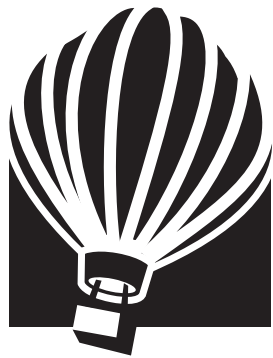


You Can Do It, Too!

**A Guide To
Raising Funds and Making Friends
for the**



National Foundation for
**Ectodermal
Dysplasias**

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Welcome

Thank you for your interest in helping to raise awareness about the ectodermal dysplasia syndromes and in raising funds to support the valuable programs and services of the National Foundation for Ectodermal Dysplasias (NFED). This booklet is designed to give you information on how to plan a successful fund raising event and media awareness campaign. The information has been provided as a useful tool to help plan your event, but can be modified to suit your ideas or needs. There is also a wealth of information available from other resources, such as the internet, other charitable organizations to which you belong or other NFED families who have done an event.

During the review of this booklet or anytime during the planning of your event, please contact the staff if you have any questions, ideas, or need guidance. The Foundation's staff is readily available and very willing to help.

Finally, once you have made a decision about which event you will be hosting in your community, please be sure to complete the Third Party Fundraiser Form on pages 24-25, and send a copy to the national office.

Why Raise Funds and Awareness?

While it is not unusual for those of us in the ED community to feel overwhelmed with a new diagnosis, ongoing treatment or other challenges, the NFED is here to tell you that there is hope. Medical and scientific research holds the promise of better treatments and, one day, the possibility of a cure. One of the most important things that family and friends in the ectodermal dysplasia community can do is raise money to support research and the programs and services of the NFED.

So many aspects of this disorder are beyond our control, but our ability to raise money is not one of them. There have been great advances in understanding the ED syndromes, but more needs to be done if we are to find a cure. We all have a vested interest in making this happen. The sooner you begin to raise funds to support the Foundation's work, the greater likelihood your loved one(s) will benefit.

Whether you raise \$5 or \$5,000, the important thing is that you do something. It's not as difficult as you may think. People will want to help. The hardest part is getting started, and that's why this fund raising booklet has been assembled. We'll show you how to turn \$10 in out-of-pocket expenses into \$500 of donations (with only a few hours of your time).

Overview

Fun, fun and more fun! That is the bottom line for all fundraising events. Most people can quickly find reasons not to do something they don't want to do. If you want to succeed, you must choose an event which you and your friends will enjoy being involved in. This will create the most energy, enthusiasm and fund raising dollars for the NFED. Plus, it will be a more rewarding experience for you!

The three primary reasons for hosting a fundraiser/media event are:

- To promote education of the ectodermal dysplasia syndromes
- To raise funds for the important work of the NFED
- To bring people together to socialize and have some fun

Whenever possible try to choose a fundraising event that has the widest possible appeal. Planning an event that will appeal to family, friends, and members of your business community will generate greater

awareness and make it easier to meet your fundraising goals. Your message will reach a wider audience and you are likely to have more fun in the process.

Enthusiasm is your best resource; without enthusiasm everything will become a chore. The more enthusiasm you provide, the easier and more enjoyable all tasks will become. Enthusiasm can be highly infectious.

When choosing a fundraising activity, remember that friends (volunteers) will perform better if they are enjoying what they are doing. If they feel what they are doing is successful and making a difference, it will help stimulate their motivation. Their *motivation* can be the key to your success. Most people will enjoy what they are doing if there is an element of fun and visible success.

The possibilities are endless. If you can think of it, you can do it. The ideas listed are just to get you started. Be sure that your volunteers know that each dollar they raise will benefit the NFED and be used for family services and education for families affected by ED.

Raising Funds: A Checklist

Event Checklist

1. Getting Started

- Ask the right questions. (p. 6)
- Choose an event. (p. 7)
- Set goals. (p. 9)
- Make a budget. (p. 9)
- Select a location, date and time. (p. 10)
- Complete Third Party Authorization Form in booklet and send back to the NFED office. (p. 24-25)

2. Planning the Event

- Develop a timeline. (p. 10)
- Contact the NFED to check on permits/licenses or registration. (p. 10)
- Recruit friends and family to volunteer on your committee. (p. 11)
- Try to recruit a local celebrity to help promote event. (p. 12)
- Make a list of possible event sponsors and contact them. (p. 12)
- Contact the Foundation office for brochures and other literature to hand out.
- Make a list of all media outlets to send press release. (p. 18)
- Write press release, using sample provided, and distribute. (p. 27)
- Follow-up with all media.
- Send a copy of all marketing pieces to NFED.
- Finalize details with vendors.
- Inform volunteers of their duties.
- Day of Event

3. Follow-Up After Event

- Pay all expenses and send final income and expenses report and checks to the NFED.
- Send thank yous to participants, sponsors, donors, media who attended.

Raising Funds

The Planning Process

Start by asking the Right Questions

The backbone of a successful fund raising activity or media event is the combination of planning and commitment. Copying an activity that was successful for some other group does not provide you with a guarantee of similar success. The planning and commitment of all those involved is critical to an event's success.

- **How much money do you want to raise from this activity?** How much front money will you need before you make money? Determining this in advance can help you decide on the type of fundraiser to have.
- **How many people can I recruit to help with the event?** Special events can be manageable and a lot more fun when tasks are shared as a group project. Don't hesitate to recruit family, friends, co-workers, and NFED families to help as part of the committee. They probably have wanted to help but didn't know how.

Whenever you ask someone for his or her opinion, input, or suggestion, you are brainstorming. Tapping the knowledge and insights of others can be a key element in selecting your event. After you do a little research among your friends, neighbors, and relatives, write a list of all your ideas and suggestions. You can use this list to help you decide on a fun event that has the greatest potential for success. Involving others in your brainstorming process will result in a stronger event and all those involved will benefit too. You may discover hidden talents and untapped resources. Your volunteers will be energized and develop a sense of ownership when they are treated as a valuable, integral part of the decision making process.

- **What type of event will work in my community?** Consider some of the following points: What type of event has worked before? What has worked for other groups in your area or been successful for other NFED families? How did they do it? Where did they do it? Once you have these answers to these general questions, you may want to find out more detailed information such as: Who did what? Why did they do it when they did it? Why was it held where it was? Was the weather or other community events involved? What are some of the specific skills and resources my group can contribute to the project?

By collecting this information you can then devise your own event that is different and hopefully better. You may gain a better idea of what to mimic and what to leave out. You may discover a niche in your area or an idea that no one else thought about. You will also gain a better understanding of what you have to provide to make it work in regards to volunteers, donations, and other details that can make or break your fundraiser. Pick an event that is realistic for you and your resources. For example, don't select a golf tournament because they are popular fundraisers, if you don't golf yourself nor know anyone who does golf.

Be realistic in selecting the type of fundraiser you plan to do. Choosing a fundraiser that is very involved and demands a lot of your time may not be the right choice for the first time.

Fundraising Event Ideas

The following suggestions are just that—*suggestions*. The NFED encourages you to develop your own ideas or use only part of these suggestions. The best events are the ones that you are most excited and motivated to host. And, as always, contact the national office for help, guidance or just to run your idea by us. The staff is very willing to help anyone who needs it

Art Show	Garden Tour
Auction	Golf Tournament
Bake Sale	Halloween Party
Barbecue	Masked Ball
Benefit Concert	Princess Tea/Superheroes Party
Bike-a-Thon	Prize Drawing
Birthday Party	Progressive Dinner
Black and White Ball	Raffle
Book Sale	Mile Run
Bowl A Thon	Services for sale
Car Wash	School Fundraisers
Carnival	Spaghetti Dinner
Children's Party	Teen Dance
Craft Fair	Tennis Tournament
Dance A Thon	Trivia Night
Easter Egg Hunt	Valentine Dance
Fashion Show	Walk-a-Thon
Garage/Yard Sale	Wine and Cheese Reception

- 1. Garage/Yard Sales.** Everyone has junk to get rid of, however they don't have the time or inclination to figure out what to do with it. This is an easy way for them to clean out their basement, garage or attic. As you know, "your junk can be someone else's treasure." As the host, you select the date for a neighborhood garage sale. Put flyers in neighbor mailboxes and call your friends. Ask them to bring their items to your home during the week before the garage sale. Organize the items with prices and stickers. Keep a log of who donated what. Later you can provide them with a list of their items that sold, which will be their actual donation to the Foundation. You should also provide brochures and information about the Foundation to all purchasers and donors. You will not only be raising money for a good cause, but you will be educating the public about ectodermal dysplasia. Shortly after the garage sale, send a flyer out to those who donated to let them know the amount of money raised for the Foundation. This will make them feel good about helping our Foundation. They will also be happy to have cleared out their garage, attic or basement.
- 2. Any "A-thon."** Read, skate, walk, bike, swim, etc. These are all great ways to raise funds and spread awareness. At some point, mostly everyone has been involved in or witnessed an "a-thon." These events are fun to plan and attract larger audiences.
 - Read-a-thon:* This event can be done during the summer months when students are off from school or it can be organized during the school year. Simply recruit a group of individuals to participate in a book-reading program. They can ask for a flat donation for their efforts or receive a "pledged" amount per book. For example, his or her uncle may pledge to pay \$5 for every book read from June through August. At the end of August, the reader informs his or her uncle that they read five books. The uncle would then donate \$25 to the Foundation.

- *Walk-a-thon*: This event can be adapted to fit other types of activities such as biking, skating or running. First you must select a location to host the event. After the date is determined, solicit sponsors for the event to help defray your costs. For instance, find someone to donate and print T-shirts, which can be given to each participant as a “thank you” for their help. Ask your supermarket for bottles of water. Ask your produce market to donate apples and bananas as a healthy snack. Find a donor to pay for port-a-potty rentals or ask the company to donate them. Place signs in public places, community bulletins, newspapers, etc. Recruit walkers (skaters, bikers, runners) and have them solicit donations from their family, friends, co-workers, etc. to support them in the event. It can be a flat donation or a pledged donation for the number of miles walked or laps skated. These events can be turned into annual events if done well. Once you host the first year, the event becomes easier each year after that.
3. **A Raffle.** Solicit items to be used as prizes to be used in a raffle. For example, you could raffle airline tickets or sporting goods from a local sports store. Try to secure one “large” donation (i.e. airline tickets, weekend get-a-way) to be used as the grand prize. Locate a place to host the raffle drawing, such as your backyard, a dance hall, a local restaurant or your community center.

Barbecues and picnics are a great central event with which to host a raffle. Find someone who will donate or cook some food and provide entertainment. If you can't find someone to donate, you can charge a fee to cover the costs of the food and drinks (either as an admittance fee or people buy what they eat or drink at the event). You can also make it a BYO (bring your own main dish and drinks). Don't feel awkward about a BYO event; they are now an accepted feature of having a get-together.

Start to sell the raffle tickets a few weeks prior to the event for a reasonable price, but sell a lot.

One suggestion is to have every fifth or tenth ticket you sell a different color. These special tickets will then go into a separate drawing just for the grand prize. This will provide incentive for the purchaser to buy more than just one.

Another idea is a 50/50 raffle. This fundraiser is less complicated than an auction, since you do not have to secure raffle items. The winner will receive one-half of the money collected and the Foundation will receive the other half.

4. **School Fund Raisers.** The success of any school fundraiser is based on the support from the school administrators and parental support. The first hurdle is to work with the school's staff to figure out the best way to raise awareness for ectodermal dysplasia and raise funds.
- Host a bake or candy sale.
 - Volunteer and organize a teen dance where a percentage of the admission ticket will be donated to the Foundation.
 - If the students are required to wear a uniform, have all students donate \$1 to 'dress-down' on a Friday.
5. **Profit Sharing.** Many companies offer profit-sharing opportunities. Commonly known organizations such as Tupperware, Longaberger Baskets, Southern Living, Party Lite, and The Pampered Chef have programs to give back to charity. There are many others, too. As the host of a party at your home, a percentage of the sales will be donated back to the charity of your choice. It does not require a lot of work on your part because the company consultant runs the show at your home. All you need to do is provide snacks and invite your friends. They will be receiving a quality product while supporting the Foundation.
6. **Car Wash.** This is a really fun way to raise money for the Foundation. Find a location where you can host your car wash. Make sure there is access to a water spigot for your hose. Recruit a group of people to wash cars. Have someone donate the soap, buckets, and rags. Make colorful

posters and hang them up around your town. When the driver arrives, provide them with a brochure about ectodermal dysplasia and the Foundation. Ask them for a donation to have their car washed, making sure the minimum amount is \$5. You may find some people will donate more than \$5. Remember to do a good job so the donor feels they received their money's worth. Once again, you will be raising money for the Foundation and educating your community about ectodermal dysplasia.

7. **The Holidays.** The holiday season is a time of good cheer and sharing, and a good time for fundraising. People are in the mood to spread their good fortune and what better way to spread their good fortune than to help the Foundation? People spend a lot of money at this time of year - on presents, decorations, travel and many other reasons.

Try to think of a way to turn the holiday season into a fundraiser that helps people to get what they want, while raising money for the Foundation. Selling merchandise such as first aid kits are a thoughtful and unusual gift idea. Gift wrapping paper is an essential item that could also be sold. You could consider bulbs, t-shirts or candles. So the secret to successful fundraising during the holiday time is to provide a product that people are going to buy anyway, instead of the profits going to a company - they go to the NFED!

8. **Combine with Others.** Try to coordinate some fundraising activity in conjunction with other local fundraisers or civic organizations, such as the Rotary, Lions, and Kiwanis' Clubs. Other groups who support community projects include the Boy Scouts, Girl Scouts, and 4-H Club. While you may have to share the money raised, you may also reach a wider section of the community, which may lead to a better financial outcome than if you chose to 'go it alone.'
9. **College Sororities/Fraternities.** These groups sometimes do fund raising and charity work for whatever organization they have "adopted." They may sponsor or host an event, or may provide the "man power" you need for an event you have organized.

Now that you've selected an event that suits your personality, comfort level, and community interest, it will be helpful to follow the steps below to make your event a success.

You'll begin by setting your goals, and then expanding them into a plan. This will help organize the details you will need to keep track when you are setting up your event. Review this list often. You may find that you forgot something or want to change an element (example: cancel the DJ and recruit a local backyard band). We have provided a sample checklist on page 5, which can be used as a guide.

Set Goals

- After you have determined your event, set goals. They should be relevant and realistic. You will find it easier to recruit your friends, keep them engaged for the duration of the fundraiser, and have them look forward to the next one. For example, your goal may be to raise \$5,000 or secure 100 items for an auction.
- Be realistic. Be careful to remember the difference between wishful thinking and realistic ambitions. Be honest when assessing how much money you can expect to raise for the NFED and how long you think it will take to raise this amount of money. Unrealistic goals can lead to frustration and disillusionment, leaving both you and your friends disappointed.

If possible, do a little homework – contact the office to research previous efforts of other NFED grassroots fundraisers, both in money raised and time taken. If you have the time and resources, choosing a larger, more detailed event can be a fun and productive way to make a name for yourself, raise awareness about ectodermal dysplasia, and raise funds for the NFED. Overall, the bottom line is to choose a fundraiser that most people in your community can get excited about.

Make a Budget

Keeping up-front costs low reduces the risk and will help the profitability of the activity. Follow these few steps and it will be easy:

- Start with your fundraising goal which would be your expected income. For example, multiply the cost for each participant times the estimated number of participants.
- Make a list of exactly what you need and what it will cost. Try to have as much as possible donated. If you can't have it donated, then borrow or rent. Buy only when you have to. When renting or buying, make sure you check for best prices. Be patient and don't be afraid to ask for special discounts, deals, or treatment. Estimate costs for the event including the venue, food, decorations, entertainment, awards, product premiums (for example, tee shirts), printing, postage, publicity, permits.
- $\text{Net Proceeds} = \text{Total Income} - \text{Expenses}$

Select a Location, Date and Time

- Give careful consideration to the location of the event. The type of event you are having will help dictate the venue. You want to be sure it's easily accessible for people who will be participating or attending. For example, if you are doing a bake sale, you may want to consider a place with high traffic such as a grocery store or a university.
- Think about the timing. Pick a date that doesn't conflict with community events such as graduation or major holidays – unless it works for you by capitalizing on it with something like a "Bake Sale" for Valentine's Day or selling treats at Halloween at your workplace.
- Check your local community calendar to see what other events are scheduled one/two months before and after your date. If a similar group is planning the same event near the same date, you may want to re-consider the date of your event. It is much easier to change a date before you are knee-deep in planning, and then have to change everything else further on down the line.
- Keep in mind the time of your event. If you are doing a garage/yard sale, research when sales in your community typically start. If you are doing a family event that includes children such as an Italian Dinner, you may want the dinner to begin and end earlier than a cocktail party for just adults.

Develop a Timeline – see appendix for an example

Once the goal, budget and event date and time have been determined, develop a combination action plan/timeline. This plan will become your working guide for all the essential steps involved in your event. To set your timeline, it usually helps to work backwards from the date of your event. Larger events usually take more than 6 months of planning. Smaller, simpler events can be successful with only a few weeks of planning.

- Develop a checklist for every task that needs to be done in each stage of the project. (For example, location confirmed, deposits due for food, tee shirts ordered.) Carefully think when you are going to need things to get done and place them on the list.
- Establish specific deadlines for each stage and spell out who is responsible for getting it done. This allows you to keep track of the progress being made in each area of responsibility and helps avoid last minute confusion.
- Be sure to allow yourself enough time to complete tasks. Also, be sure to check with vendors to see when they will need deposits, orders, etc.

Permits & Licenses

- Check with your local authorities. Depending on where you live and what fundraiser you have chosen to host, a permit may be required for food handling, raffles, and alcohol sales.
- Make sure you are in compliance with all local safety regulations and insurance requirements.
- Most public events require the NFED to be registered in the state. Contact the NFED to see if your state is registered. If not, the Foundation will work with the state to ensure the proper registration is filed.

Recruit A Volunteer Committee

Find family members, neighbors and friends to help you. Don't be afraid to ask. You will probably find that they have been wanting to help in some way but didn't know how. When working with them, remember these important points:

- Remember: people who are involved in the "brainstorming" and planning stages are much more motivated to complete the actual work required to produce a successful event.
- Make this a fun experience. Be sensitive to people's capabilities and respectful of their time constraints.
- Be specific about what the job involves when assigning tasks, including setting clear deadlines for when each task needs to be completed.
- Train your workers. Let "veteran" workers explain procedures and help new recruits acquire the skills they need.
- Check "outside" sources such as youth and senior groups, or church, school and service organizations for volunteers who may be interested in lending their talent, time and expertise to your project.
- Provide volunteers with the materials they need to solicit support of your event such as flyers, NFED brochures or other event information.

Keep Accurate Records

Complete and detailed financial records are important. Be sure to track all expenses and income. In addition, keeping accurate and documented files on the timetable of events, names and addresses of sponsors, donors and volunteers and a recap of what worked and what didn't can be an invaluable tool for planning a successful event for the future.

Helpful Hints for A Successful Fundraising Event

Always remember, fund raising events can offer more than just a way to raise money. They offer ways of building recognition of the NFED within your community. Events bring people together socially who have a shared belief or concern. These events can offer people a chance to develop new skills or a sense of achievement. Friendships are born of a common cause and businesses can network while giving back to your community.

Networking - Who do you know, who do they know

Your goal is to connect the NFED and our mission to individuals and businesses that can help you achieve your goals. You will be raising ectodermal dysplasia awareness among others in your

community. Networking can be practiced at work, at social functions or anywhere you believe there is an opportunity to help spread the word.

Tips on Asking for Donations

- Remember, people give to people.
- You are not asking for yourself. You are asking for the NFED.
- When personally asking for donations, look the part! Appearance counts. Your job is to help the potential donor to feel good about helping our Foundation.
- Don't be afraid of hearing "no." It is not a personal rejection. Simply move on to the next person. Remember selling or canvassing can be seen as a numbers game—you will get so many "no"s to every 'yes'. Remind yourself every time you get a 'no' you are closer to a 'yes'.
- Remember to emphasize the benefits to potential donor.
- Only have those who really have a genuine interest in helping be involved in your fundraiser. It is very noticeable when people are not enjoying what they are doing and this will hurt your returns.
- Before you approach a possible donor, practice your sales pitch with friends, family, and other committee members.
- Incentives are a great way to improve your bottom line, either by enticing people to pull out their wallets or by motivating even slightly better performances from your volunteers. Examples include free tickets to your event, free raffle tickets, a complimentary luncheon after the event at an exclusive restaurant, etc.
- Always remember to say "please" and "thank you." These words can work wonders for both volunteers and donors. Nothing will turn away a volunteer more than feeling under-recognized or unappreciated. If you have a large group of volunteers helping you, single out and congratulate different people in front of their peers.
- Let people clearly see how you are raising your funds and that they are going to the NFED. Use Appendix B on page 26 as a tear-out for proof that their donations are being spent wisely and appropriately.

Celebrity Recruitment

Getting a celebrity to help out your cause can be a difficult task, but it could be worth your efforts if the rewards are high. Remember, celebrity involvement may not work for all kinds of fundraisers.

- First, do a little research to select a suitable celebrity who would be most receptive to your request. You don't need to aim for a major television celebrity, local celebrities can work just as well (i.e. instance, your regional newscaster, weatherman, radio personality or sports player). Since ectodermal dysplasia is rare, you may not be able to find a celebrity who has been directly affected by the disease. However, other factors such as an interest in health issues or body images may help your search.
- If possible, connect with someone who knows a celebrity or knows someone who knows a celebrity. You can simplify your request by a face-to-face meeting and you have stronger chances of receiving a favorable response. If you know someone who is affected by ectodermal dysplasia, particularly a child, bring him or her with you to your appointment. Most people have difficulty saying "no" to a child.
- If you don't know anyone who knows the celebrity you choose, or is connected with his/her employer, you could write a letter directly to the celebrity. Start with a statement or summary clearly stating your request. Be specific and detailed. Tell them why you chose this particular person. It will let the celebrity know that he/she was specifically targeted and well thought out, not just a mass direct mail campaign. Be

sure to send your request far in advance of your event date. Celebrities have busy schedules that are often planned months in advance.

Be sure to introduce the NFED, state our mission, and tell them why you are planning this fundraiser. Be honest and accurate, and do not apologize for the Foundation being small or ectodermal dysplasia being rare —this may work in our favor. Be sure to mention that the NFED is a federally recognized 501 (c) 3 non-profit organization. When you send your letter, you want it to stand out so write it on special paper, use an eye-catching color, or use an odd shaped envelope.

Consider including a list of our Board members and their professional affiliations too. There could be a chance that the celebrity or one of their associates knows or works with one of these affiliations. Any connection will help.

Within a few days of sending the letter, follow-up with a personal phone call to the celebrity. This will demonstrate credibility and commitment to the project. Don't get discouraged if they don't return your call. It may take a few tries before you successfully connect with them. Also, send a thank you note after speaking to them.

Recruiting Corporate Sponsors

Recruiting sponsors for your event can be crucial to its success and to the amount of funds you raise. The first contact with a possible sponsor is critical. Your instincts will tell you if the relationship is worth pursuing. Remember, there is no point in spinning your wheels trying to secure sponsorship from someone who is uninterested. Your time is valuable and you need to spend it productively. Knowing someone at the company will increase your chances of success. Find out what contacts your committee members have and what companies they work for. Think about what kind of recognition your sponsor will get for their sponsorship (event tickets, name on flier, logo on shirt, etc.)

There are three kinds of sponsorship. You can secure sponsorship for mostly everything relating to your event.

1. In – Kind Sponsorship – This type of sponsorship is when a company or individual provides a service or good(s) for your event. For example, if you are planning a walk-a-thon, you need bottles of water for the walkers. Contact a local supermarket or convenience store and request enough bottles of water for your projected audience. Most companies are happy to provide a product or service for a worthy event. Always remember to recognize them appropriately at the event and in the media.

2. Event Sponsorship – This type of sponsorship is when a company or individual provides money to cover a particular expense of the event. For example, you want to provide T-shirts to every walker at your walk-a-thon. Since you have asked every T-shirt company to donate the shirts but have been unsuccessful, you approach another company to provide the money to buy the T-shirts. In exchange you will have their logo screened on the T-shirt for recognition.

3. Unrestricted Sponsorship – This type of sponsorship is when a company or individual provides money with no restriction on its purpose. You can use this money for anything you may need to buy related to the event. This money becomes very useful when you have exhausted all in-kind or sponsorship donations for a necessary element of your event (i.e. port-a-potties for a walk-a-thon). You can use this money to purchase the necessary items or service.

Make sure the contact information you leave behind with a possible donor is accurate. You may want to provide several contact options for these donors, if you are not always readily accessible.

One of the most important rules in securing sponsorship is to **follow-up** on all requests. If the potential donor requires more information, be sure to provide it for them in a timely fashion. If the request is related to a donation, consider including a pre-stamped, self-addressed return envelope for convenience. Contact the NFED office for brochures or literature about ectodermal dysplasia to include in your solicitation. Always follow-up with a thank you letter with a real signature.

Remember to always follow-up with the possible donor within a week after your initial contact.

Consider Unusual Donors

Local businesses are the ones who are approached most often by people raising money. Local businesses can only give so much, so the results may be negative or very small. Consider other unusual sources for support. Think about mid-size companies of all kinds, not just the large corporations.

Once you've decided what event you are hosting, brainstorm ideas of possible donors that are not in your local area, but could supply you with the items you desire. Ask your local businesses to provide the names and contact information of their suppliers. They will appreciate not being asked for the donation and will probably be very helpful. Armed with that information, contact these suppliers and ask for your donation.

Just because a possible donor is not located in your area does not automatically discount them from helping your event. There are many large, national, and international companies that will consider helping you. Many of these companies have policies to help out non-profits wherever possible.

Some additional places to access the names of unusual donors:

- Your business telephone directory (yellow pages). This may involve a bit of time but finding the appropriate page and calling a list of companies can reap rich rewards.
- As previously mentioned, approach local companies for names of their suppliers of products that you are interested in, then approach the suppliers directly. A referral by a local company can be a wonderful advantage and help you look good to the potential donor.
- Keep your eyes open when walking through a shopping center or while driving around. Take a drive through an industrial park and see what companies are located there. You may find a company you did not know about and find a way to use their product in your fundraiser.

A wonderful example of utilizing unusual donations is a story about another non-profit including a face-lift in their auction. Not only was this unusual, it tapped into a business that does not normally receive requests for donations. It improved their chances of a positive response. In addition, it added humor and surprise to their auction and attracted a lot of attention in their community.

With a little imagination, detective work, and a desire to succeed you can find and acquire new donations for your event.

EDucation

Besides raising funds, another major purpose of the event is to raise awareness. Whichever type of event you choose, be sure to have information on ectodermal dysplasia and the NFED available. Include information on your flyer and/or distribute brochures along with the flyer. Contact the NFED for materials.

Celebrate Your Success

Don't wait until after the project is over to let committee members know they are appreciated. Be generous with well-deserved praise and recognition along the way. Always follow-up with thank you notes to donors, sponsors, and volunteers.

Please let us know about the event you're planning so we can share it with other volunteers from the ED community. Send us photos and a recap of the day's activities so we can feature it in our quarterly newsletter, *The EDucator*.

Evaluate

Evaluation can help you avoid making the same mistakes and improve the return on your next effort. Remember no fundraiser has ever been run perfectly. There is always something that can be done better.

- When you evaluate, look at both what went wrong and what went right. By looking at what went wrong, you can either prevent any mistakes from happening again or reducing the chance of it repeating. And, of course, you review what went right so you include it again.
- You can evaluate the event individually or with your key volunteers. Involving more opinions will help your chances of improving the event in the future. Try to keep in mind that you don't have to make changes for changes sake. There must be a clear reason for the change
- What, if anything went wrong? What can we do about it?
- Did we meet our goals? If no, then why not?
- How close did we stick to our budget?
- Did anyone complain and if so about what?
- How did the committee work together?
- Was anyone overworked?
- Did anyone's temper get out of hand? If so, how can that be prevented?
- Did everyone enjoy themselves?
- How much money did we make?
- Could we have made more? How?
- Did anything unexpected happen? If so, why?
- What was the best part of our event? Why?
- What are the problems we faced?
- Did the community respond positively?
- Did we publicize the event well enough?

Be honest and make sure you take notes of all that is discussed and decided. This information will truly be invaluable for next time and may help other fundraisers wanting to help the NFED.

No Time to Plan An Event But Still Want to Help? ***Ways to Raise Money Without Having an Event***

Letter Writing Campaign

Raising money through a letter writing campaign can be a great way to raise money without having an actual event or can be used in conjunction with an event. This can be your personal way of supporting our annual Ectodermal Dysplasia Awareness Campaign every February; although it can be done at any time of the year. Here are some ideas to help get you started on your Letter Writing Campaign.

Benefits of a Letter Writing Campaign

- First, it's relatively simple and a low-cost way to raise money.
- Second, writing personal letters provides you with the means to reconnect with family and friends. Writing to them will allow you to clearly explain the impact of this disorder on your family and will lessen any confusion or misunderstandings on their part.
- Third, people will want to help. Channeling their energy in a positive way, by asking them to make a donation, will empower you and them, as most want to help but don't know how. Bearing witness to the outpouring of support from friends and family will give you an emotional boost.

Create a List

- Include friends, family, neighbors and co workers (both past and present!) A minimum of 25 people should not be difficult to compile. You can draw upon holiday card lists, address book entries, wedding reception guest lists, etc.

Write a Personal and Informative Letter

There is a sample solicitation letters included in this booklet. Feel free to adapt it to your needs. Access to a computer with word processing capabilities is highly recommended, especially for larger lists. It will help you to complete the letters much faster.

- Begin by telling your own personal reason for writing the letter.
- EDucate the reader about the ectodermal dysplasia syndromes. For example, include that it is a genetic disorder, describe its complexity, the body parts affected, and explain that as many as 7 in 10,000 births are affected by the ED syndromes.
- Tell the reader about the NFED and the services it provides. It can be more effective if you tell about a personal experience and a specific benefit you have received from the foundation. (The NFED provides funding for cutting edge research, a treatment fund, education programs for healthcare professionals and support services for affected individuals and families. 87% of all donations directly supports these programs and services.) Explain how their gift will make a difference.

Make It Easy For People To Donate

- Ask the reader to help you make a difference by making a donation. If your letter writing campaign is supporting a specific event, be sure to include the name, date, organizer's name, and overall financial goal. Be sure to also tell the reader what you have set as your personal fundraising goal.
- Inform them to make all checks payable to the NFED. Include a self-addressed envelope and let them know their donation is tax deductible. If they would like to donate by credit card, they can do so

online at www.nfed.org or by calling the NFED at 618-566-2020. Or, the NFED can provide you with a form to include with the letter to take credit card donations.

Other Ideas for Your Mailing

- Provide an NFED brochure in your mailing. Simply contact the NFED and we will provide a sufficient number of brochures for your letters.
- When purchasing postage, ask for stamps with themes of love. Another good idea is to include a scanned photo or several photos of the family member affected with ectodermal dysplasia. If you do include an actual picture, be sure to attach a sticker on the outside envelope that says “Do Not Bend,” which will bring attention to your letter.

When Should You Send It?

Donation letters can be sent out at any time, however there are certain periods of the year that are more effective than others. Specifically, the week just prior to Thanksgiving can be very effective. Conversely, the period just after the holidays is not a good time to send out a letter, since many families have spent a lot of money on presents. The month of February is Ectodermal Dysplasia Awareness Month and provides the perfect opportunity to have a campaign.

Keep Good Records

- Maintain an updated record of your complete mailing list and copies of all letters you send.
- Keep an accurate log of all donations, including the name, address, amount, and gift method.
- Send the checks back to the NFED office within two weeks of receiving them. You do not want to keep your friends (and donors) waiting for their check to clear the bank. Plus, it is appropriate for all donors to receive a “thank you” letter from the NFED office in a timely manner. The thank you letter will also serve as documentation needed for charitable deductions on their federal income taxes.

Always Follow Up With A Thank You Letter

- Tell your donor how much you appreciate their generosity and how their help has made a difference to you personally – and the NFED community in general. You can order NFED note cards to use for your thank you notes. See the appendix for a sample thank you note.
- Recap any specifics about the event. Tell the reader how much was raised by the event and by your own personal efforts – and include comparisons to the original goals for each.

How to Turn \$15 into \$500	
<i>Mailing List</i>	<i>Expenses</i>
10 relatives (siblings, cousins, parents, aunts, uncles,)	Stationery/envelopes = \$5
10 friends, co-workers, neighbors, etc.	Postage: 25 letters x \$.37 = \$9.25
5 friends of your parents, in-laws, uncles, cousins, etc.	
25 – Total number of letters sent	Total Expenses - \$14.25
An average donation of \$20 per letter will result in \$500	

Other Quick and Easy Ways to Raise Money

1. Collect your loose change in a jar. Include money from the laundry, your purse, or your car.
2. Take baked treats to work along with a donation can and some NFED brochures.
3. Baby-sit. A great time is during church services or at school open houses. Donate your babysitting earnings.
4. Celebrate your birthday each year by invite people to your birthday party and ask that in lieu of gifts they make a contribution to support the NFED.
5. Work Day: Devote a few hours on a weekend to help a neighbor to earn extra dollars.
6. Consider selling something you collected avidly as a child if it's been stored in your basement for more than 5 years. Coins and stamps, in particular, have usually increased in value over the years. But your collection of rocks, toy ships, rockets, arrowheads or dolls can also be valuable. Since you probably paid little or nothing as a child to acquire these items, you get the added bonus of a tax deduction when you donate the income from the sale of the collection.
7. Collect items for recycling. Ask all your friends to save their cans, bottles, plastic and paper for you and turn them into a buy back recycling center.

Asking Someone Directly

Face-to-face solicitation (meeting potential contributors in person and asking them for money) is the most effective way to enlist support from people outside your circle of friends and family. The maxim for fund raising from individuals is clear: the more personal the contact, the higher the likelihood of a positive response. At times your only goal will be to raise funds, when this is the case your best option is to simply ask for money donations. You can accomplish this by donation canisters, letter campaign, door-to-door knocking or any other form of a straight out request. You should simply explain the reasons why you are raising the money, how their donation will be spent, and the benefits of their donation (i.e. help fund a young investigator to find a better treatment for your type of ectodermal dysplasia.)

By having a simple and planned approach to asking for donations, you will not have the expenses of a special event. Asking directly for a cash donation may be the single hardest activity for volunteers to do. You may find it easier to sell tickets in a raffle or plan a fund raising event, rather than to ask for a cash donation.

Types of Gifts

Make Honor/Memorial Donations

When a loved one dies, some family members have solicited donations in memory of the deceased. Also, in lieu of holiday gifts, friends and family are sometimes asked to make a donation to the NFED.

Upon receiving these special donations, the NFED will send a card to the family of the deceased or to the person to whom the honor gift has been given. This not only acknowledges the individual but also spreads the word about NFED and its services.

Corporate Donations and Matching Program

This area is perhaps our greatest, untapped resource. Most large corporations budget for charitable contributions. Many people prefer to give to causes that help their employees or families. These funds are usually available on a first-serve basis. Hence, if you never ask, you surely will never receive.

Payroll Deductions

Many friends and co-workers give to important causes each year by using this painless tool. The Foundation receives donations through the Combined Federal Campaign (CFC) or United Way from many of our families and friends. Contact your Human Resources Department for more information. In the CFC, the NFED is listed under the Health and Medical Research Agencies federation, #0230 under our DBA name of "Skin and Dental Dysfunction Foundation.

Estate Planning/Leaving a Legacy

Please contact the NFED office if you know someone who might consider making a planned gift to the NFED. Many planned gifts originate from those with only modest incomes. Individuals with wealth are also good candidates. All candidates must have a serious commitment to the organization. The NFED does have a brochure available which outlines the various options.

- *Bequests.* This is the simplest, most flexible, planned gift. The best candidates for bequests are individuals aged 55+, without heirs. Bequests are made in wills, living trusts, and other estate plans. Categories include Specific Outright Bequest, Remainder Bequest, or Contingent Bequest.
- *Life Income Gifts.* This plan offers the donor income in return for making an irrevocable gift. The income may be variable or fixed and last for lifetime(s), a certain numbers of years, or both.
- *Charitable Lead Trust.* This trust provides the Foundation with income for a term of years and leaves the remainder to the donor's heirs.
- *Life Insurance.* This designation provides the NFED to receive benefits upon the death of the insured.
- *Gifts of Stock* – Donors can give gifts of long-term appreciated stock.

Raising Awareness

The more media attention we can create for the NFED, the better. Since we do not have the funds to hire a professional PR firm to get the attention we deserve, it is time to rely on our own ingenuity to get the job done. Many newspapers, cable outlets, local TV stations, bulletin boards at community centers, etc., can be used to advertise an event at no cost.

Promote ED Awareness in Your Workplace

Find out what your company's charitable programs and interests are. Find out how your employer supports non-profit organizations.

- Does your company provide grants through a foundation? Do they offer sponsorship for community events? Participate in a matching gift program? Does it support volunteerism and provide ways for employees to get involved?
- Ask if you can set up a table display on ED during Ectodermal Dysplasia Awareness Month.
- Request the company's grant guidelines and send the information to the NFED.
- Double Your Donation! Many companies offer Matching Gifts Program as a way to encourage employees to contribute to charitable organizations. Most of these match dollar for dollar and some will even double or triple the amount of your gift. Ask your company's personnel department to learn if they offer such a program. If they do, submit their form with your donation.
- Some companies also have a program called Dollars for Doers that matches volunteer hours with a cash grant to an organization. i.e. Fannie Mae, Kodak, Verizon, Whirlpool.

Promote Awareness in Your Community

Service Organizations, Social Clubs, and Small Businesses

Ask friends who belong to local business associations, service clubs, sororities, antique collecting groups, support groups, bridge clubs, etc. to discuss the NFED in their group and pass the hat for donations. This is a great opportunity to spread awareness – and a once-a-year sweep of even small organizations can yield \$100 from each.

Research the giving policies of service clubs in your own community. They usually have formal guidelines for grant amounts above \$1,000, but you can often raise \$200 - \$500 with a simple proposal and oral presentation. This can be especially effective if you are a member or actively involved in any of these organizations.

The NFED can provide you with a general presentation in a Microsoft Power Point format on a CD-Rom. You would need to have access to a computer and projector to show it.

Tips on How to Generate Local Media Coverage

- Develop a list of local media including health/medical reporters at newspapers, television news programs, and radio shows in your community.
- Write a brief letter stating why it is important for them to feature the ectodermal dysplasia syndromes. Be sure to include your contact information as well as for any other local families who are affected and willing to be interviewed. Include a photo but be aware that they will not return the photo.

- Contact the NFED for fact sheets and other press materials to include with your letters.
- Follow up your letters with a phone call. Inform the media that the NFED can also arrange for them to speak with physicians who are experts on the disorder.
- The times of the year when it may be of most interest is the summer (because of sweat issues) and February which is Ectodermal Dysplasia Awareness Month.

Another successful way to communicate with the media is through a press release.

What is a press release?

A press release is a free way to communicate and get noticed by the media outlets: newspapers, radio, and television stations. Having a press release picked up or used by a media outlet is better than an advertisement. A press release is a "news item." It is used to inform, not sell. You use a press release to inform the public about you, your event or the Foundation and why it is important for the public to know about you, your event or NFED.

A press release identifies the problem and offers a motivating solution, i.e. you need to raise funds for ectodermal dysplasia research to identify the causes and find a cure. The public can help by attending your event or supporting your cause.

How do I write a good press release?

There are two ways: get help from a professional or try it on your own. It must grab the attention of the person who decides if you are newsworthy enough to be given attention.

To be successful, you must get it to the right person such as the assignment editor for television and the medical/health reporter for newspapers. By making a phone call to the media outlets of your choice or visiting their website will usually reveal the name of the appropriate person. Be specific when telling them why you are calling. Find out the exact name, title, and address of this person and properly address it to him/her.

Once the right person sees your press release, you need to grab their attention out of all the other releases they receive. Use a catchy phrase, title, or logo to catch their eye so that they will continue to read the rest of your release.

Now that you have caught their attention, one of three things will happen. The worst is that your press release will end up in the trash. The others are that your press release will be published as you have written it or you will receive a call for more information and maybe wider coverage. All this will depend on your message and your presentation.

Here are some helpful tips to give you a better chance of avoiding the first and least desired result - the trashcan.

- *Is my release newsworthy?* Your release should compare similarly to the stories in the media at the moment in regards to interest and local flair.
- *Should I put all the details in my release?* If you would be satisfied to have your release published as written, then yes. If you would prefer to try to get a call requesting more information, you should try to put enough detail to be informative, yet leave out enough detail to motivate a call for more information.
- *Are all my details in the release correct?* Make sure that all the details are as accurate as possible. Never lie, stretch, or bend the truth. This will create negative long-term consequences.
- *Should I customize my release for specific news outlets?* Absolutely. A release that will work for radio may not work for a newspaper or vice versa. Also, what works for one newspaper may not

be appropriate for another servicing the same area. Take some time to tailor your release; it will be repaid by having more successes. Most media reporters or editors have extremely busy schedules and simply do not have the time to sort through all the releases they get. They will pay attention to those that require the least amount of time and attention to make them usable in their format and style.

- *Should I use NFED letterhead?* Always. The letterhead sends a message that the release is official. It also should include a name and contact details, should verification or more details be required. Call the office for a supply of letterhead.
- *Are deadlines important?* Extremely. Call and find out about all deadlines. Each media will have their own deadlines - learn them and submit your releases accordingly.
- *Should I include a photo?* Always. Remember the old saying "a picture tells a thousand words." Ectodermal dysplasia is often a visible disorder and by adding a descriptive photo, it will help draw attention. Your photo will not be returned so use one that you can part with. In the end, the photo may get cut from the printed release, but it will help attract initial attention. Most media outlets prefer a black-and-white photo.
- *What should I do after I send my release?* One week to a few days (depends on deadlines) after you send it, call the editor or the person who will decide if your release will be used and ask if they require any more details. By making this call, you will have the opportunity to introduce yourself to the editor, making your release more personal. It may also bring your release into view, if originally rejected, for reconsideration. You will also be available to answer any questions they may have.

If you have the courage, ask him/her a few questions, which will provide feedback on how to improve your next release.

- *How should I present my release?* The release should always be typed using double spacing on one side only. All pages should be numbered and contain your name, address, phone and email. You should also provide the NFED's phone number, email address, and website. If your release is being sent to only one location, consider having the word "exclusive" some place where it will be easily seen.

The first page should contain your news details; the second page should be a biography on you or the NFED. You can access a lot of the NFED's information from our website at www.nfed.org. It is important that you keep the release concise, precise and to the point.

- *What common mistakes should I avoid?* Missed deadline; misspellings; reads too much like an advertisement; too long; too short; poorly written; content unsuitable; untimely; not enough local flair; incorrect address; or too little relevant details.

There are also books available on writing press releases, so check out your local library or bookstore. Once you have written your press release, contact the NFED for them to review it. Staff can help proofread for you and verify that all information is accurate.

How Do I Deliver My Press Release?

Whenever possible deliver your press releases by hand so you can introduce yourself, as well as the NFED. Putting a face and personality to the story will help increase your chances. It is a lot easier to toss a piece of paper in the trash than to say "no" to a happy, smiling, friendly face. Also you can answer questions on the spot. Keep in mind that you are not the only one looking for page space or air time, so the more accessible you are, the better your chances of success. If you cannot deliver in person, find out how the reporter or editor prefers to receive press releases whether it's through email, mail or fax.

Remember to always thank the individual for their time, even if you receive a negative response. You must remain patient and build up the relationship over time, eventually they may run your story simply because they like you.

Call often and try not to get discouraged or give up. What is rejected by one media outlet may be exactly what another is looking for. Most local newspapers, radio and television stations have some format for promoting non-profit organizations for no charge. It is up to you to find them and make the most of what these services have to offer.

Additional Ideas to Raise Awareness

- Contact local government officials for a proclamation stating that February is Ectodermal Dysplasia Awareness Month. This can be a useful tool in generating media coverage.
- Write letters to the editorial section of your local newspaper.
- Take ED information packets to dentists/pediatric dentists or dermatologists in your community. Contact the NFED to request your packets.
- Speak to your child's class or school about the ED syndromes. Read the NFED's children's books, *Lionel Learns What Matters Most* or *Carver's New Smile*.
- If your company has a newsletter, ask them to write a feature on ED for Children's Dental Health Month and Ectodermal Dysplasia Awareness Month.
- Send an email message to all of your friends and loved ones. Explain that February is Children's Dental Health Month and Ectodermal Dysplasia Awareness Month. Invite them to learn about children who may develop just a few if any teeth by visiting the NFED web site: www.nfed.org.
- Leave NFED brochures at businesses that you patron, with their permission.

How the NFED Can Help You

Need a helping hand? Call the NFED to discuss your questions and concerns. We can put you in touch with the real pros – other NFED volunteers across the country who have successfully raised friends and family in their own back yards!

Get in touch with the NFED to provide fact sheets and press kits you need to generate media coverage about the ectodermal dysplasia syndromes in your own community.

Appendix A: Authorization Form

Third Party Fundraiser Proposal
National Foundation for Ectodermal Dysplasias

Thank you for your interest in raising funds for the National Foundation for Ectodermal Dysplasias (NFED). We are grateful to have you support the organization in our mission to help all individuals affected by ectodermal dysplasia.

The Board of Directors has developed the following guidelines pertaining to fundraising events to benefit the NFED that are sponsored by third parties (individuals or organizations other than the NFED and its staff).

- The Board of Directors respectfully requests all individuals or organizations wishing to host a fund raiser to benefit the NFED to complete a Third Party Fund Raiser Proposal prior to the event.
- The NFED will notify the applicant of the status of your fundraiser proposal within 7 days of receiving it.
- The Board requests that all proceeds and a final income/expense report are submitted to the NFED within 30 days following the event.
- Third parties are prohibited from setting up a separate bank account in NFED’s name in conjunction with a fund raiser.

The NFED is pleased to assist you in planning your fundraiser by offering the following:

- Permission to use NFED name and logo for the event
- Advertising it in The EDucator, as space permits
- NFED educational materials
- Notification of NFED families in area of event
- Assistance with design of materials/flyers
- Guidance and suggestions with event planning
- Securing media coverage of the event, if possible

I understand the NFED’s guidelines for third party fundraiser and agree to abide by them.

Signature

Date

Printed Name

The NFED has reviewed this proposal and agreed to lend its name to this event.

Signature
Carol Agne
NFED Director of Development

Date

(over)

Third Party Fundraiser Proposal

Please complete the information below and return to the NFED office.

Name of Contact Person Organizing Event _____

Name of Organization/Company (if applicable) _____

Contact Address _____

City _____ ST _____ Postal Code _____

Phone _____ E-mail Address _____

Kind of Fundraiser _____
(i.e. golf tournament, raffle, dinner)

Date of Fundraiser _____ Location of Fundraiser _____

Cost/fee for donor to participate in fundraiser _____

Number of people expected to attend event _____

Please attach a proposed budget of income and expenses.

Any other planning details you would like to share:

If you have any questions about completing this form or about your event, Carol Agne at the NFED can assist you. Contact her at the following:

National Foundation for Ectodermal Dysplasias
410 E. Main St., P.O. Box 114
Mascoutah, IL 62258-0114
Phone - 618-566-2020
Fax – 618-566-4718
E-mail – Info@nfed.org
Web Site – www.nfed.org

Appendix B: Tear-Out Fact Sheet

What are the ectodermal dysplasia syndromes?

- The ectodermal dysplasia (ED) syndromes are a group of heritable disorders which are characterized by at least two derivatives of the ectoderm (i.e. teeth, hair, nails, glands) developing and functioning abnormally.
- ED comes in many forms. At least 150 different ED syndromes have been identified based on the combination of symptoms an individual has. Symptoms range from mild such as a missing tooth and thin hair to more severe such as skin erosion.
- Charles Darwin identified the first ED syndrome in the 1840s.

What causes the ED syndromes?

The ED syndromes are the result of a genetic mutation passed from parent to child. In some cases, the genetic mutation occurs spontaneously in the affected person. The ED syndromes are not contagious.

How many people are affected by the ED syndromes?

We are not certain. We do know, however, that many more people are affected by ED syndromes than was ever thought possible. The number is estimated **as high as 7 in 10,000 births** (published in the 1990 edition of *The Birth Defects Encyclopedia*).

How does ED affect people physically?

- Individuals affected by ED frequently have abnormal hair. Scalp and body hair may be thin, sparse, and very light in color, even though beard growth in affected males may be normal. The hair may be excessively brittle, curly, or even twisted.
- Fingernails and toenails may be thick, abnormally shaped, discolored, ridged, slow-growing, or brittle. The cuticles may be prone to infections.
- The skin may be lightly pigmented. In some cases, red or brown pigmentation may be present. Skin can be prone to rashes or infections and can be thick over the palms and soles.
- Many individuals affected by ED syndromes cannot perspire. Their sweat glands may function abnormally or may not have developed at all. Without normal sweat production, the body cannot regulate temperature properly.
- Abnormalities in the development of tooth buds usually result in missing teeth or in the growth of teeth that are peg-shaped or pointed. The enamel may also be defective.

How do the ED syndromes affect lives?

- Many individuals affected by ED syndromes cannot perspire. Air conditioning in the home, school and work place is a necessity.
- Most people with ED syndromes have missing or malformed teeth. Dental treatment is necessary, beginning with dentures as early as age three, multiple replacements as the child grows and perhaps dental implants thereafter. Orthodontic treatment may also be necessary.
- Precautions must be taken to limit upper respiratory infections and care must be provided for the skin to prevent cracking, bleeding and infection.

Appendix C: Sample Corporation Solicitation Letter

Date

Dear:

The National Foundation for Ectodermal Dysplasias (NFED) is the only organization in the country dedicated to serving individuals affected by ectodermal dysplasia (ED) syndromes. The ED syndromes are a group of more than 150 syndromes causing the hair, nails, teeth and glands to develop and function abnormally. Typical symptoms may include the inability to perspire, sparse hair and multiple missing teeth. According to the *Birth Defects Encyclopedia*, as many as 7 in 10,000 individuals is affected by these rare conditions. Symptoms range from mild to severe.

As a member of the NFED, I/we are committed to helping find better treatments, increasing research and supporting programs for affected individuals and families. That is why I/we are writing to you today. I/we are hosting a (insert your event here) on (insert date here) on (insert date here). The goal of this event is to raise awareness and funds for the NFED because our (insert affected family member name here) is affected by (type of ED here).

Please support our efforts by donating (insert whatever you are asking for here) to our event. The proceeds from our event are being raised on behalf of the NFED and will go a long way to supporting their services. I have attached a brochure, which describes ED and the Foundation's services in greater detail.

Your donation is fully tax-deductible to the extent allowed by law. I/we will be providing a report to the Foundation of all donations. You will receive a letter from the Foundation for your tax purposes. If you would like more information about the NFED, I invite you to visit their website at www.nfed.org.

I/We look forward to your favorable response. If you require additional information or have any questions, please feel free to contact me/us at (insert your phone number here).

Sincerely yours,

Your Name

Appendix D: Informal, Personal Letter

Summer 2004

Dear Friends & Family,

I hope this letter finds you well & enjoying the “dog days” of summer. Our boys are definitely in the summer mode going to bed late and getting up even later. Ahh to be a kid again!

Well, I am writing this letter to ask if you would help me with a very important letter campaign. This campaign is quick & painless and will bring great joy to our family and the National Foundation for Ectodermal Dysplasias (NFED). As you know Philip & Nolan have a rare genetic disorder called ectodermal dysplasia (ED). This affects their hair, skin, teeth and sweat glands. The NFED has helped us in so many ways dealing with the boy’s medical, dental & emotional health and well being. This Foundation also provides financial support, advice, guidance, and research into ED. Please go to their website to find out more information. www.nfed.org

We want to give back to them by raising money for all their programs. We are especially excited about all their research efforts and their dedication to finding a cure. All of their funding comes from private donations and grants. They do not get any federal funding. Here is how you can help us help them. We are asking that you kindly give \$10, \$15, \$20 or more. “Don’t give until his hurts. Give until it feels good.” We are grateful for any amount. If a lot of people give a little it will add up quickly. We are hoping that you will also take this letter and forward it to 20 other friends and family members. Just copy the letter and put a sticky note on it asking them to join in our cause. This could mean a whole new beginning for Philip and Nolan and their children someday.

Please make the check out to the NFED and mail it to PO Box 114, 410 E. Main Street, Mascoutah, IL 62258-0114. Please indicate that the money is in honor of Philip & Nolan Pond so we can keep track of the amount raised. We hope to raise \$3,000 by August 31, 2004. If you would like to know how much we have raised send me your email address.

We are blessed to have our children in our lives and we look forward to them having a happy, healthy and productive life. I once read “We make a living by what we earn. We make a life by what we give”. Thank you for giving people affected by ED a chance to lead a normal life.

Best Wishes,

Beth, Michael & the boys

Appendix E: Sample Press Release

FOR IMMEDIATE 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 syndrome.

The NFED is the only organization in the country dedicated to serving individuals affected by ED syndromes. The ED syndromes are a group of more than 150 syndromes causing the hair, nails, teeth and glands to develop and function abnormally. According to the *Birth Defects Encyclopedia*, as many as 7 in 10,000 individuals are affected by these rare conditions. 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.)

Proceeds from the event are being raised on behalf of the NFED. The Foundation provides reliable publications, a support network of families, education conferences for families and care providers, a web site, scholarships, a treatment fund, a research program and more.

The NFED's mission is to be the authoritative resource for information on the ectodermal dysplasia syndromes; provide services that meet the physical, emotional, informational and social needs of affected individuals and their families, and that help them lead a more normal life; and support research on the ectodermal dysplasia syndromes. The NFED serves more than 3,800 families affected by ED in 50 states and 66 countries.

For more information about the ED syndromes or the (insert name of event here), contact (insert your name and contact information here), More information is also available at the NFED's web site, www.nfed.org.

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Appendix F: Contact Brainstorming Sheet

Who Do You Know? Who Can Help You?

List 5 family members.

- 1.
- 2.
- 3.
- 4.
- 5.

List 5 friends.

- 1.
- 2.
- 3.
- 4.
- 5.

List 5 people you know through your business life.

- 1.
- 2.
- 3.
- 4.
- 5.

List 5 businesses that you frequent personally.

- 1.
- 2.
- 3.
- 4.
- 5.

List 5 neighbors.

- 1.
- 2.
- 3.
- 4.
- 5.

Appendix G: Sample Thank You Letter

Date

Contact Name
Company'
Address
City, ST ZIP

Dear (Contact Name),

Thank you for your donation to the (name of event) to benefit the National Foundation for Ectodermal Dysplasias (NFED). With your help, we raised (amount here) for the Foundation.

(Add a paragraph here which summarizes your event and its success.)

Proceeds from the event will be used to sponsor ectodermal dysplasia (ED) research projects, to provide children and adults affected by ED with the dentures, dental implants or other medical and dental care that they need, and to underwrite information packets for new families. Eighty-seven cents of every dollar raised goes toward services, treatment and research.

Thank you for your generosity and your continued support of the Bash. We are grateful. We hope we can count on your help next year for the Fifth Annual Event, scheduled for (date here).

Gratefully,

Your Name

Appendix H: NFED Office Contact Info

Materials Available For Your Event

- General Brochure on NFED/ED
- Annual Report

Staff

Mary Kaye Richter, Executive Director

Carol Agne, Director of Development

Kelley Atchison, Director of Family Support and Outreach

Jodi Edgar Reinhardt, Director of Public Relations

Mary D. Fete, RN, MSN, CCM, Research Program Coordinator

Malinda Heuring, Director of Education

Beverly Meier, Director of Finance

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