



BOWLING FOR BITES TOOL KIT

nfed

Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

INTRODUCTION

You can help people affected by ectodermal dysplasias have a brighter future by raising funds for National Foundation for Ectodermal Dysplasias (NFED) programs. 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 guide walks you through the steps to set up your own Bowling for Bites event and explains how the NFED can help.

Supporting you, supporting each other.

If you have any questions, contact:

Lea Richardson, NFED Manager, Community Engagement, 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!

EASY TO FOLLOW STEPS

There are two kinds of bowlers. Bowlers who wouldn't miss the opportunity to play every week and those who bowl once in a blue moon just for fun.

The goal of a successful "Bowling for Bites" fundraiser is to merge these two groups to raise funds and create awareness for the NFED.

"Bowling for Bites" can be a Bowl-A-Thon Event or a Crazy Bowling Event. Both can be pledge events with a pre-determined minimum registration fee that includes shoe rental, two hours of bowling and snacks/drink. The registered bowlers are encouraged to collect pledges and/or sponsors in addition to the registration fee. Provide some incentive prizes that reward the participants who fundraise the most. This will create some extra motivation for them to find lots of pledges and/or sponsorships!

To help you ensure your "Bowling for Bites" is a strike and not a gutter ball, here are some helpful guidelines.

Choose A Location

It's best if you start planning about four months in advance by calling or visiting bowling alleys in your area. The most important consideration when choosing a bowling alley is the level of cooperation and collaboration by the manager and what he or she can do to help you raise the most money possible.

You can either use an entire bowling alley or just a few lanes, depending on how big you plan your fundraiser to be.

Pick a target weekend date. Make sure you avoid major holidays and check your community calendar for other scheduled events.

Negotiate with the Bowling Alley

Not a natural negotiator? Then ask for help from someone who's not afraid to ask. Find out which bowling alley offers the best package deal for your fundraiser and don't be afraid to request free shoes for all bowlers, a free soda from the bowling center's cafeteria, and bowling alley passes to give away as prizes.

Try getting them to rent the lanes to you for FREE. Point out the fact that you are a fundraising cause and that your fundraiser will be good advertising/marketing for their venue! Give them the NFED brochure and a little fact sheet. Tell your story. Explain that the NFED is a 501(C)(3) charitable organization.

Request Donations and Sponsorships

What would any charity event be without tons of fabulous prizes for the attendees?

One of the quickest ways to collect prizes for your bowling event is to hit the streets with letters/flyers requesting donations (Gifts-in-Kind – see sample form) or sponsorships, especially if you are giving t-shirts at your event as part of registration (see sample letter). Stop by your favorite restaurants, boutiques, pet store, barber shop, beautician, insurance agent, or grocery stores, and make your pitch. Most places will be able to tell you on the spot whether they can help out and others will either say, "No," or they'll take your letter to give to their manager or send to "corporate." Don't get discouraged.

Bowlers Need Energy

Never underestimate the power of food to keep bowlers active, alert, and happy. Try to have finger food donated. If not, order low-cost food such as pizzas or subs, veggies and dips, or other finger foods. Check with your bowling alley what their rules are about bringing in food and not using their restaurant.

Publicize Your fundraiser

This is usually the most important part of any fundraiser. About two months before your bowling event, it's time to drum up some bowlers! You have a place, a date, a time, and permission. Hopefully, your bowling alley has a built-in customer base you can tap into. Always start with people you know. Inviting friends, family, neighbors and co-workers is the best way to make your event a success. Of course, getting your community involved is also fantastic.

Here are two ways to help spread the word:

- **Online** - Post on Facebook, tweet, email everyone you know. Tell them what you're doing, when and where, and don't forget the why. Tell people how important it is to you to raise awareness about ectodermal dysplasias and maybe your specific syndrome. Ask them to promote your event by sharing on their social media. Don't forget to tag the bowling alley in your post or tweet for added exposure. And let us know at the NFED. We can publicize your event on our website, in our newsletter, and on our social media as well.
- **Flyers** - Contact us to help you create a flyer and info sheets. Then, ask businesses, stores and organizations in your community to post them. Schools, libraries, hospitals, grocery stores, nail salons and more - if they have a window or a bulletin board, it can't hurt to ask!
- **Press Releases** - Send them immediately to your local papers, television stations and/or radio stations. The most important rule is being to the point and sending the releases weeks before the event. (See Press Release sample.)
- **Keep in Touch** - As people start registering for your event, capture their email addresses and send them weekly reminder notes and encourage them to get pledges and/or sponsors. If you're still gathering prizes at this point, you can entice your bowlers' by telling them what's in store. Maybe a \$25 gift card to Applebee's as a prize might encourage someone to ask a co-worker for a donation. Announce you are having a raffle or a silent auction and mentioned what you are raffling off or what baskets you have at the silent auction to bid on.

Recruit Helpers

You can make this fundraiser more fun and more effective by having a team of volunteers available to help set up, staff it, and clean up afterwards. Try to get people who are friendly and outgoing so they are comfortable welcoming people and thanking them for supporting the fundraiser.

Contact us for our key messages about ectodermal dysplasias, your specific syndrome and the NFED, which you can share with your volunteers. If you're recruiting volunteers who aren't familiar with ectodermal dysplasias, be sure to take a little time before you set up to share key messages about ectodermal dysplasias or your specific syndrome with them. You don't need to turn them into experts, just give them some basic information so they can explain to other people why they are there.

The more jobs you can hand out to others, the easier it'll be to run this event. You will of course need to check up on those volunteers to make sure that those jobs get done!

A few weeks before your bowling event, develop a detailed plan of who will do what before and at the event. Include a timeline and assign a person to each area of your event – registration, prize table(s), bowling games (if applicable), food setup, announcements, etc.

Never, never, never assign every element to one person, as a single individual cannot be in all places at all times. Besides, you yourself want to enjoy your experience as well! (See Volunteer Hours Log-In Sheet.)

Take Pictures

Plan to take lots of pictures. Bring a camera and ask all your volunteers to bring theirs (or smartphones with cameras) so you can get lots of pictures of your fundraiser in action. Ask permission of participants

who are bowling and your volunteers before taking their picture. (See photo release form)

Collect Donations

There are many ways that you can accept donations You can use any of these options exclusively, or combine them.

- **Cash** - Simple and easy! Write down their names and complete address to keep track. All donors will receive a donor acknowledgement letter from the NFED. Deposit cash and mail a check or money order to NFED with you list of cash donors.
- **Checks** - Checks should be payable to NFED with Bowling for Bites in the memo so that we can identify it as your fundraiser. After you collect all the checks and cash, you can send it to the address below with a short note.
NFED
Attn: Lea Richardson
6 Executive Dr. Ste. 2
Fairview Heights, IL 62208-1360
- **Online** - We will have a drop down on our "Donate Now" page on our www.nfed.org website with your event's name. The NFED can also create your own web page for your event. (instruction form in appendix). This is your very own personal fundraising web page to share your story and collect donations and registrations. The money goes directly to the NFED. If you use this option, but also have cash and checks to send in, that's okay. Send them by mail and we will add those donations onto your fundraising page so that you can see your grand total. If you have any questions, please contact at 618-566-6871 or email lea@nfed.org.

Thank Participants and Sponsors

Your event is over. It was a terrific success! It's time to relax...almost.

There's one final element to your event. It is important that you send thank you notes to every applicable individual and company, including an email to the bowlers themselves updating them on the monies raised.

People who are thanked and appreciated are happy people. They will be ready and eager to join in or help out again next time.

Basic Rules of Traditional Bowling

A game of bowling consists of 10 frames. The goal is to knock down all ten pins on the first shot, earning a strike. If the bowler fails to knock down all ten pins on the first shot, they take a second shot. If the bowler knocks down all of the pins after this second shot, he or she earns a spare. In the 10th and last frame, a bowler who gets a strike on his or her first shot gets to throw two additional balls. A bowler who gets a spare in the 10th frame gets to throw one additional ball.

If a bowler earns a strike on the first ball, it is scored as ten, plus the count the bowler achieves on the next two balls. For example, if a bowler earns a strike in the first three frames, the bowler will earn 10 pins for the first shot, plus ten more for each of the additional strikes, yielding a score of 30 for the first frame. When a bowler gets a spare, he or she gets 10 pins, plus the score on the next ball. For example, if a bowler gets a spare in the first frame, and then knocks down 9 pins on the first ball of the second frame, he or she would receive ten pins for the spare, plus nine, yielding a first frame score of 19.

Crazy Bowling

Crazy bowling is bowling with a twist. Whether you love or loathe traditional bowling, you'll get a kick out of trying this wacky list of bowling moves on your next ten frames. Be sure to invite all your friends to join in the fun and be prepared to share a memory charged with laughter. It's really a lot of fun. Give it a try!!!It's for a great cause: The NFED.

Crazy Bowling Instructions

Scoring for crazy bowl is similar to traditional bowling, except where noted. Each frame presents a different challenge. Use the list below or make up your own. You may want to bring a pair of dice, a pair of mittens, and a blindfold with you.

Frame 1 - Have someone stand in front of you, legs spread. Roll the ball through their legs.

Frame 2 - Bowl with eyes closed or blindfolded.

Frame 3 - Bowl wearing fingerless mittens (not gloves, in other words). Oven mitts would really up the challenge.

Frame 4 - If you're a righty, bowl with your left hand. If you're a lefty, bowl with your right hand.

Frame 5 - Sit on the floor and bowl by pushing the ball forward with your feet.

Frame 6 - Roll a pair of dice. If you get that score on your first roll, it counts as a strike.

Frame 7 - Bowl in slow motion.

Frame 8 - Get someone else in the bowling alley, who is not with your group, to bowl one frame for you.

Frame 9 - Bowl backwards, either between your legs or in whatever other way you can manage.

Frame 10 - Spin in circles five times and then bowl immediately.

More Crazy Bowling Ideas

- Bowl on one foot.
- Predict the score of your first roll. If you get it, it counts as a strike.
- Lay on your stomach and bowl.
- Sit on someone's knee and bowl.
- Have two people roll the ball at one time.
- Have each person make up a challenge before starting the game.

Prize Giving

Arrange some certificates / trophies to give out at the end so that everyone is rewarded for something—no matter whether it's a good or bad thing. For example:

- The highest score
- The lowest score
- The most strikes
- Never scoring a strike
- The most spares
- The most gutter balls (unless you use bumper guards for kids)

Are You Ready to "Bowl for Bites"?

Good luck! For help or information, contact Lea Richardson at 618-566-6871 or lea@nfed.org.

APPENDIX

DONATION FORM

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

Please use a separate form for each item donated.

Item _____ Retail Value _____

Description _____

Restrictions and Limitations (if any) _____

Name of Company/Individual Donating Item _____

Person to be acknowledged _____

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 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.

SAMPLE SPONSORSHIP LETTER



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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

SAMPLE PRESS RELEASE

Contact: Your Name
Phone: Your Phone Number
Fax: Your Fax Number
Email: Your Email Address

(Insert Name of Your Event Here)

Your town, your state (Insert date) – On (insert date and time), the National Foundation for Ectodermal Dysplasias (NFED) will be the recipient of funds raised from (insert your event) hosted by (insert your name here) in (insert your town). The (insert names here) are hosting this event in honor of their (insert affected individual's name here), who is affected by an ectodermal 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 (insert your event) will feature (insert interesting facts about your event here. List names of well-known community members who are attending/supporting. If charging an entrance fee, include it. List names of big sponsor, if any. Include anything you think would be of interest. Include all details and how individuals can participate.)

For more information about the ectodermal dysplasias or the (insert name of event here), contact (insert your name and contact information here).

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.



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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: _____

City: _____ State: _____ Zip Code: _____

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	

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

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.

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