

HD ARMY Ambassador Event Leader Guide

Fund raising to benefit the
Huntington's Disease Foundation

The mission of the Huntington's Disease Foundation (HDFI)

is to serve as the trusted resource
for the Huntington's disease (HD)
community by raising awareness,
providing disease education, and
funding research.

This Third Party Event Leader Guide is provided by the Huntington's Disease Foundation as a public service to our community.

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Huntington's Disease FOUNDATION

thank you!

THANK YOU for joining *HD ARMY Ambassador team*! Passionate and dedicated individuals like yourself who take action in the fight against Huntington's disease are making a difference in the lives of those affected by the disease.

HD ARMY Ambassadors are advocates who actively fundraise, promote, and host third-party events to raise funds and awareness about Huntington's disease. The funds you raise directly enhance patient services, fund research, and support HD signature programs for the Huntington's disease community. Thank you for joining others from around the globe in letting the world know that we need a cure today.

If you have any questions, please feel free to contact Doug Michael, President, at DougM@HDFI-USA.org or visit our website at HuntingtonsDiseaseFoundation.org. Once again, thank you! We appreciate you taking on this vital role to benefit the Huntington's disease community!

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about the Huntington's disease Foundation

WE IMAGINE A WORLD WITHOUT HUNTINGTON'S DISEASE.

The Huntington's Disease Foundation is focused on our mission to act as the trusted resource for all who are affected by this disease. We have developed relationships with industry partners and upheld our position as the honest broker to inform those affected by Huntington's disease of important scientific breakthroughs and educational material.

Childhood friends Trey Gray and Doug Michael, along with their dear friend, Anett Pappas, founded the Foundation in 2015. Trey experienced firsthand the devastating effects of HD when he was diagnosed in 2003 with Huntington's disease. His children have a 50/50 chance of inheriting this disease too. His family members (mother and uncle) have both died of Huntington's disease and Trey witnessed the pain and struggle as they went through each dreadful phase of HD.

Huntington's Disease Foundation is a register 501(c)(3) non-profit charity. This Foundation was created to keep Trey's dream alive by finding a way to turn his disease into something positive. With creating this Foundation the founders are able to stay focused with the vision and be able to reach more people at a more personal, heart felt level. We are dedicated to continuing to bring awareness to the forefront and continue to hope, encourage and support – no matter how big or small – to help advance the pursuit of a HD cure. It is our vision and dedication that led to the creation of the Foundation.

welcome to the HD Army!

steps for a successful fundraiser

CHOOSE AN EVENT TYPE

- The most successful events combine something that is fun and meaningful to you and your family, as well as interesting to your community.

CHOOSE YOUR DATE AND LOCATION

- Once you have an event type, choose your desired date and potential locations. *HD ARMY* Ambassador Event Leaders are responsible to obtain any required permits or insurance.

ASSEMBLE YOUR EVENT TEAM

- Recruit your family, friends, and co-workers to help you with your event.

ESTABLISH YOUR GOALS

- Determine your fundraising goals and create a work plan for you and your event team. Assign event team members specific tasks to complete.

COMPLETE YOUR ONLINE EVENT REGISTRATION

- Once you have finalized your event details, please fill out the ***HD ARMY Ambassador Event Registration Form*** at:

HuntingtonsDiseaseFoundation/HDArmyEvent. or mail in attached form.

SPREAD THE WORD

- Congratulations—your event will be added to the *Huntington's Disease Foundation* event calendar on our website and announced on our social media. Now it's time to invite everyone you know! Post to your Facebook page, send an email invitation, tweet about your event, be creative!

ENJOY

- You have put together an incredible plan and now is the day to enjoy your guests and your event!

event ambassador basics

We created this *HD ARMY Ambassador Event Leader Guide* to help answer your questions and provide you with resources and tools to make planning and hosting your third party event a positive experience. Below is an overview of your responsibilities as a *HD ARMY Ambassador Event Leader*.

YOU ARE RESPONSIBLE FOR

- As an Event Leader, you must fill out the **HD ARMY Ambassador Registration Form**.
- You are responsible for all costs and expenses including permits, liability insurance, licenses—especially those for raffles/games of chance.
- You must ensure that your event complies with all federal, state, and local laws governing charitable fundraising and gift reporting.
- You are responsible for media coverage. Your local newspaper, radio, and television station would love to hear from you!
- You are in charge of recruiting volunteers to help at your event.
- You are responsible for marketing. Advertise your event by creating and posting flyers, and post on social media!
- All fundraising for a third party event is to be conducted for the exclusive benefit of the Huntington's Disease Foundation.
- Huntington's Disease Foundation requests that you provide your final net proceeds in one check made payable to the Huntington's Disease Foundation, as well as a completed **HD ARMY Ambassador Closing Form** within 15 days of your event. The Huntington's Disease Foundation will provide a single acknowledgement to the *HD ARMY Ambassador Event Leader* for the event proceeds.

Please mail your check and Event Closing Form to:

Huntington's Disease Foundation, C/O *HD ARMY AMBASSADOR/EVENT NAME*
P.O. Box 912
Salado, TX 76571

fundraising faqs

I want to host an event to benefit the Huntington's Disease Foundation. What are some examples of events I can organize?

Thank you for hosting a third party event to benefit the Huntington's Disease Foundation! Some examples of successful events have included:

- Conducting a Dress Down Day/Jeans Day at work
- Hosting a Dine Out for Huntington's disease Fundraiser at your local restaurant
- Organizing a silent auction
- Walk/Run
- Holding a spare change drive
- Creating a personal fundraising page
- Organizing a bake sale
- Bowling to benefit the HD

Will my supporters receive tax credit when they donate to my event?

Contributions made to a *HD Army Ambassador* event are not considered a tax donation due to IRS regulations, so your supporters will not receive a tax receipt. We are so thankful for their support, which helps make it possible for us to provide resources to patients and caregivers every day, and maintains our momentum in serving the HD community by increasing research funding, broadening disease education outreach, and enhancing patient support services.

A local company wants to give their services as an in-kind contribution. Will they receive a tax receipt?

The Huntington's Disease Foundation does not issue tax receipts for in-kind contributions due to IRS regulations.

I would like to have sponsors for my third party event help me cover expenses. Will the Huntington's Disease Foundation be able to issue tax receipts for their support?

Per IRS regulations, the Huntington's Disease Foundation does not issue tax receipts for sponsors. The Huntington's Disease Foundation is not permitted to share any of its licenses, permits, or tax exemption benefits with *HD ARMY Ambassador* Event Leaders or their sponsors.

Can I use the Huntington's Disease Foundation's tax exempt status for my event?

The Huntington's Disease Foundation is not permitted to share any of its licenses, permits, or tax exemption benefits due to IRS regulations, therefore *HD ARMY Ambassador Event Leaders* are not permitted to use the Huntington's Disease Foundation's tax exempt status in conjunction with their events.

May I use the Huntington's Disease Foundation's tax exempt status to purchase items for my event?

The Huntington's Disease Foundation is not permitted to share any of its licenses, permits, or tax exemption benefits due to IRS regulations.

The venue where I want to host my event requires that I have liability insurance. Can I use the Huntington's Disease Foundation's insurance?

The Huntington's Disease Foundation is unable to insure your event. The Huntington's Disease Foundation is not permitted to share any of its licenses, permits, or tax exemption benefits with *HD ARMY Ambassador Event Leaders*.

I sent my third party event proceeds to the Huntington's Disease Foundation but still need to pay for expenses. Will Huntington's Disease Foundation be able to pay for the expenses with a portion of the proceeds?

The Huntington's Disease Foundation cannot pay expenses for third party events. The *HD ARMY Ambassador Event Leader* should deduct the amount needed to cover expenses from the event gross proceeds and then turn in the net proceeds to Huntington's Disease Foundation.

Will a Huntington's Disease Foundation representative be able to come to my event?

Thank you for inviting us! If you would like a Huntington's Disease Foundation member accept the check and/or address your guests at your event, please contact Doug Michael at DougM@HDFI-USA.org.

I have some awesome photos from my third party event. What can I do with them?

We would love to see your photos and share them with our online HD community. Please send them to **AnettP@HDFI-USA.org**. In the title enter: Event Photos.

I've hosted my event but would like to do more. What I can do now?

We love your enthusiasm and offer to help! There are a few ways that you can get involved beyond doing events. We would also love to see you at the *Huntington's Disease Foundation's Symposium: CURE HD through Awareness*, which is a unique conference that brings together patients, caregivers, health care professionals, and industry representatives dedicated to finding a treatment and a cure for Huntington's disease. You can contact us directly to check on volunteer work since we do many events throughout the year and we always are looking for help.

How do I close out my event?

Once your event has concluded there are a variety of things you can do:

- First, evaluate your event. Make a list of what worked well and identify any areas for improvement.
- Second, send your **Event Closing Form** and event proceeds to the Huntington's Disease Foundation.
- Third, take time to think all those who helped you with your event. You can personalize the thank you note in this guide.
- Last, please consider setting a date and time for next year's event and let us know so we can include it on our event calendar.

event closing form

EVENT NAME

DATE

AMBASSADOR EVENT LEADER

EMAIL

IN HONOR/MEMORY OF/GENERAL (INCLUDE NAME AND RELATION TO YOU)

CITY

STATE

ZIP

Phone

AMOUNT RAISED COST OF EVENT TOTAL CONTRIBUTION

WHAT ABOUT YOUR EVENT WENT WELL (MEDIA, DAY OF, ETC.)?

WHAT WOULD YOU LIKE TO IMPROVE FOR NEXT YEAR?

PLEASE COMPLETE THIS FORM AND SEND IT TO THE HUNTINGTON'S DISEASE FOUNDATION WITHIN 30 DAYS OF YOUR EVENT:

Huntington's Disease Foundation, C/O HD ARMY AMBASSADOR/EVENT NAME
P.O. Box 912
Salado, TX 76571

sample fundraising letter

<DATE>

<RECIPIENT NAME>

<RECIPIENT ADDRESS 1>

<RECIPIENT ADDRESS 2>

<RECIPIENT CITY, STATE ZIP>

Dear Friends and Family,

This year I am excited to join *Huntington's Disease Foundation* as an *HD ARMY AMBASSADOR* Event Leader. As a *HD ARMY AMBASSADOR Event Leader* I will be hosting a <NAME OF ACTIVITY> in <MEMORY/HONOR> of <NAME OF LOVED ONE>. I am making a commitment to raise funds and awareness for the Huntington's Disease Foundation (HDFI) because <YOUR ANSWER HERE>. I am dedicating my efforts to the Huntington's Disease Foundation because we need to find a cure for HD.

Huntington's disease (HD) is an incurable, hereditary brain disorder. It is a devastating disease for which there is no currently "effective" treatment. Nerve cells become damaged, causing various parts of the brain to deteriorate. The disease affects movement, behavior and cognition - the affected individuals' abilities to walk, think, reason and talk are gradually eroded to such a point that they eventually become entirely reliant on other people for their care. Huntington's disease has a major emotional, mental, social and economic impact on the lives of patients, as well as their families. The progression of the disease leads to complete dependency in daily life, which results in patients requiring full-time care, and finally death. 1 in every 10,000 Americans has the disease - 30,000 people. It is estimated that at least 150,000 other Americans have a 50% risk of developing HD, while thousands of their relatives carry a degree of risk too.

The mission of the Huntington's Disease Foundation is to serve as the trusted resource for the Huntington's disease (HD) community by raising awareness, providing disease education, and funding research.

I'm asking for your support as I raise awareness and funds for the Huntington's Disease Foundation. My personal goal is to raise <FUNDRAISING GOAL> and every dollar makes an impact. Please help me reach my goal by making a contribution now. Please visit my personal online fundraising page at <INSERT URL> to make a secure gift online or contact the Huntington's Disease Foundation at HuntingtonsDiseaseFoundation.org. I invite you to join me in making a difference in the lives of those affected with Huntington's disease.

Thank you in advance for your generous support!

Sincerely, <EVENT HOST>

sample thank you letter

<DATE>

<RECIPIENT NAME>

<RECIPIENT ADDRESS 1>

<RECIPIENT ADDRESS 2>

<RECIPIENT CITY, STATE ZIP>

Dear <GUEST>,

Thank you for attending my event to benefit the Huntington's Disease Foundation (HDFI). Your participation helped me raise critical funds that allow the Huntington's Disease Foundation to raise awareness, provide disease education, and fund research. Events like <NAME OF YOUR EVENT HERE> are essential to raise much needed funds and awareness for the Huntington's Disease Foundation's mission and I couldn't have done it without you.

I appreciate your participation and hope to see you at next year's event!

Sincerely,

<EVENT LEADER NAME>