency or cerebral ALD, although it has been known to occur in a small percentage of women.

Women with ALD can develop mild to severe symptoms.

Because women with ALD often have symptoms of their own, many prefer not to use the term "carrier," as this falsely implies they only "carry" the mutation without developing symptoms.

Adrenomyeloneuropathy (AMN) is ALD that commonly starts in adulthood and affects the spinal cord and nerves.

Men with adrenomyeloneuropathy (AMN) may experience the following symptoms: walking and balance problems, pain, numbness, or tingling in the legs, mild to moderate weakness of the arms/hands, urinary disturbances or incontinence and bowel urgency or incontinence, sexual dysfunction

Sources: ALD Connect, National Organization for Rare Diseases (NORD), ALD Info ([www.adrenoleukodystrophy.info](http://www.adrenoleukodystrophy.info))



## Outrun ALD Virtual 5K Fundraising Toolkit

One of the best ways to support X out ALD's mission is to join us for our annual event, the Outrun ALD Virtual 5K. See below for how to get started, make the most of fundraising, and ideas for hosting your own local event.

### [Register or donate here](#)

- **Create a team!**

Give your team a fun or creative name (or not!). Post photos and share your story on your team/fundraising page and on social media. Your story and passion for the cause can be as brief or detailed as you choose, but personalizing it in any way makes a difference.

X out ALD features teams and families on social media up until the event and would love to share your journey. Look for an email from us once your team is formed or reach out to us at [info@xoutald.org](mailto:info@xoutald.org). See below for our request.

Whether you are new to the Outrun ALD 5K event or a returning supporter, please include a brief introduction of your family and share how you came to learn of the ALD diagnosis and/or how you are connected to someone with ALD. Let us know where you are supporting us from and share as much or little as you choose about your family and/or ALD journey.

Courageous Conner's Crusaders Mac  
Attacks ALD Odean Dream Team Niko,  
Ira & The Revolution Team 505 Austin's  
ALD Dominators Franken Family Lund  
Lab Team Tiger Can't Stop, Won't Stop  
GTS Financial Nash's Ray of Light Odin's  
Ravens Lots of Love, Luka Team  
Treyton For the Wilsons Team Teddy  
Triple Threat Against ALD Aaron Loving  
Determination Zero Out X-ALD for Zeb  
EitanStrong Marty's Mission Callaway's  
Crew Team Joey The Lucas Project  
Nathan's Squad Team Blake  
#tilthebattleiswon The Grayson  
Mission Leon & Gionni Titus' Wingmen  
Noah Nails ALD Scarpellis Team Tucker  
Knockout ALD Shay's Roundup Alec's  
Army Miracle for Jayden Jacob ALD  
Lopez Family Wyatt Gabriel The PACK  
Team Gusasaurus Strolling Shaperos  
Coffee Girls TeamBrax



- **Set a goal.**

You can always adjust your goal up or down but it's important to set a number to strive for. Your supporters will want to help you reach that goal. Did you know X out ALD set a goal of \$10K for the inaugural event and raised well over \$100K? Set your sights high!

- **Share your fundraiser.**

Invite people to join your team! Friends, family and colleagues can join your team by registering, donating or both! You can share your team page via email or social media. You can even connect a Facebook fundraiser to your RunSignup fundraising page.

Visit our FAQs page as chances are your friends and family will have some of these same questions. Explain what a virtual 5K means and help your supporters understand the difference between registering and donating.

Make it easy for your supporters to donate by providing a link that takes them straight to where they can register and/or donate. RunSignup will create a personalized URL for your fundraising page. Create QR codes to use at fundraisers or to print and display at your event (see QR code example on page 15). You can use Canva to create QR codes which can direct supporters to X out ALD's donation page on the website, your RunSignup fundraising page and/or Venmo.

- **Maximize your circle of supporters.**

Social media is a great way to share your fundraiser and raise awareness, but don't stop there. Many people are active on social media but you can likely widen your reach even more.

### **Employer**

Consider sending an email to your team or department at work inviting them to support the cause. We've even had businesses form their own team.

On another note, see if your employer offers matching and ask your friends and family to check with their employers also! Many employers offer matching donation programs.

Consider looking into whether or not your employer has the ability to sponsor events and if so, ask if they can support this cause (**sponsor form**).

### **Volunteer Organizations**



If you volunteer, use this as an opportunity to raise awareness with fellow volunteers and invite them to join the cause!

### **Sports, clubs and other youth organizations**

If your kids are involved in sports or other activities, invite the team to join.

### **Schools/daycare**

Consider asking if you can send an email or message through the school app connecting with your child's daycare, school, etc. Invite students, parents and teachers to support your team or send a flyer/invitation that can be posted in your child's classroom, staff lounge, etc.

### **Get creative**

Are you or is anyone you know an independent sales consultant (Beautycounter, Pampered Chef, Tupperware, Norwex, etc.)? Consider holding a special fundraiser or partner with a friend to do so and donate a percentage of sales to X out ALD.

- **Plan a local event.**

Invite your family, friends and colleagues to join you for a walk around your neighborhood, go for a hike, run around a lake or even just gather for a barbeque!

The possibilities are endless but here are some ideas to incorporate into a local, in person event:

- Custom cookies or cupcakes
- Food/ice cream truck
- Relay
- Kids fun run
- Prizes for top finishers
- Post ALD facts along the route
- Chalk drawings/encouraging messages along the route
- Bean bag tournament, yard games, barbeque
- Sign Gypsies (or similar rent-a-sign business)
- Bouncy house
- Music
- Photo frame signs, poster boards, etc. for photo opportunities





Hand painted rocks to mark the trail



Photo border



Custom cookies

If you are holding an in person event in a public space, remember to check with local parks and recreation/city officials to confirm whether or not a permit is needed, if there is an associated cost, law enforcement required for points in the route that cross busy streets, etc. If you are planning on a walk/run, here is a checklist to get you started on some items that may be useful:

- Folding tables
- Bottled water
- Juice boxes
- Coffee
- Snacks
- Route print out
- Garbage/recycling bins
- Scissors/tape
- First aid kit
- Donation box
- Hand sanitizer
- QR code for donations
- Balloons, banners, maroon/gold decor
- Mile markers/signs or arrows to mark the route
- Chalk drawings along the route (encouraging messages, facts about ALD, etc.)





- **Take photos!**

Take photos before, during and after your event and either email them to [info@xoutald.org](mailto:info@xoutald.org) or tag us on social media. Note: if your profile is not public and/or we are not tagged, we will not see it!

- **Show your gratitude.**

You cannot say thank you enough. Let your supporters and team members know the difference they have made; share the accomplishments of your team and the organization as a whole and tell them what it means to you. A personalized written thank you is suggested but a thank you in any form is better than none!







## FAQs

### **What is the University of Minnesota Leukodystrophy Center and ALD Comprehensive Clinic?**

The University of Minnesota Leukodystrophy Center's multidisciplinary team of specialists has unsurpassed, world-class experience in the diagnosis, monitoring and care of pediatric and adult patients with inherited leukodystrophies. The ALD Comprehensive Clinic was established to provide easy access to a team of ALD experts who can help families navigate an adrenoleukodystrophy diagnosis and provide coordinated care for this complex condition.

### **How will the funds raised be utilized?**

All funds raised by X out ALD are donated to the ALD Research Fund at the University of Minnesota, where the researchers are focused on improving treatment options and outcomes for ALD boys, regardless of their stage of disease.

### **How can fundraising make a difference?**

Many excellent ideas for improving treatment outcomes never come to fruition due to a lack of funding. Fundraising makes a difference in ensuring these ideas can be explored and hopefully translate into more effective and safer treatments.

### **What is a virtual event?**

Outrun ALD is a virtual 5K which means there are no rules! There is not a physical location for the event which allows you to plan or join a local event, walk/run/bike on your own, or do nothing at all! The options are endless and we love seeing everyone make the event their own. The virtual format has allowed participation from coast to coast and beyond.

### **What percentage of my registration fee/donation goes toward research?**

Thanks to our sponsors, 100% of registration fees and Outrun ALD donations are donated to the ALD Research Fund.



### **How do I get an Outrun ALD t-shirt?**

Register! One 2023 Outrun ALD t-shirt is included with your \$25 registration fee. Just be sure to do so by our registration deadline of July 24. After that date, we are unable to include a t-shirt with registrations.

### **What if I don't have a team?**

We've got you covered! You can register under "No team? No problem."

### **What is the difference between registering and donating?**

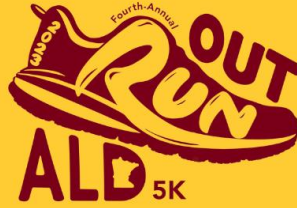
Registration is \$25 (plus minimal processing fee); a 2023 Outrun ALD t-shirt is included with your registration. We would love for you to join us from wherever you are on September 16 for a 5K or event of your choosing but it is not necessary. If you prefer to give a straight donation, you can donate any amount you choose; no t-shirt is included.

### **How can I sponsor the event?**

We have two sponsorship levels: maroon and gold. The minimum donation required to sponsor is \$250. View sponsor levels [here](#). Donations through sponsors cover the cost of t-shirts and shipping. Any excess sponsor donations are donated to the ALD Research Fund.

### **What if I'm not available to walk/run on the event date?**

You can choose a different date or forgo the 5K. Regardless of what you choose to do or when you choose to do it, please send us photos! You can email to [info@xoutald.org](mailto:info@xoutald.org) and/or tag us on social media.



## How can I support the event?

- **Register** for the event. Create or join a team and encourage your family and friends to join.
- **Donate** to X out ALD. If you prefer to give a straight donation, you can bypass registering for the event and donate any amount of your choosing. You can donate through the **event website** or **X out ALD's website** which offers PayPal or credit card options. **NEW!** X out ALD is now on Venmo.
- **Sponsor** the event. Sponsors cover the cost of t-shirts and shipping. 100% of excess sponsorship donations are donated to the ALD Research Fund. If you are interested in sponsoring the event or know of any person or business who may be, please let us know or view/complete the sponsor form **here**.
- **Share!** Whether or not you are able to register or donate, you can always share with your family and friends via social media, email or word of mouth. Awareness is a vital part of our mission and fundraising efforts.

## How can donations be made?

Donations can be made in any of the following ways:

- **Visit the X out ALD Website:**  
[Donate \(xoutald.org\)](http://xoutald.org)
- **Checks can be mailed directly to X out ALD at:**  
X out ALD  
10537 Thomas Avenue South  
Minneapolis, MN 55431
- **Venmo**
- **Facebook and Instagram**



## General Fundraising Tips

- **Make it personal! How has ALD impacted your life?**

ALD is a disease that does not present the same in any two individuals. It could be your child who is affected, an aunt or uncle, father or mother, or another family member. You could be a newborn screen family, a transplant family, or a family that has come due to a later diagnosis. Telling your story about how ALD has affected you can be very compelling and impactful in your fundraising efforts. Use photos and update often. Posts with images alongside your story can create higher engagement with your network.

- **Don't be shy! Establish a goal.**

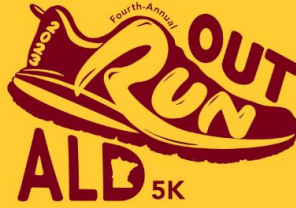
Fundraisers with a specific target have a greater likelihood of reaching their campaign goal. You would be surprised how your story may resonate with your target audience and how many people want to see you reach your goal. The proximity effect is powerful. Setting this target can influence what a donor may choose to contribute. You will be surprised by how many people in your network genuinely want to see you “cross that finish line.”

- **Harness the power of social media.**

We live in a virtual age where social media has a far-reaching grasp globally to deliver our message. With the advent of platforms such as Facebook, Instagram and Twitter, there are multiple ways to get the message out about fundraising for ALD. Even if people cannot donate directly at the time, they may share your fundraiser and your message will reach a much wider audience. For instructions on how to set up a Facebook or Instagram fundraiser, please see page 28.

- **Be the first to donate!**

Whether setting up a team for Outrun ALD or creating a social media birthday fundraiser, by being the first to donate, you will demonstrate to your network of supporters how dedicated you are to supporting the research being done to save lives and improve treatment options and outcomes for boys with ALD.



- **Birthday/Anniversary/Wedding/Party fundraisers**

It is becoming increasingly common to see individuals set up fundraisers and ask for charitable donations in lieu of gifts when celebrating important events. This can be done for adult and children's birthday parties alike. There are many invitation platforms such as Invitd and Evite that are making this increasingly easier to do. Using social media and/or invitations to events and parties can be an excellent way to engage your network.

- **Donations in lieu of party favors**

Some people choose to make a donation to a charity in lieu of traditional party favors. This is an increasingly common practice.

- **Email campaigns**

While most people do connect on social media, there are some who choose not to. Sending an email with a link to your fundraiser or story and team page can greatly increase the chances that your story will be received and reach a wider audience.

- **PayPal**

Did you know that you and your friends and family can set up X out ALD as your favorite charity on PayPal? At every checkout, there is the option to donate \$1. These funds can add up over time and every dollar counts.

- **Education is key**

Education is paramount to any fundraising endeavor. If people understand the prevalence of ALD and why it is essential to develop safer and more effective treatments, it can greatly assist in increasing donations. Before setting up fundraisers or requesting donations, educate people about ALD to help them understand the need for funding this lifesaving research.

- **Be creative and have fun!**

Get creative! There are many different ways to engage your friends, families and colleagues in raising funds to support your team.



- **Don't be afraid to ask more than once.**

Many times, well meaning contacts have the intention of participating or donating, but the chaotic nature of our lives gets in the way and our message can be forgotten. Also, due to algorithms in social media platforms, your message might not reach your intended audience the first time. Sending your message more than once will ensure you reach a wider audience.

- **Company Sponsors/Matching. It never hurts to ask!**

Quite often companies are looking for new ways and new organizations to designate their charitable giving. Making connections with contacts and the organizations they are involved with can greatly increase your audience and increase donations. Many companies will match an employee's donation to a charitable organization. Check to see if your employer offers matching and/or ask your friends and family to do the same.

- **Remember to say thank you.**

When fundraising for any kind of charitable organization, you can never say thank you to those who donate and support your efforts enough. Respectful and grateful donor stewardship is essential. There are many ways to say thank you and the more ways it is done, the greater the impact. You can thank people directly on your team page, through email, on social media and/or through a thoughtfully worded handwritten note.

Keeping track of when someone donates to your team is important. It is always better to thank people soon after a donation is received. Also, a personal approach, rather than an automated response is usually best.

#### **Thank your donors**

- as soon as they have made a donation
- if they have referred a new donor to your team
- when certain milestones have been met
- in event updates
- on social media because it will let them know they are appreciated and might encourage others to give





- **Update after the fundraiser.**

It is always a wonderful idea to keep in touch with your donors after the fundraiser is over. Following up with them and showing them what their donations have helped accomplish can make it more likely that they will support you again in future years. While there are updates from X out ALD on social media, a personal message is always well received.



## Templates and Examples

### Writing Your Personal Story



Team Can't Stop, Won't Stop is back for the third year!

We are Dan, Cassie and Brock Groh and we are a part of the team Can't Stop Brock, Won't Stop Trevell. Brock celebrated his third transplant anniversary in January or as we like to call it his re-birthday. His MRI, X-rays, neuropsych testing and lab results were all positive news and Dr. Lund gave him an A+ report! Brock remains asymptomatic since being diagnosed with cerebral ALD in 2018. As always, Brock celebrated with bacon!

Brock is continuing to enjoy life each and every day. He finished third grade, loves soccer and would go to every single Minnesota Loons game if he could. We are navigating the adrenal insufficiency life and for his age, Brock does well communicating how he feels. A big shoutout to Dr. Bradley Miller who makes this way of life easier.

In May, we had the privilege of speaking at a fundraiser for the M Health Fairview Masonic Children's Hospital. Dan and I don't enjoy public speaking, but right before we went up on stage Brock asked where his microphone was. Next time we will make him speak! He takes every opportunity he can to raise awareness about ALD, his favorite hospital and his favorite doctor. He did The Griddy on stage (if you know, you know) and the Minnesota crowd loved it. We are forever grateful for Brock's health. We will continue to pay it forward by trying to X out ALD!

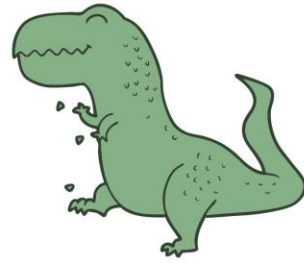


## Sample Invitation Wording

adrienne  
+ wikkie

INSTEAD OF GIFTS, WE HOPE YOU WILL  
CONSIDER MAKING A DONATION TO X OUT  
ALD, A CHARITABLE ORGANIZATION THAT IS  
CLOSE TO OUR HEARTS!

X OUT ALD IS A MINNESOTA BASED 501(C)(3) DEDICATED TO RAISING  
AWARENESS OF ADRENOLEUKODYSTROPHY (ALD) AND SUPPORTING  
RESEARCH OF THE DISEASE AND ITS TREATMENT AT THE UNIVERSITY  
OF MINNESOTA LEUKODYSTROPHY CENTER.



STOMP AND ROAR!

GARRETT IS TURNING 4!

August 4, 2023, 2 PM  
Any Street, 123 Anywhere Street

A FRIEND LIKE YOU IS THE ONLY GIFT I NEED!  
IF YOU WISH TO GIVE A GIFT, PLEASE CONSIDER  
MAKING A DONATION TO X OUT ALD.



## Sample Wording for Donations in Lieu of Party Favors

Thank you

TO OUR FAMILY AND FRIENDS  
AFTER CAREFUL THOUGHT AND CONSIDERATION  
WE HAVE CHOSEN A SPECIAL WAY TO SAY  
THANK YOU FOR SHARING THIS DAY WITH US

IN LIEU OF TRADITIONAL PARTY FAVORS WE  
HAVE MADE A DONATION IN YOUR HONOR TO  
X OUT ALD

THANK YOU FOR THE GIFT OF YOUR PRESENCE AS  
WE CELEBRATE THIS DAY TOGETHER!



**Donate to X out ALD here!**



**SCAN ME**



## RunSignup Instructions

### How to register/donate.

1. Click [here](#) to go to 2023 Outrun ALD's RunSignup page.
2. **If you already have an account with RunSignUp**, click Sign In and log into your account.
3. From here, you can register and/or donate. Profiles from previous years are saved in your account and can help fast track the registration process. **Tip:** If you created a team last year, you will have the option to bring that team back and an email will be sent to all prior team members inviting them to register.



4. **If you do not have an account with RunSignUp**, click Create Account and follow prompts.



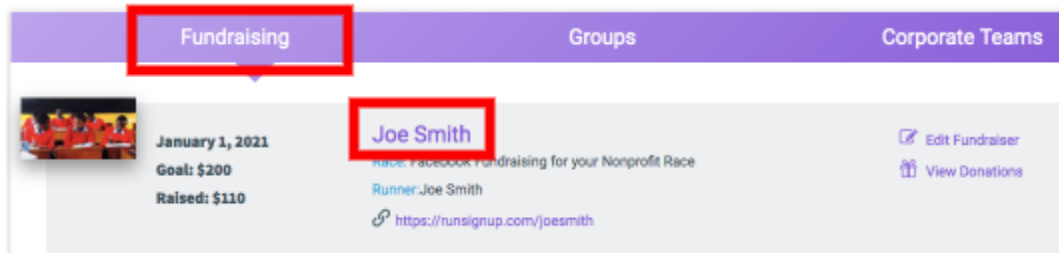


### How to invite others to register/donate.

Share this [link](#) or find your personalized donation link on your fundraising page that will take supporters directly to your fundraising page. **Tip:** Once you register and/or create a team, your custom fundraiser URL will be in the confirmation email.

### How to connect a Facebook fundraiser to RunSignup.

1. Sign in to RunSignup.
2. Go to your profile.
3. Scroll down to your fundraising section of your profile.
4. Click on your fundraiser name to go to your fundraising page.
5. On your fundraiser page, click Create Your Fundraiser on Facebook!



**Technical issues?** If you or someone you know is having a difficult time completing registration or donating, please reach out to us at [info@xoutald.org](mailto:info@xoutald.org). We don't want a technical issue to prevent anyone from registering, donating or sharing the cause.



## Facebook and Instagram Fundraiser Instructions

Facebook Fundraiser Instructions located [here](#).

Instagram Fundraiser Instructions located [here](#).

### Tips for social media fundraising campaigns:

- Most campaigns have a fundraising goal from \$200 – \$500.
- Most campaigns are active between two to four weeks.
- Take your time writing the description. It's an opportunity to tell your story, the cause's importance, why you're passionate about it, and encourage donations.
- Invite others to view your campaign and ask others to share.
- Share your campaign as a post. It's ok to share it more than once!
- Once your fundraiser is live, don't forget to promote it across your social channels.
- It should feel part of an overall content strategy, so it's a good idea to remind your audience about the fundraiser on stories or through the captions of your posts.
- If you have time, send everyone who donates a direct message thanking them for their support; this personal touch is a great way to acknowledge contributors and strengthen the sense of community around your fundraiser.