



FIRST

Foundation for Ichthyosis & Related Skin Types®

Educate • Inspire • Connect

**Awareness
&
Grassroots
Fundraising
Guide**

Table of Contents

1. Welcome	1
2. Why Raise Funds?	2
3. Overview	3
4. Fundraising Event Ideas	4
a. Personal Letter Writing	5
b. Asking Someone Directly	6
c. Raffle	6
d. 50-50	7
e. Silent Auction	7
f. Combine with Others	8
g. School Fundraiser	8
h. The Holidays	9
i. Any "A-thon"	9
j. Garage Sales	9
k. Profit Sharing	10
l. Car Wash	10
m. College Sororities/Fraternities	10
n. Honor/Memorial Donations	10
o. The Carnival	10
5. The Planning Process	12
a. Planning and Commitment	12
b. Setting Goals	12
c. Develop a Plan	13
d. Permits & Licenses	13
6. Helpful Hints	14
a. Networking	14
b. Budgeting	14
c. Asking for Donations	14
d. Celebrity Recruitment	15
e. Generating Community Interest	16
f. Contacting Sponsors	16
g. Unusual Donors	17

7. Creating Ichthyosis Awareness.....	19
a. What is a press release?.....	19
b. How do I write a good press release?	19
c. How do I deliver my press release?	21
8. Evaluation	22
9. General Procedures/Information	23
10. Other Ways of Fundraising	24
• Estate Planning/Leaving a Legacy	
• Bequests	
• Life Income Gifts	
• Life Estate	
• Charitable Lead Trust	
• Life Insurance	
• Corporate Donations and Matching Gift Program	
• Payroll Deductions	
11. Sample Forms, Letters, and Brochures	25
a. Authorization Form Policy	26
b. Authorization Form	27
c. Alcohol Use at Grassroots Events.....	28
d. Ichthyosis Fact Sheet.....	29
e. Corporate Solicitation Letter	30
f. Informal, Personal Letter	31
g. Press Release	32
h. Event Checklist.....	33
i. Registration Form	34
j. Donation Form	35
k. In-Kind Donation Form.....	36
l. Silent Auction Bid Sheet.....	37
m. Budget.....	38
n. Timeline	40
o. Planning Calendar	42
12. National Office Contact Information	43

Welcome

Thank you for your interest in helping to raise awareness about ichthyosis and in raising funds to support FIRST's valuable programs and services. This booklet is designed to give you information on how to plan a successful grassroots fundraising 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 internet searches and community organizations.

During the review of this booklet or anytime during the planning of your event, please contact the national office 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 review and complete the Authorization Forms on pages 26, 27, and 28, and send a copy to the national office. Once we receive your information, we'll do everything we can to help make your event a success. We can work to publicize your event. We can help determine whether a state permit or license is necessary for your fundraiser and help file any necessary paperwork.

Why Raise Funds?

While it is not unusual for those of us in the ichthyosis community to feel overwhelmed, FIRST 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 ichthyosis community can do is raise money to support research and the programs and services of the Foundation.

So many aspects of this disease are beyond our control, but our ability to raise money is not one of them. There have been great advances in understanding the mechanisms of the ichthyoses, 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 fundraising booklet has been assembled. We'll show you how to turn \$19 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 grassroots 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 in which you and your friends will enjoy being involved in. This will create the most energy, enthusiasm and fundraising dollars for the Foundation. 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 ichthyosis and the related skin types
- To raise funds for the important work of FIRST
- To bring people together to socialize and have some fun

Whenever possible try to choose an 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.

Fundraising Ideas

Brainstorming: Selecting an Event

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.

The following suggestions are just that—suggestions. The Foundation encourages you to develop your own ideas or use only part of these suggestions. The best events are the ones that our members 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.

Fundraising Suggestions

(detailed explanations available*)

Personal Letter Writing*	Asking Someone Directly*	The Carnival *
Combine with Others *	School Fund Raisers*	The Holidays*
Any “a-thon”*	Garage Sale*	Profit-Sharing*
Car Wash*	Fraternities/Sororities*	Honor/Memorial*
Raffle/50-50/Silent Auction*	Dress down day	Poker Tournaments
Bake sale & hoagie sale	Breakfast with Santa	Sporting Events (5k
Halloween trail	Community dinners	runs, volleyball
Parties (wine tasting, tea)	Service for donations	tournaments, walks)
Bingo (and all of its variations; chicken scratch, cow plop, basket, etc.)	(leaf raking, snow shoveling, cleaning)	Golf Tournament ***

*** Call the National office for the “Golf Tournament How-To Guide.”

Personal Letter Writing Writing personal letters to family and friends requesting donations is a very effective way to raise money for ichthyosis research. There are many benefits in making the effort to write these letters. 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 disease 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. Bearing witness to the outpouring of support from friends and family will give you an emotional boost and increase your faith in the nature of people.

When planning your donation letters, figure out whom you will contact and what style of letter you will mail to them. At the very least, you should include your relatives and close circle of friends (and the closest friends of your parents and in-laws). A minimum of 25 people should not be difficult to compile. You can draw upon Christmas card lists, address book entries, wedding reception guest lists, etc.

There are two sample solicitation letters, *Corporate Solicitation Letter* on page 30 and *Informal, Personal Letter* on page 31 for your use. Feel free to adapt them to your needs. These letters have been very successful in raising money and will help you raise money too. Access to a word processor or a computer with word processing capabilities is highly recommended, especially for larger lists. It will help you to complete the letters much faster. The Foundation staff can help you if you do not have access to a computer.

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 Foundation also encourages you to provide a brochure in your mailing. Simply contact the Foundation and we will provide a batch of brochures for your letters. When purchasing postage, ask for stamps with themes of love. Another good idea is to include a scanned photo of the family member affected with ichthyosis. If you do include a picture, be sure to attach a sticker on the outside envelope that says "Fragile," which will bring attention to your letter.

Have all donors make their checks payable to the FIRST. Send the checks back to the 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 office in a timely manner. The thank you letter will also serve as documentation needed for charitable deductions on their federal income taxes.

How to Turn \$19.50 into \$500	
Mailing List	Expenses
10 relatives (siblings, cousins, parents, aunts, uncles, etc.)	Stationery/envelopes = \$7.00
10 friends, co-workers, neighbors, etc.	Postage: 25 letters x \$.50 = \$12.50
5 friends of your parents, in-laws, uncles, cousins, etc.	
25 – Total number of letters sent	Total Expenses = \$19.50
An average donation of \$20 per letter will result in \$500.00	

Start your letter with a personal statement. A plea for help or a description of the affected individual's situation is a great way to begin. Then briefly describe what ichthyosis is, and how their donation can make a difference.

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 fundraising 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 ichthyosis.)

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. To many people it seems like begging, so think carefully about how you want to do this. You may find it easier to sell tickets in a raffle or plan a fundraising event, rather than to ask for a cash donation.

Raffle Recruit some friends and solicit items to be used in a raffle. Examples are asking an airline for free tickets or a local sports store to donate sporting goods, etc. 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, or your church basement.

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 meat 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.

50-50 Having a 50-50 raffle is an easy way to raise additional money for your event. It involves the sale of raffle tickets with the proceeds being split evenly between the winner and the Foundation.

Your only expense is the raffle tickets (a double ticket roll). Winners are always happy with a cash prize. All you need is one or more ticket sellers. Raffle tickets normally sell for \$1 apiece, with an incentive for multiple purchases such as three tickets for \$2, or five tickets for \$4, etc. Using a price incentive for multiple tickets can often increase your total sales and builds a larger 'pot' to split with the lucky winner.

All ticket stubs are placed in a hat or other container from which one lucky number is drawn. The 'take' is tallied and one-half awarded to the holder of the lucky number. The drawing is normally held toward the end of the event, and the lucky number holder must be present to win. If not claimed within a set time limit which can be as short as a minute or two, a second number is drawn and awarded the prize. Generally speaking, the larger the prize, the longer time allowed for the original winner to claim his or her prize.

Silent Auction A silent auction is an auction where people write their bids on a piece of paper, and whoever has the highest bid wins the item.

In securing your donated item use the "In-Kind Donation" form on page 36 for your record keeping. Make sure to get all the information asked on the form, that way if you'll be holding your event next year, you'll have a list of companies and contacts to go back to.

In preparing for your auction, print a silent auction bid sheet (sample found on page 37) for each item. Write the name of the item, who donated the item, and the FMV (Fair Market Value). Include a minimum bid and minimum bid increase increments. (One rule of thumb for minimum increase: \$1 for items up to \$50, \$2 for \$50-\$100, \$5 for over \$100).

Lay out all the items and the bid sheets so people can see them. Tape the bid sheets down next to the item. It's easy for bid sheets to get blown or knocked around.

Monitor the table to make sure bid sheets are staying in place and people are providing all their personal information and following the minimum bid and minimum increase rules.

Give people plenty of warning as closing time approaches. Make announcements at least 10 and 5 minutes before. People will want to bid right up to the very end.

When the bidding time ends pick up all the pens and sheets so no one can be sneaky. You can circle the winning bid and draw a line through the empty spaces of the bid sheets, so no one can add their name after the closing time.

Sort the sheets by last name (winner) in alphabetical order. If anyone has won more than one item, staple those sheets together. That way you only need to have them pay once.

Call your bidders (winners) up one at a time by name for them to make payment. Payment can be made by cash, check, or credit card. When paying by credit card it is important that you write down the card number and expiration date.

If there are leftover items, from people who went home and don't know they won, you will have to take the gifts home and call the winner from the phone number listed on your bidding sheet. You may have people who don't want to pay for the things they bid on. Call the next person on the bid sheet and see if they still want the item.

Things you'll need:

- Bid sheets
- Masking tape or packaging tape
- Transparent tape (for taping bid sheets to table)
- Painter's tape to hang signs on walls (painter's tape is much less likely to peel paint from the walls when taking things down)
- Markers
- Pens (Lots of these on hand! At least one for every bid sheet).
- Whiteout tape, not liquid
- Tables

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, 4-H Club, etc. 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.'

School Fundraisers 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 ichthyosis 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 \$1.00 to 'dress-down' on a Friday.

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 FIRST? 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 this season into a fundraiser that helps people to get what they want, while raising money for the Foundation. First aid kits are a thoughtful and unusual gift idea. Gift wrapping paper is an essential item that has yet to be overdone. Bulbs, t-shirts and candles are items that deserve a closer look. So the secret to successful fundraising at Christmas 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 Foundation!

Any “A-thon” Read, skate, walk, bike, bowl, 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 \$5.00 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 \$25.00 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.

Garage 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 ichthyosis. 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.

Profit Sharing Many companies offer profit-sharing opportunities. Commonly known organizations such as Tupperware, Longaberger Baskets, and 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.

Car Wash This is a really fun way to raise money for FIRST. 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 ichthyosis and the Foundation. Ask them for a donation to have their car washed; making sure the minimum amount is \$5.00. You may find some people will donate more than \$5.00. 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 ichthyosis.

College Sororities/Fraternities These groups sometimes do fundraising and charity work for whatever organization they have "adopted." They may sponsor or host an event or may provide the "manpower" you need for an event you have organized.

Honor/Memorial Donations At the time of death, 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 FIRST.

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

The Carnival This type of event requires considerable planning and numerous volunteers. Try to enlist the help of another organized group such as a school, church, and civic organization.

Sell tickets at a centralized ticket booth rather than at individual activities. Also sell tickets in bulk such as 20 tickets for \$5.00 or 40 tickets for \$10.00. Solicit donations of prizes from local food restaurants. Ask local pet stores to donate coupons for one free goldfish to give as prizes. Most

people won't actually redeem them, but they usually will buy other items from the store, which makes this a good promotion for the merchant.

If the prizes are not donated, buy in bulk. Be sure to have extras. Assume that your carnival will be a huge success. If there are any extras, you can use them at next year's event. Plan on making this an annual activity and let everyone know about your plans for continuing.

Set up an information/awareness booth. FIRST can provide you with brochures to distribute to guests. Be sure to have plenty of contribution envelopes available for people who ask for the Foundation's address.

Contact the office for simple ideas for activities at your carnival. Examples include, fishing with magnets, panning for gold, bean bag toss, penny toss, face painting, thumb print drawing, pick a lollipop, duck pond, knock down the pyramid, bingo table, balloon characters, guess your age, football toss, and clothespin drop. You can also have pony rides and a petting zoo. Other ideas include, a magic show, a bounce house, dunk tank and play zone.

The Planning Process

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).

Planning and Commitment

The backbone of a successful fundraising 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.

Setting Goals

After you have determined your event, an essential key to ensure success is proper goal setting. Goals should be relevant, realistic and meaningful. 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.

Setting a realistic goal will help keep you focused and motivated. 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 Foundation 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 Foundation grassroots fundraisers, both in money raised and time taken. 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.

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 ichthyosis, and raise funds for the Foundation. Overall, the bottom line is to choose a fundraiser that most people in your community can get excited about.

Develop a Plan

Once the goal has been determined, it is time to develop a combination action plan/timeline. This plan will become your working guide for all the essential steps involved in your event.

First, check local community calendars 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.

To set your timeline, it usually helps to work backwards from the date of your event. Carefully think when you are going to need things to get done and place them on the list. Larger events usually take more than 6 months of planning. Smaller, simpler events can be successful with only a few weeks of planning.

A sample *Timeline* can be found on page 40. We've also included a *Planning Calendar* template (page 42) to aid you with your event.

Permits & Licenses

Depending on where you live and what fundraiser you have chosen to host, a permit may be required. Most public events require the Foundation to be registered in the state. Contact the Foundation to see if your state is registered. If not, the Foundation will work with the state to ensure the proper registration is filed.

Helpful Hints

Always remember, fundraising events can offer more than just a way to raise money. They offer ways of building recognition of our Foundation 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

Your goal is to connect FIRST and our mission to individuals and businesses that can help you achieve your goals. You will be raising ichthyosis 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.

Budgeting

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:

- Make a list of exactly what you need.
- 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.

A sample *Budget* can be found on pages 38 and 39.

Asking for Donations

When personally asking for donations, look the part! Appearance counts. Your job is to help the potential donor 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 members.

Set some goals. These goals will aid in your success by keeping you on track and motivating you to

keep working.

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 Foundation. Use the *Ichthyosis Fact Sheet* (page 29) 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.

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, for instance, your regional newscaster, weatherman, radio personality, or sports player. Since ichthyosis 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 with a face-to-face meeting and you have stronger chances of receiving a favorable response. If you know someone who is affected by ichthyosis, 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 introduce the Foundation, 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 ichthyosis being rare —this may work in our favor. Be sure to mention that FIRST 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.

Generating Community Interest

What do I need to make my event successful? To answer this question, you need to follow these two simple rules: 1) Look at what others have done and, 2) Ask a lot of people a lot of questions.

Simply start by answering these basic questions of who, what, when, where, why and how. Who did it? What did they do? When did they do it? Where did they do it? Why did they do it?

Once you have these answers to these general questions, you may want to record answers to more detailed questions 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? When doing market research, remember there is no such thing as a stupid question!

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 with volunteers, donations, and other details that can make or break your fundraiser.

Contacting Sponsors

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.

There are three kinds of sponsorship. A successful event usually uses a combination of all three. 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 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-athon. 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 options for these donors, if you are not always readily accessible.

One of the most important rules in securing sponsorship is to follow-up to 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 office for brochures or literature about ichthyosis 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. It sends a strong message to the caller that they are valued.

For record-keeping use *Donation Form* on page 35 and the *In-Kind Donation Form* on page 36 for all gifts/donations received for your event.

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.

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.

Creating Ichthyosis Awareness

The more PR attention we can create for FIRST, the better. Many newspapers, cable outlets, local TV stations, bulletin boards at community centers, etc., can be used to advertise an event at no cost. Another successful way to communicate with the media is through a press release.

The staff at the FIRST office will be happy to create a press release for you and send it out to the media outlets in your area. Please contact Director of Operations, Lisa Breuning to arrange for a press release for your event.

If you prefer to send out your release, FIRST offers tips to help you.

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 FIRST. The public can help by attending your event and supporting your cause.

How do I write a good press release?

Writing a good press release can be difficult. To help you in your efforts, FIRST has created a template that you can use. The key is to grab the attention of the contact who decides if your event is newsworthy.

To be successful, you must get it to the right person. Making a phone call to the media outlet(s) in your area or visiting their website will usually help you determine the appropriate contact for your release. 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, and photo 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. Your press release will be published as you have written it; you will receive a call for more information and maybe wider coverage, or your press release will not get picked up. All this will depend on your message and your presentation.

Here are some helpful tips to give you a better chance of the release being published.

- Is my release newsworthy? Your release should compare similarly to the stories in the media at the moment with interest and local flair.

- Should I put all the details in my release? Yes, you should include all relevant information in your release without being too long. Ideally, the release should be one page.
- 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. 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 include the FIRST logo? **Always.** The logo sends a message that the release is official. It also should include a name and contact details, should verification or more details be required.
- Are deadlines important? **Extremely.** Call and find out about all deadlines. Each media outlet 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." Ichthyosis is a very visible disorder and by including a photo, it will help draw attention. In the end, the photo may get cut from the printed release, but it will help attract initial attention.
- What should I do after I send my release? A few days after you send it, call the contact person to check if they received it and ask if they require any more details. By making this call, you will have the opportunity to introduce yourself, 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 he/she may have.
- How should I present my release? The release should always be typed and be limited to one page only, if possible. You should also provide FIRST'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. It is important that you keep the release concise, precise, and to the point.

- What common mistakes should I avoid? Missed deadline; 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.
- A Press Release Template can be found on page 32.

How Do I Deliver my Press Release?

Whenever possible deliver your press releases via email. Then, follow up with a phone call to the media outlet in a few days.

Evaluation

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 mistakes from happening again or reduce 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.

The following questions will help guide the evaluation process: What, if anything went wrong? What can we do about it? Did we meet our targets? Did anyone complain and if so about what? Was anyone overworked? Did anyone's temper get out of hand? Did everyone enjoy themselves? How much money did we make? Could we have made more? Did anything unexpected happen? If so, why? What was the best part of our event? Why? What are the problems we faced?

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 grassroots fundraisers within the Foundation.

General Procedures/Information

Pre-Event

Grassroots event organizers **MUST** complete a *Grassroots Authorization Form* (see page 27) and submit it to the national office prior to the event.

Grassroots event organizers who are including alcohol in their Grassroots Event must sign and return *Policy for Alcohol Use at Grassroots Event* (see page 28) and submit it to the national office prior to the event.

- FIRST cannot cash a check written to FIRST and return cash to you.
- FIRST cannot reimburse you for out-of-pocket expenses without a receipt.
- FIRST is not responsible for contracts you signed and/or negotiated.

Determine what, if any, materials you will need from FIRST. Available materials are:

- General Brochure
- Ichthyosis: An Overview Booklet
- Ichthyosis: The Genetics of Its Inheritance Booklet
- DVD: Living with Ichthyosis – A Teenage Perspective
- DVD: A FIRST Story
- Disease and Resource Handouts
- FIRST Banner

Pictures, pictures and more pictures! We want to publish your event in our quarterly *Ichthyosis Focus* newsletter and on our website. Send your pictures along with a paragraph or two telling us about your event. **Please try to include group photos with the event leadership. Make sure that you are in a few photos also.** Identify the people in the photos by name. Remember to include your event name, date, and the location of your event. Send or email your information and photos to Lisa Breuning, FIRST, 2616 N. Broad St., Colmar, PA 18915 or lbreuning@firstskinfoundation.org.

Post-Event

Give thanks and recognition to those who made your event possible. Send out a note, or an email, to your volunteers and sponsors letting them know how successful the event was. Contact any newspaper columnists or radio disc jockeys who promoted your event to thank them and let them know it was a success. Write a letter to the editor of your local newspaper thanking the people who helped.

Mail all cash, checks, etc., along with the completed donation forms to the national office. All donations will be entered into our database which will generate an acknowledgement letter thanking your donor(s) for their donation. This letter will serve as their receipt for income tax purposes.

OTHER WAYS OF FUNDRAISING

To raise money for FIRST does not always mean you have to hold a fundraising event. There are others ways to make a difference without hosting an event. Some examples are as follows:

Estate Planning/Leaving a Legacy. 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.

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.

Life Estate. This provides the Foundation with the gift of a residence or farm while allowing the donor the right to continue to live there for the remainder of his or her life.

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 foundation to receive benefits upon the death of the insured.

Corporate Donations and Matching Gift Program. This area is perhaps our greatest, untapped resource. Most large corporations budget for charitable contributions. Many prefer to give to causes that help their employees or families. These funds are usually available on a first-served 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 United Way or Combined Federal Campaigns from many of our members. Contact your Human Resources Department for more information.

For additional information on the above types of fundraising please contact the national office for further assistance.



SAMPLE FORMS AND LETTERS

- Authorization Form Policy.....26
- Authorization Form.....27
- Alcohol Use at Grassroots Events28
- Ichthyosis Fact Sheet29
- Corporate Solicitation Letter30
- Informal, Personal Letter31
- Press Release.....32
- Event Checklist33
- Registration Form34
- Donation Form35
- In-Kind Donation Form36
- Silent Auction Bid Sheet37
- Budget38
- Timeline40
- Planning Calendar42



Foundation for Ichthyosis & Related Skin Types, Inc.[®] (FIRST) Volunteer Fundraiser Proposal Authorization Form

The Foundation is pleased to assist you in planning your fundraising event by offering the following:

- Permission to use the Foundation's name and logo for the event
- Advertising in the Foundation's quarterly newsletter, *Ichthyosis Focus*
- Educational materials for distribution and assistance with design of flyers
- Notification of Foundation members in area of event
- Guidance and suggestions with event planning

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

- FIRST requires all individuals or organizations wishing to host a fundraising event to benefit the Foundation complete the Third Party Fundraising Proposal prior to the event.
- FIRST will notify the applicant of the status of the fundraising event within seven days of receipt.
- FIRST requires all proceeds and a final income/expense report be submitted to the Foundation office within thirty days following the event.
- Third parties are prohibited from setting up a separate bank account in the Foundation's name in conjunction with the fundraising event.



**Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST)
Grassroots Fundraiser Authorization Form**

Name of Contact Person Organizing Event: _____

Name of Organization/Company (if applicable): _____

Contact Address: _____

Home Phone: _____ Email: _____

Type of Fundraiser: _____

Date of Fundraiser: _____ Location: _____

Will there be a registration fee to attend your event? Y or N

Registration amount: \$_____

Number of people expected to attend event: _____

Please attach a proposed budget of income and expenses

Any other details that are relevant to the event that you would like to share:

I understand and agree to comply with FIRST's guidelines for a third party fundraising event.

Your Signature

Date

Foundation Representative

Date

Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST)
2616 N. Broad Street
Colmar, PA 18915
www.firstskinfoundation.org



Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST) Policy for Alcohol Use at Grassroots Events

Name(s) of Responsible Party(ies) (Printed): _____

The purpose of this policy is to specify the requirements for those events at which alcoholic beverages (including, but not limited to beer, wine and liquor) may be available. By choosing to serve alcohol at a FIRST fundraiser, and because FIRST neither supervises the event nor provides any representatives, you agree to the following policies:

- I (we) will comply with all applicable state, federal, and local laws and regulations that relate to the sale, distribution and consumption of alcoholic beverages.
- I (we) agree not to sell, distribute or supply alcoholic beverages to any person who is under the legal age in the relevant state or town where the event is held, or who is unduly or visibly intoxicated or disorderly.
- I (we) agree to designate one or more persons to monitor the distribution and use of alcoholic beverages.
- I (we) agree to obtain all necessary permits, insurance, security, etc. as required in the city or town where the event will be held.
- I (we) will not permit, tolerate, encourage or participate in “drinking games.”
- I (we) will provide sufficient quantities of non-alcoholic beverages and food throughout the event to serve 100 percent of the attendees.
- The event must be closed and limited to invited and/or registered guests.
- I (we) will conduct the sale of alcoholic beverages through a licensed vendor and/or in accordance with applicable state and local laws.

Date: _____

Authorized Signature

Date: _____

Authorized Signature



Ichthyosis Fact Sheet

What is Ichthyosis?

Ichthyosis is a family of genetic skin diseases characterized by dry, thickened or thin, scaling skin. In some forms of ichthyosis, the natural shedding process is slowed or inhibited, while in others the production of skin cells is faster than normal. Dermatologists estimate that there are at least twenty varieties of ichthyosis, with a wide range of severity and associated symptoms.

What Causes Ichthyosis?

Ichthyosis is the result of a genetic mutation passed from parent to child. In some rare cases, the genetic mutation occurs spontaneously in the affected person. Ichthyosis is not contagious.

How Many People Have It?

Ichthyosis affects more than one million Americans. Ichthyosis comes in many forms, ranging from mildly dry skin to intense scaling, cracked, and thick skin. The more severe types are rare.

What are the Symptoms of Ichthyosis?

Ichthyosis is usually present at conception and it is obvious at birth that something is wrong with the baby's skin. However, in some cases the symptoms do not become apparent until sometime during the first year of a child's life.

Symptoms of ichthyosis range widely depending on the type of ichthyosis involved. Some symptoms include: extremely dry skin; constant build-up of scales; dehydration; itchy skin; difficulty sweating; thinning hair; protruded eyelids; and increased risk of infection. Ichthyosis can be a disfiguring disease and has numerous social and psychological implications.

How is Ichthyosis Treated? Is There A Cure?

There is no cure for ichthyosis, only treatments to help manage the symptoms.

What Can I Do To Help?

Support research on ichthyosis, improved treatments, and education of the public about the disease and its symptoms by donating to the important work of the Foundation. Because ichthyosis is a rare condition, many people, including doctors, simply do not know what it is.

What is FIRST?

The Foundation for Ichthyosis & Related Skin Types,® is a national non-profit organization founded in 1981, that offers information, education, advocacy, and support services to persons affected with ichthyosis and their families. The Foundation funds research into finding the causes, better treatments and a cure for ichthyosis. To receive more information about contributing to or becoming a member of FIRST, please call 800-545-3286 or visit www.firstskinfoundation.org.

**Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST)
Corporate Solicitation Letter**

Date

Dear Friends:

The Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST) is a national non-profit organization dedicated to helping individuals and families affected by ichthyosis. Ichthyosis is a group of rare genetic skin diseases that affect more than 16,000 babies each year. The disease is characterized by very dry, cracked, scaling and thickened skin. In addition to the medical implications, ichthyosis is a very visible disease. Affected individuals must also handle the psychological factors attributed to their appearance.

As a member(s) of this Foundation, **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]**. The goal of this event is to raise awareness and funds for the Foundation because our **[insert affected family member here]** is affected with **[type of ichthyosis 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 Foundation and will go a long way to supporting their programs and services. **I/We** have attached a brochure, which describes ichthyosis 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 FIRST for your tax purposes. If you would like more information about the Foundation, kindly visit their website at www.firstskinfoundation.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

**Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST)
Informal, Personal Letter**

Date:

Dear Friends **[insert personal name]:**

As many of you know, our **[insert name and relationship]** was born with a rare, genetic skin disease called ichthyosis. While the diagnosis has helped us to understand the disease, the symptoms are very difficult to deal with.

Ichthyosis is a rare, genetic skin disease characterized by dry, cracked, scaling and thickened skin. Dermatologists estimate that there are at least twenty varieties of ichthyosis, with a wide range of severity and symptoms.

[Insert personal paragraph here, i.e., (Name) has to apply a special cream on his/her skin four times per day, which stings and makes him/her cry every time. (Name) takes two-hour long baths every night to soften the scales, which makes them easier to remove. (Name) has been teased by his/her friends for having different looking skin.]

The good news is that there is hope. **I/We** are part of a national organization called the Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST). This Foundation provides support, advice, guidance, and research into ichthyosis. Through this group of people, we have been able to join other families and influence scientific progress much more rapidly than if we did it alone.

Please help us by giving \$15, \$25, \$50 or more. Kindly make your check payable to the Foundation for Ichthyosis & Related Skin Types, Inc.® and mail it directly to the Foundation at 2616 N. Broad Street, Colmar, PA 18915. Your donation will help FIRST continue to conquer this rare disease.

[Name] is so **[use descriptive words such as bright, happy, light-hearted, etc., include a sentence about something they are looking forward to.]** We are blessed to have (name) in our lives and look forward to a bright future.

With our deepest thanks,

Your Name

Sample Press Release

FOR IMMEDIATE RELEASE

Contact: *Your Name [or FIRST Staff Person]*

Your Phone Number [or FIRST's phone number 215-997-9400]

Your email address [or FIRST contact email address]



TITLE

Sub-title

Your City, STATE [DATE] – [State what your event is, where it will be held and that it is a fundraiser for the Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST). Mention briefly why or how you chose this event, and how you are connected to ichthyosis, ie son/daughter is affected with [type of] ichthyosis.]

Include engaging high-quality photo to attract attention.

Ichthyosis is a family of rare, genetic skin disorders that causes the skin to become scaly, and crack and peel. Ichthyosis also prevents the skin from sweating, which can lead to complications from overheating.

“There is no known cure for ichthyosis, only treatments,” stated Moureen Wenik, Executive Director of FIRST. “It is our hope that *[with the funds raised from this event]*, we can continue to conduct more extensive research and provide services to the members of FIRST taking us one step closer to finding a cure and better management of the disorder. We can’t thank *[the family name]* enough for their efforts and support.”

According to FIRST, each year, more than 16,000 babies are born with some form of ichthyosis, of those, approximately 300 are born with a **moderate to severe form**. This disease affects people of all ages, races, and gender. The disease usually presents at birth, or within the first year, and continues to affect the patient throughout their lifetime.

For more information about **[event]**, contact **[your contact information, or FIRST office contact information if you prefer]**.

About the Foundation for Ichthyosis & Related Skin Types, Inc.®

The Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST) is the only nonprofit foundation in the United States dedicated to families affected by the rare skin disorder ichthyosis. Approximately 300 babies each year are born with a moderate to severe form of ichthyosis. FIRST educates, inspires, and connects those touched by ichthyosis and related disorders through emotional support, information, advocacy and has supported more than \$1.6 million in research funding for better treatments and eventual cures. For more information, call toll-free at 1-800-545-3286 or visit www.firstskinfoundation.org.

###



Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST) Event Checklist

- Ask questions and gather information to determine community interest
- Check community calendar for other planned events
- Choose an event
- Complete Volunteer Fundraising Authorization Form in booklet and send back to
Foundation office
- Recruit volunteers/friends to help. Be sure to send frequent thank you letters to all
donors and volunteers who help you.
- Set a goal
- Develop a working plan and timeline
- Contact the Foundation to check on permits/licenses or registration
- Set a budget - make a list of exactly everything needed for event
- Try to recruit a local celebrity to help promote event
- Make a list of possible event sponsors
- Contact the Foundation office for brochures and other literature to hand out
- Establish mailing list to promote event
- Develop promotional materials (flyers, posters) and distribute
- Make a list of all media outlets to send press release
- Write press release, using samples provided, and distribute



Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST)

(EVENT NAME)

The Foundation for Ichthyosis & Related Skin Types, Inc.®(FIRST) is a national nonprofit organization dedicated to helping families with the genetic skin diseases collectively called ichthyosis. The Foundation provides support, information, education and advocacy for individuals and families affected by ichthyosis. Ichthyosis is a family of genetic skin diseases characterized by dry scaling skin that may be thickened or very thin. Dermatologists estimate that there are more than twenty varieties of ichthyosis, with a wide range of severity and symptoms. Our research funding program supports investigators and new ideas about causes, treatments and potential cures. Please join us and help personalize here and many others who are affected with ichthyosis!

WHERE: _____

WHEN: _____

DONATION: \$ _____

-----✂-----✂-----✂-----

REGISTRATION FORM

Please fill out and return the completed form and registration fees to:

CONTACT INFORMATION:

First Name Last Name

Street Address

City State Zip

Cell Phone Email Address Home Phone

Registration amount: \$ _____

Type of Payment

- Cash
- Check # _____
- Credit Card: (circle one) Discover, Visa, MasterCard, American Express

Credit Card #: _____ Expiration Date: _____

Thank you for your support of FIRST!

The Foundation for Ichthyosis & Related Skin Types, Inc.® is a registered 501(c)3 and all donations are tax-deductible as allowed by law.

www.firstskinfoundation.org



2616 N. Broad Street
Colmar, PA 18915

215.997.9400 • 800.545.3286
Fax: 215.997.9403
info@firstskinfoundation.org
www.firstskinfoundation.org

Donation Form

Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Organization: _____

Telephone: (H) or (C) _____ Email: _____

Amount of Donation: _____

General Donation Event Sponsorship _____

(designated for)

Type of Payment:

Cash

Check # _____

Credit Card: (circle one) Discover, Visa, MasterCard, American Express

Credit Card #: _____ Expiration Date: _____

Thank you for your support of FIRST!

The Foundation for Ichthyosis & Related Skin Types, Inc.[®] is a registered 501(c)3.

All donations are considered tax-deductible to the full extent of the law.

Our Federal Tax Identification number is 94-2738019

www.firstskinfoundation.org



2616 N. Broad Street
Colmar, PA 18915

215.997.9400 • 800.545.3286
Fax: 215.997.9403
info@firstskinfoundation.org
www.firstskinfoundation.org

In-Kind Donation Form

Name: _____

Company Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Telephone: () _____ Email Address: _____

Description of gift/donation (please be specific):

Fair Market Value \$ _____

Signature: _____ Date: _____

Thank you for your donation!

The Foundation for Ichthyosis & Related Skin Types, Inc.® is a registered 501(c)3.

All donations are considered tax-deductible to the full extent of the law.

Our Federal Tax Identification number is 94-2738019

www.firstskinfoundation.org



Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST)
Budget (Sample)

EXPENSES

ITEM	\$ AMOUNT
Facility Rental	
Parking	
Security	
Food	
Service	
Entertainment	
Speakers	
Transportation	
Hotels	
Equipment Rental:	
Tables	
Chairs	
Linens	
China	
Glassware	
Flatware	
Stage	
Sound System	
Projector/Screen/Computer	
Decorations	
Favors/T-Shirts/Incentives	
Graphic Design/Artwork	
Printing	
Save-the-Date/Invitations/Tickets	
Brochures/Posters/Fliers/Press Packets	
Signage	
Bid Sheets/Programs	
Postage/Mail House	
Photography	
Total	



Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST)
Budget (Sample) (Cont'd)

INCOME

SOURCE	\$ AMOUNT
Ticket Sales	
Donations/Pledges	
Sponsorships	
Raffle Tickets	
Food/Beverages	
Silent/Live Auction	
50/50 Raffle	
Total	

Net Income (Income minus Expenses) [\$\$\$]



Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST) Timeline

SIX MONTHS BEFORE THE EVENT

- Recruit a committee to help plan the event
- Choose an Event
- Check community calendar for other planned events
- Decide on date and time of the event
- Choose a location – call for prices and availability
- Determine if an auction/raffle will be held at the event
- Complete and return Volunteer Fundraising Authorization form(s)
- Contact Foundation to check on permits, licenses or registrations
- Set a goal
- Set a budget
- Target sponsors for monetary and in-kind donations
- Develop a working plan using your Planning Calendar (page 45)
- Begin to develop promotional materials, flyers, brochures, posters (we can help you with this)
-

FIVE MONTHS BEFORE THE EVENT

- Send letters to local businesses asking for sponsorships and donations
- Establish mailing list to promote event

FOUR MONTHS BEFORE THE EVENT

- Prepare and mail “Save the Date” cards
- Follow-up with letters mailed to local businesses (sponsorships and donations)

THREE MONTHS BEFORE THE EVENT

- Meet with committee and check on progress of sponsorship
- Finalize promotional materials
- Make a list of all media outlets to send press release

TWO MONTHS BEFORE THE EVENT

- Send flyers, brochures to local businesses, friends and family advertising your event
- Utilize social networking to promote event
- Order printed materials (t-shirts, banners or other specialties)
- Finalize sponsorship signage
- Write Press Release and distribute

ONE MONTH BEFORE THE EVENT

- Pick up any remaining in-kind donations
- Have forms/tickets ready for auction, 50-50 and raffle
- Confirm all arrangements with event location
- Meet with committee to assign tasks for day of event

ONE WEEK BEFORE EVENT

- Meet with facility staff to finalize all arrangements
- Follow-up with outstanding donations

DAY OF EVENT

- Arrive early and meet with committee to confirm tasks
- Set-up registration table and raffle table(s)
- Place sign/banners in appropriate locations

POST EVENT

- Send thank you letters to volunteers and sponsors
- Reconcile all monetary donations and mail to the Foundation



Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST)
National Office Contact Information

Staff

Christopher Boynton, Chief Executive Officer
Lisa Breuning, Director of Operations
Denise Gass, Advancement Director
Christine Wassel, Community Engagement Director

Address

PO Box 1067
Lansdale, PA 19446-0687

Phone

215-997-9400
800-545-3286 (toll-free)
215-997-9403 fax

Web

www.firstskinfoundation.org

Email

dgass@firstskinfoundation.org