

Don't Sweat It 5K Run/Walk NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS TOOL KIT



NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

INTRODUCTION

You can help people affected by ectodermal dysplasias have a brighter future by raising funds for the National Foundation for Ectodermal Dysplasias (NFED). Fundraising events have an added benefit. They help raise awareness for the different types of ectodermal dysplasias and the NFED. The more people who know about ectodermal dysplasias in the medical and dental communities and the general public, the more likely people will help advance our mission.

The most powerful way we can raise funds and awareness is through you—our volunteers. You are our champions. You are the one making your mark. Your circles of relatives, friends, co-workers, and neighbors, your knowledge, your personal journey and your commitment cannot be matched by anyone outside of our community.

This toolkit walks you through the steps to set up your own Don't Sweat It Run/Walk and explains how the NFED can help.

Supporting you, supporting each other.

If you have questions, contact: Lea Richardson at 618-566-6871 or lea@nfed.org

Thank you for supporting and advancing our mission to empower and connect people touched by ectodermal dysplasias through education, support and research!

HOW TO HOST A DON'T SWEAT IT RUN/WALK

SECURE YOUR LOCATION/ROUTE

The great thing about hosting walks is that people can walk anywhere, so finding a location that works is usually pretty easy! Check out area parks, schools, churches, neighborhoods and malls. Make sure your route begins and ends at the same place if at all possible.

A few things to keep in mind when selecting a site:

- Is there adequate parking for the event?
- Are there restrooms available?
- Is there a power source in case you need a cooling area?
- Do you need a permit? If so, please file it immediately as these can take time to be approved. Most permit fees are waived for non-profits so contact us if there will be a charge.
- Is there heavy traffic or anything else that might pose a problem?
- Is insurance required for the location? If it is, please let us know ASAP.

DETERMINE A TIME AND DATE

Please check local event calendars to make sure that you are not competing against another walk, 5K or major event in your area. Also, it is important for you to decide if you will have a rain date or if your event will be held "rain or shine." Most run/walks are held in the early morning but your event is not limited to the morning hours. You may opt for something different, such as a sunset walk or a midnight stroll.

Sample Schedule:

6 a.m. – 7 a.m.	Set-up
7 a.m. – 8 a.m.	Registration
8:15 a.m.	Opening Ceremonies
8:45 a.m.	Walk begins
10:45 a.m.	Event gathering with refreshments
8:45 a.m.	Walk begins

PRICING

Suggested pricing for this event is as follows:

- \$15 Kids 12 and under (Does Not Include t-shirt)
- \$25 Early Bird Registration (guaranteed t-shirt for each participant)
- \$30 After Deadline or Day of Event (t-shirts available while supplies last)

HANDLING REGISTRATIONS

We are going to make this very easy for you! People can still manually register for your walk by mailing their forms to our office or to you, but we also have another way to register. Direct your participants to the NFED website, where you will have a page dedicated to your event. The page will keep a live total of the number of people that have registered for your event as well as a count on the money you have raised. Checks received in the office will be added to the total on a daily basis.

SETTING GOALS AND FUNDRAISING

The goal for each walk is 100 participants, but you want to raise as much money as possible for NFED's mission. To raise additional funds, encourage participants to consider soliciting individuals and/or businesses to pledge to your walk by making a donation. If each participant commits to raising a minimum of \$25, then you could raise \$2,500.

Suggested techniques to raise additional pledges include:

- Ask family and friends not walking to contribute a certain dollar amount to your walk.
- Have individuals check with their employers about matching gift programs.
- Solicit donations in honor of an individual with ectodermal dysplasia.

Don't forget to remind your supporters that 100% of their donation benefits the NFED, contributions are tax deductible and checks from participants should be made out to the NFED.

SPONSORSHIPS AND DONATIONS (Don't let this scare you!)

Sponsorships are a vital part of hosting a walk. Remember, anyone or any company can sponsor your event. As a host, you should try to secure at least three key sponsors in order to minimize the expenses for your event.

- Food Sponsor(s) This can be an "in-kind" donation from a restaurant, grocery, bakery, etc. You are looking for light foods like granola bars, fruit and bagels. The company logo will be placed on all marketing materials if sponsorship is secured by the date of your walk.
- Beverage Sponsor(s) Bottled water is the easiest but fruit juices, sports drinks are usually pretty easy to get donated. The company logo will be placed on all marketing materials if sponsorship is secured by the date of your walk.
- Prize Sponsor(s) Since Don't Sweat It Walks are traditionally noncompetitive events, prizes are unnecessary. If you would like to add door prizes, a raffle or an auction to your event, feel free to use the donation letter found in the packet. Please note that it is very important that you fill out a donation form for each vendor that supplies you with an item. This is how they will receive proper tax credit and will be the information we use to send them a thank you letter.

Please understand that the NFED will not cover any expenses for your event. Therefore, if you are working with an individual or company for a food sponsorship and he or she offers you a check, THEY SHOULD NOT WRITE IT TO THE NFED unless prior written approval was given for NFED to pay expenses. Ask sponsors to make the check out to the vendor you will be using. Make a copy or have them give you a copy of their check and have them fill out the donation form to ensure they receive proper tax credit. If they have any questions they are welcome to contact our office and speak with Lea Richardson, at 618-566-6871.

RECRUITING PARTICIPANTS & SPONSORS

You can't have a run/walk without having anyone to run or walk in it. Also, volunteers should always be welcomed to help your event go smoothly.

Here are some suggestions for effective recruitment:

- Ask friends, neighbors, family members and co-workers.
- Contact local community groups such as the Girl Scouts and Boy Scouts.
- Partner with local colleges and universities, including fraternities, sororities and athletic departments.
- · Call area high schools, churches, and civic organizations.
- Contact local walking/running clubs. (Ask to put flyers in bags at their upcoming events.)

- Contact local corporations about putting teams together. Ask if you can share the information about the event with their employees or if you can send an electronic invitation.
- Place posters and flyers in local supermarkets, restaurants, salons, health clubs or any place you currently do business.
- Talk about it and have flyers with you everywhere you go! Word of mouth is very powerful.

CONTACTING LOCAL MEDIA

If you have a personal contact at any of your local media outlets, utilize them to the fullest. Let us know ASAP if you think any media station would be interested in sponsoring your walk. Media sponsors are not easy to come by, but if your walk gets the attention of a morning show or a beloved news anchor, it can add up to a lot of wonderful free publicity.

If you have any questions regarding the media, contact Jodi Edgar Reinhardt, NFED Director, Marketing and Communications, at (618) 566-6875 or by email at Jodi@nfed.org.

DESIGN YOUR EVENT WEB PAGE

We can develop a webpage dedicated to your event. Fill out the web design information sheet in the packet and return it to lea@nfed.org or mail it to:

NFED c/o Lea Richardson 6 Executive Dr., Ste. 6 Fairview Heights, IL 62208-1360



EVENT CHECKLIST #1: ORGANIZING THE EVENT

- Returned information sheet to NFED
- Location secured
- Permits obtained
- Date secured
- □ Insurance certificate on hand
- Desters, flyers, registrations, banners and donation forms ordered
- Event added to the NFED web site
- Individual registration page built on NFED website
- Reviewed and understood the fundraising component
- Secured title sponsor
- Secured food sponsor
- Secured beverage sponsor
- Secured door prizes, auction items, raffle items
- □ Issued donation forms for all in-kind items
- Recruited participants
- Distributed posters and flyers around town
- Recruited volunteers for the day of the event
- **O**rdered and received sponsor banners/nfed banner, materials, t-shirts
- Contact a local EMT service to see if they could have personnel standing by

EVENT CHECKLIST #2: A WEEK PRIOR TO YOUR EVENT

- U Volunteer assignments created for the day before and the day of the event
- Arrangements made to have food and beverage donations picked up
- □ Items assembled for the registration table
- □ Items assembled for the food and beverage table
- NFED items boxed and ready (brochures, banner, t-shirts, talking points, pictures for the walking path)
- Goody bags assembled (not required)
- Tables and chairs secured for registration table, food and beverage, and water stations
- Prepared list for materials needed at starting line and finish line

EVENT CHECKLIST #3: THE DAY OF YOUR WALK

- Arrive at least 1 hour prior to registration
- Drive the walking path if possible and look for any hazards
- Post directional signage and NFED pictures along the walk area
- Set up registration table
- □ Set up food and beverage table next to the registration area. Snacks (bagels, muffins, and/or fresh fruit) and beverage (water, juice and/or sports drinks) are typically provided before and after a walk.
- **Get** Set up mid-point water station with small disposable cups, pretzels, bananas, etc.
- Sponsors and/or vendors arrive early to set up their booths or tables

THE EVENT PROGRAM

- Begin your walk with a brief program highlighting the NFED and why you chose to host the event. If you are dedicating the event to honor someone affected, ask him/her to say a few words or just to say hi.
- Ask your title sponsor or local celebrity to welcome the participants and remind them of how much their generosity and kindness means to individuals affected with ectodermal dysplasias. He/She could use the NFED fact sheet for talking points.
- Next, have a five or 10-minute pre-stretch. Thank the group once again for supporting your event and for helping the NFED. Sound a horn or pull a ribbon to start the walk!
- WHEW! They are off and walking. It's almost over. Remind yourself of the amazing way you felt when the race started. This was all because you said YES and accepted the challenge THANK YOU!
- Replenish the snack and beverage table so that it is ready when the walkers return.
- Start breaking down the registration supplies and securely place all donations in the lock box and put away. Clean up. Make sure someone drives the course and cleans up all remaining trash.

FOLLOWING THE EVENT

- Forward the names and addresses of all volunteers to the NFED so that we can issue thank you notes to them right away.
- Forward all monies, registration forms, donation forms, sponsorship agreements and any other paperwork to the NFED within 45 days of the event.
- Provide the NFED a listing of names and addresses for all in-kind sponsors, copies of receipts/ invoices/checks as proof.



INFORMATION REQUEST FORM

(Please fill out, sign and return as soon as possible.)

Name			
		Zip	
Phone	Cell		
Email			
Where will your event be	held?		
On what date?		Time	
Are you dedicating this e	event to anyone?		
What is your relationship	to this person?		
Have you contacted the	venue? yes no		
Do you need a permit for	r this event? yes no		
Do you need insurance?	yes no		
How many people are yo	ou expecting?		
Who will you be contacti	ng as potential sponsors:		
Title Sponsor			
Beverage Sponsor			

I, ______, understand that the NFED will not cover any expenses for this event and that all sponsorships checks (excluding title sponsor) should be made out to the vendor providing the products. Any overage will be included in a separate check made out to the NFED.

Host

Date

Return form to NFED, c/o Lea Richardson, 6 Executive Dr., Ste. 2, Fairview Heights, IL 62208-1360.



Local Media Contacts

Local Newspaper(s):

Name:
Address:
City, State, Zip:
Main Phone:
Website:
Health and Medical Reporter:
Email:
Entertainment Reporter:
Email:
Lifestyle Reporter:
Email:
Event Calendar:
Email:
Local Television Station(s):
Name/Network:
Address:
City, State, Zip:
Main Phone:
Website:

AM Assignment Editor:_____

Email: _____

PM Assignment Editor:_____

Email: _____

Promotions Manager:_		
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Email: _____

Local Radio Stations

Name/Format:
Address:
City State Zin:
City, State, Zip:
Main Phone:
Website:
AM Assignment Editor:
· · · · · · · · · · · · · · · · · · ·
Email:
PM Assignment Editor:
Email:
Promotions Manager:
Email:



REGISTRATION FORM

Registration	Start Time -
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Walk Start Time -

All pre-registered walkers will receive a Don't Sweat It Run/Walk T-Shirt Not pre-registered: T-Shirt provided while supplies last.

Indicate size below: Adult: XXL XL L M S Youth: L(14-16) M(10-12) S(6-8)

Contact Information. Please print.

Name_	
Addres	S
City	State ZIP
Phone	Email
	 I am registering as an individual - \$25 pre – registration by Individual Fundraising Goal
	 I am the captain of a team - \$25 per team member pre-registration by Team's Fundraising Goal \$
	• After Registration Fee \$30
	Children under the age of 18 - \$15 pre-registration by After \$20 registration fee.
	 I want to volunteer the day of the event.

Team Registration

Team Name		
Team Member Name	Size	Fee
		- -
		-
		-
		_

Enclosed is my / my team's total reg	istration fees of \$		
Check made payable to NFED	Money Order	Visa	MasterCard
Discover			AMEX
Credit Card Number Sec Code			_Exp Date
Name on Card			
Signature			

Waiver release:

I, ________, understand that participation in the event is potentially hazardous, and that a registered party should not participate unless they are medically able and properly trained. I understand that events may be held over public roads and facilities open to the public during the event and upon which hazards are to be expected. Participation carries with it certain inherent risks that cannot be eliminated completely ranging from minor injuries to catastrophic injuries including death. I am at least 18 years of age, or am signing on behalf of the participant who is below 18 years of age. I understand and agree that in consideration of being permitted to participate in the event, myself and any registered party, the heirs, personal representatives or assigns of myself or the registered party do hereby release, waive, discharge and covenant not to sue active for any and all liability from any and all claims arising from participation in the event by myself or any registered party.

Signature_____Date____

Name of Minor

Mail completed form with payment to

NFED c/o Lea Richardson 6 Executive Dr., Ste 2 Fairview Heights, IL 62208-1360

Thank you for your participation!

Questions? Contact Lea at the NFED at 618-566-6871 or lea@nfed.org. Or, visit us at www.nfed.org.



TITLE SPONSORSHIP PROPOSAL

As the Title Sponsor, your company will receive:

- Bannering and signage rights throughout the course
- Space at the event to set up and display your company and/or products
- Logo placement on all printed materials including posters and flyers
- Logo placement on the t- shirts
- Welcoming rights at the beginning of the walk
- Special recognition at the walk
- Logo inclusion in print materials and event web page

In return, the NFED will receive:

\$1,000 Title Sponsorship Fee (due upon signing)

Please Note: To be included in all print materials including posters, flyers, print, etc. agreement must be signed before

Agreed and Accepted By:

Name		Date		
NFED Representative		Date		
Address				
City	State _		ZIP	



SNACK/FOOD SPONSORSHIP PROPOSAL

As a Snack/Food Sponsor your company will receive:

- Bannering rights at the walk
- Sampling rights at the walk
- Special thank you at the kick off
- Logo inclusion in print materials and event web page

Please Note: To be included in all print materials including posters, flyers, print, etc. agreement must be signed before

Agreed and Accepted By:

Name		
Title		
Address		
City	State	ZIP



BEVERAGE SPONSORSHIP PROPOSAL

As a Beverage Sponsor your company will receive:

- Bannering rights at the walk
- Sampling rights at the walk
- Special thank you at the kick off
- Logo inclusion in print materials and on event web page

Please Note: To be included in all print materials including posters, flyers, print, etc. agreement must be signed before

Agreed and Accepted By:		
Name		
Title		
Address		
City	State	ZIP





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Dear

The National Foundation for Ectodermal Dysplasias (NFED) is the worldwide expert on ectodermal dysplasias and the only advocacy organization in the U.S. dedicated to individuals living with these disorders. Our mission is to empower and connect people touched by ectodermal dysplasias through education, support, and research. We help more than 8,500 individuals throughout the United States and in more than 80 countries.

We are pleased to announce that, on , we will hold a Don't Sweat It Run/Walk in and we respectfully ask for your support. Our goal is to raise \$ and are asking for your help.

Your donation will aid the NFED in continuing its mission of helping children who cannot sweat, have missing or no teeth, have very thin or sparse hair and may be bullied because they look different from other children.

The NFED is a 501(c)(3) organization (EIN #37-1112496) and will provide you with a donation receipt when we pick up your donation.

On behalf of the Don't Sweat It Walk hosts, the NFED, and our families, thank you in advance for your consideration. For additional information, please feel free to contact me at 618-566-6871 or at lea@nfed. org or visit us online www.NFED.org.

Sincerely,

Lea Richardson Manager, Community Engagement

SAMPLE SPONSORSHIP LETTER



NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Date

Name Address City, State and Zip Code

Dear Salutation,

The National Foundation for Ectodermal Dysplasias (NFED), founded in 1981, is the only organization in the United States that assists individuals affected by ectodermal dysplasias; symptoms that include mild to severe defects in the hair, teeth, nails, and sweat glands. The NFED provides education, support, and treatment assistance to more than 8,500 individuals throughout the United States and in 80 countries.

On (Date of Event), the YOUR NAME family will hold their (Your EVENT NAME) in (CITY/STATE). We would like to respectfully ask for your support. We are currently seeking sponsors who can donate (mention what you are looking for) or a monetary donation for the event and would like to ask for your help.

Your sponsorship will help the NFED to continue its mission of helping children who cannot sweat, who have missing or no teeth, who have very thin or sparse hair and who are bullied because they look different from other children. Proceeds from this event will provide support services, treatment, and research for those affected by ectodermal dysplasias.

On behalf of the (Your Name), the NFED, and our families, thank you in advance for your consideration. For additional information, please feel free to contact me at (YOUR PHONE NUMBER) or Lea at the NFED at 618-566-6871 or lea@nfed.org. You can also visit the NFED's website at www.NFED.org.

Sincerely,

Your Name Address City, State and Zip Code



SILENT AUCTION BID SHEET

Item: _____

Item Description: _____

Donor : Bids must be in increments of \$5.

Bidder Names (please print) & Bid Number if applicable	Bid Amount
	MINIMUM
	BID \$5
Winning Bid	
Bidder's Name:	

Bidder's Signature: _____



SAMPLE PRESS RELEASE

Contact: Phone: Email:

Your town, your state- On, the National Foundation for Ectodermal Dysplasias(NFED) will be the recipient of funds raised fromhosted byin. Theare hosting this event in honor of their, who is affected byectodermal dysplasia.

The NFED is the only organization in the country dedicated to serving individuals affected by ectodermal dysplasias. The ectodermal dysplasias are a group of more than 180 syndromes causing the hair, nails, teeth and glands to develop and function abnormally. Symptoms range from mild to severe.

The will feature

For more information about the ectodermal dysplasias or the

, contact

About the Ectodermal Dysplasias

The ectodermal dysplasias are genetic conditions that involve defects in the hair, teeth, nails and sweat glands. Other parts of the body also may be affected. There are more than 180 different types of ectodermal dysplasia which are recognized by the combination of physical features an affected person has and the way they are inherited. Symptoms can range from mild to severe. Hypohidrotic ectodermal dysplasia is the most common syndrome and features multiple malformed and missing teeth, the inability to perspire and sparse hair. Only in rare cases does ectodermal dysplasia affect lifespan and very few types involve learning difficulties. The ectodermal dysplasias affect men, women and children of all races and ethnic groups.

About the National Foundation for Ectodermal Dysplasias (NFED)

The NFED is the leading resource in the world serving the ectodermal dysplasias community. The mission of the NFED is to empower and connect people touched by ectodermal dysplasias through education, support and research. Located in Fairview Heights, Ill., the Foundation is in contact with more than 8,500 families in more than 80 countries. The NFED is a private, tax-exempt, not-for-profit organization pursuant to section 501(c)(3) of the Internal Revenue Code.



DONATION FORM

The following item has been donated to the Don't Sweat It Run/Walk to benefit the National Foundation for Ectodermal Dysplasias.

Please use a separate form for each item donated.
Item______Retail Vaue______
Description ______

Restrictions and Limitations	(if	[:] any)	
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Name of Company/Individ	ual Donating Item		
Person to be acknowledge	d		_
Address			
City		State	ZIP
Phone	Cell Phone		_
Fax	E-mail		
Solicited by			
Donation accepted by	for		_

• Please check if pick up is required.

Thank you from the Don't Sweat It run/Walk Committee and the National Foundation for Ectodermal Dysplasias. Your support is sincerely appreciated. Proceeds benefit ectodermal dysplasias research, services for affected families and treatment.

Donations are tax deductible to the full extent allowed by law. The NFED is a not for profit organization with section 501(c)(3) status. The EIN is 37-1112496.



EVENT WEB PAGE DESIGN

Please fill out the following information so that we may design your personalized website.

NAME	
ADDRESS	
PHONE	
EMAIL	
EVENT NAME	
LOCATION	
ADDRESS	
SPECIAL DIRECTIONS	
DATE	
EVENT DESCRIPTION Please include a short description of your event.	
\$ GOAL	
# OF EXPECTED PARTICIPANTS	
EVENT CONTACT	
PHONE	
EMAIL	
REGISTRATION FEES	
EVENT SCHEDULE	

VOLUNTEERS NEEDED Please list any volunteer jobs you will have available and the hours they are needed.	
DONATION LEVELS Do you have donation levels you would like to use or would you like to use the NFED levels?	
GOAL ACHIEVEMENT NOTE Please write a quick note to send to participants that hit their fundraising goals.	
SPREAD THE WORD Please write a generic email message that people can use to share the website.	
HOME PAGE INTRO Please include your relationship to ectodermal dysplasias and why you are fundraising for the NFED.	

Please email this completed form along with any of the following items to Lea Richardson at lea@nfed.org.

- Logo or flyer for your event, if you had these made.
- At least six pictures to use on your page. (Anything related to your event; can be of family, pets, event location, etc.)
- Sponsor logos and web addresses.



PHOTO RELEASE FORM

I hereby grant to the National Foundation for Ectodermal Dysplasias, OWNER, the irrevocable right and unrestricted permission to use and publish pictures that he/she has taken of me or in which I may be included with others, to copyright the same, in whole or in part, individually or in any and all media now or hereafter known, and for any purpose whatsoever, for illustration, promotion, art, editorial, advertising and trade, or any other purpose whatsoever without restriction as to alteration

I hereby release and discharge Owner from any and all claims and demands arising out of or in connection with the use of the photographs, including without limitation any and all claims for libel or invasion of privacy.

I am of legal age and have the right to contract in my own name. I have read the above and fully understand the contents thereof. This Release shall be binding upon me and my heirs, legal representatives, and assigns.

Printed Name:			
Signature:		Date:	
Signature of parent (if subject is	a minor):		
Birth Date Minor:			
Address:			
Citv:	State:	Zip Code:	



CASH LOG

Event Name

Host Name _____

Cash received from the following people who would like an acknowledgment letter from the NFED.

Name	Address	City	State	Zip	Email	Cash Amount
				1		
			İ			



VOLUNTEER HOURS LOG-IN SHEET

Event Name

Host Name _____

Name	Complete Address	Email	Hours





The contact us at NFED.org, info@nfed.org or 618-566-2020