



Building Friends for a Cure Manual



Dare to believe that ordinary people affected by a life-threatening illness can raise its awareness from the depths of obscurity, establish the means to marshal scientific research, and join forces to advocate the federal government to protect our own rights. We, Alphas, have done just that and together we will find a cure for Alpha-1 Antitrypsin Deficiency."

Take Action and Make a Difference: It's up to you!
Contact: Angela McBride at amcbride@alpha1.org

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INTRODUCTION

WHAT IS THE COMMUNITY FRIEND-BUILDING CAMPAIGN?

The community friend-building campaign is designed by the Alpha-1 Foundation to make new friends and nurture those friendships made throughout the year. We cannot do it alone; we need you! We are thrilled that you have agreed to be part of a network of people who will work closely with the Alpha-1 Foundation to generate publicity and raise funds. The campaign is designed to extend the geographic reach of the Foundation, and foster stronger links between the organization and the community.

Simply, the time has come for the Alpha-1 community to join forces in an organized manner and create awareness for Alpha-1 Antitrypsin Deficiency. The need to increase testing among at-risks populations is at an all time high, and the only way to do this is through coordinated efforts across the country. In addition, our goal should be to focus our efforts in fulfilling our **mission of increasing awareness and raising funds for more research, which will lead to a cure for Alpha-1.**

HOW DO WE GET STARTED?

It just takes your commitment and dedication and if possible, consider joining forces with other Alphas in your community. You can split the responsibilities and have fun while you create innovative projects for the campaign.

There are two key areas of focus:

- Community Fund Raising: Organize a special event in your community, start a letter writing campaign or encourage your friends to purchase or sponsor projects like our Alpha-1 awareness wristbands/car magnets to raise funds for Alpha-1 research. The funds generated by projects like these are integral to support the Alpha-1 Foundation's mission.
- Outreach and Awareness: Educate your community about Alpha-1 through grassroots efforts. You can work with the press to generate media coverage in the form of TV segments, radio interviews and print articles, or, you can also make arrangements for speaking engagements to educate civic and community groups about Alpha-1.

You should set some initial goals and you may want to work with some of the Alpha-1 Foundation staff to make your goals measurable and attainable.

WHAT RESOURCES DOES THE ALPHA-1 FOUNDATION PROVIDE?

The Alpha-1 Foundation can help you by providing:

- Dedicated staff members to assist you with initial organization and ongoing support.

- Updated informational and educational materials on Alpha-1.
- Over the phone training sessions for you and your volunteers.
- Writing of ongoing press releases and letters to help disseminate standard messages and information.
- A dedicated page on the website highlighting your local activities.

WHAT ACTIVITIES AM I EXPECTED TO PERFORM?

You may choose to host a large community event, organize several days to distribute Alpha-1 informational materials, execute a series of smaller events for your friends and acquaintances, or meet with members of the press to talk about Alpha-1 and early detection. The volume of such initiatives is completely up to you since you know your community better than anyone else. You decide what works best for you and for your community. Remember, you do have the Alpha-1 Foundation staff available to provide you with materials, support and guidance.

HOW OFTEN DO I NEED TO IMPLEMENT EVENTS OR OBTAIN PUBLICITY?

You decide how much you can do. We are just delighted that we can count on you.

RAISING FUNDS

Volunteers and friends play a huge role in raising revenue to support the mission and programs of the Alpha-1 Foundation. Committed individuals who serve as volunteers have a direct impact on the programs and services the Alpha-1 Foundation provides to the Alpha-1 community.

You can take action and raise money by becoming involved in **fundraising efforts**, which include **special event planning, letter writing campaigns** and **potential donor introductions**.

Learn how you can help by reviewing the following pages, which outline a variety of fundraising opportunities. For more information, please contact Angela McBride, *Director of Corporate Relations & Community Engagement*, at (877) 228-7321, Ext. 233 or via e-mail at amcbride@alpha1.org

ORGANIZING A SPECIAL EVENT

If you are interested in organizing a special event in your community, the Alpha-1 Foundation can provide valuable insight and guidelines to assist you. Please use the suggestions listed on the next page to help determine what type of event you would like to plan.

Step 1 - Pick a Type of Event

The amount of time you have to commit to this project will help determine what type of special event you are interested in organizing in your area. Be sure to fill-out the application and budget forms, and submit them to the Alpha-1 Foundation in conjunction with the signed special event agreement. Endorsement from the Foundation is necessary in order to proceed with event planning.

Step 2 - Recruit a Committee

You will need to recruit volunteers to help you organize your event. Remember that the number one reason why people participate is because you personally ask them to take an active role. To start, make a list of people that you have helped in the past with their cause by making a donation or volunteering your time for their event. It is also important to recruit committee members that can either help organize the event or can afford to come to your event. For example, if you organize a golf tournament, make sure that you recruit active golfers to help sell your golfing spots.

Step 3 - Determine a Budget

Before you determine the cost to attend your event, go through your expenses. Once you have an idea of your expenses, you can set the cost for people to attend the event or determine the recommended donation amount. Remember that you are organizing the event to make a profit. Participants will want to know how much of the ticket price will be given to the Alpha-1 Foundation. You will need to set your prices accordingly in order to benefit both the participant and the Alpha-1 Foundation.

Step 4 - Use the Alpha-1 Foundation as a Resource

Remember that the Alpha-1 Foundation staff is available to help you meet your fund-raising goals. We can help you brainstorm, provide suggestions and put you in touch with volunteers who have organized a similar event.

SELECTING AN EVENT:

Below is a list of events that volunteers throughout the country have organized or participated in on behalf of the Alpha-1 Foundation. If you are interested in organizing a special event in your community, please review the following event menu for some ideas.

- **Garage Sale** – These events can generate anywhere from \$200 to \$5,000 with a relatively low expense ratio. Encourage your neighborhood, school or community to donate items and volunteer to staff the sale.
- **Golf Tournament** – Golfers enjoy participating in tournaments to benefit a charity because often these tournaments are held on private courses that a golfer may not have access to on a regular basis.
- **Themed Dinner** – This can be an elegant black-tie affair, an evening with a comedian or held in conjunction with a holiday (St. Patrick's Day, Valentine's Day, Halloween, etc.). Dinners also provide an opportunity to raise additional funds through a live and/or silent auction. Charity dinners can easily raise anywhere from \$10,000 to \$100,000 based on the market you want to target.
- **Walk-A-Thon** – Participate in a local Marathon! This is a great way to motivate a community and generate funds for the Alpha-1 Foundation. The key to a successful walk is RECRUITMENT, RECRUITMENT, and RECRUITMENT! **Step Forward for Alpha-1**, under the guidance of the Alpha-1 Foundation, can provide you with simple strategies to ensure that your walk/run is a successful fundraiser.
- The above event list provides various fund-raising vehicles that you can organize locally to raise revenue for the Alpha-1 Foundation. Please keep in mind that many other opportunities are available based on your interests and contacts. The Foundation staff can make available to you guides on how to maximize your efforts for any of the above options.

Just remember, ask and you shall receive!

Below are three important and simple rules to remember about asking for a donation for a good cause.

- **The #1 reason people give to a charity is because they are asked!** Give others the opportunity to support you in your fundraising efforts. Your friends, family members and co-workers will be glad you asked them to help.
- **Ask people who have asked you to buy an item or make a donation to their cause in the past.** Who sold you Girl Scout cookies, Kiwanis peanuts,

magazines, etc.? Did you make a donation to your neighbor's fundraising drive or sponsor someone in a walk?

- **Contact businesses that you frequent.** Ask your drycleaner, doctor, hair salon, lawn service or plumber. Look in your checkbook to see who you pay on a regular basis and ask for a donation.

GUIDELINES

The information provided below explains the role the Alpha-1 Foundation will play in assisting you with your fundraising event. It outlines legal information and financial obligations regarding fundraising for the benefit of the Alpha-1 Foundation and is designed to give credibility to all fundraisers:

1. The Alpha-1 Foundation must be made aware of all fundraisers and fundraising events.
2. The Alpha-1 Foundation believes that a reasonable percentage of the gross revenues from all fundraising events should be directed to the organization's mission. Therefore, a third-party that organizes an event to benefit the Alpha-1 Foundation is required to keep expenses to 25% of gross revenue.
3. All events held at a specific location require the necessary permits, and insurance will be required. To obtain the appropriate insurance, the Foundation requires at least 4 weeks notice.
4. In the case of a sporting event, a signed waiver/release from all participants is required. The Foundation can provide you with the appropriate waiver for your event.
5. If an item is sold as a fundraiser for the Alpha-1 Foundation, the item to be sold must be non-controversial in nature. The public must be told the specific amount from the sale of each item that goes to the Alpha-1 Foundation, which is considered a donation to the Foundation.
6. Permission must be obtained from the Alpha-1 Foundation to use its name and logo, and strict reproduction guidelines must be followed.
7. All promotional materials related to an event benefiting the Alpha-1 Foundation must be reviewed and approved by the Alpha-1 Foundation prior to its production and distribution. This includes, but is not limited to, invitations, press releases, newspapers articles, etc.
8. The Alpha-1 Foundation must be informed of any effort to recruit financial underwriters or sponsors in order to ensure that there is no duplication of efforts.
9. The Alpha-1 Foundation is not able to handle any of the administrative aspects of an event. It does not have the manpower to handle the administrative tasks like invitation distribution, compiling RSVPs or selling tickets.
10. Organizers of the event are responsible for complying with all IRS regulations regarding the event. IRS regulations are quite specific and are provided for your review.
11. Organizers of the event should provide publicity for this promotion and commit the necessary funds from its advertising budget.
12. All proceeds are required within 10 days after the conclusion of the special event or promotion. **All checks must be made to the Alpha-1 Foundation**

and sent overnight with a tracking record to the Alpha-1 Foundation, 3300 Ponce de Leon Blvd, Coral Gables, Florida 33134 ATTN: DEVELOPMENT

All disbursements (payment of expenses) are made through headquarters in Miami when check requests are received. Check requests must fall within the approved budget parameters. The requests should be sent to the Development Administrator through fax (305-567-1317) or email (amcbride@alpha1.org) who will review them against the budget submitted with the planning form.

PLEASE PROVIDE AT LEAST TWO WEEKS NOTICE FOR CHECK REQUESTS.

13. For acknowledgement purposes, be sure to provide an excel sheet with the names, addresses and amount of donation to:

Community Outreach
Alpha-1 Foundation
3300 Ponce de Leon Blvd,
Coral Gables, Florida 33134
Or send via email to:amcbride@alpha1.org

Sample Event Application

SPECIAL EVENTS AND PROMOTIONS TO BENEFIT THE ALPHA-1 FOUNDATION

Date of Application: June 23, 2006

Organizer:

Name: John Doe
Address: _____
City, State, Zip: _____
Daytime Phone: _____
Fax: _____
Email: _____

Event Description: Labor Day Dinner - Dance

Money Generated Through: Sponsorships, Ticket Sales,
Silent Auction, and Raffle

Date(s): Saturday, September 2, 2006
Rain Date(s): _____
Hours: _____
Location: Doral Community Center

Budget Information (Refer to attached worksheet):

Projected Revenue: \$24,500.00
Projected Costs: \$ 6,048.00
Projected Donation: \$18,452.00

Publicity/Promotion (List all areas, ie., brochures, interviews, ads, etc.):

Press releases, articles in Community
newspapers, Radio

Please send completed form to the:

Alpha-1 Foundation
C/O Community Outreach
3300 Ponce de Leon Blvd
Coral Gables, Florida 33134

Approved by: _____

*(Please **Do Not** detach these sheets from the manual. You will need them for future reference. Instead, photocopy these pages and then fill out and return to the Foundation.)*

Building Friends for a Cure! Event Application

SPECIAL EVENTS AND PROMOTIONS TO BENEFIT ALPHA-1 RESEARCH

Date of Application: _____

Organizer:

Name: _____
Address: _____
City, State, Zip: _____
Daytime Phone: _____
Fax: _____
Email: _____

Event Description: _____

Money Generated Through: _____

Date(s): _____
Rain Date(s): _____
Hours: _____
Location: _____

Budget Information (Refer to attached worksheet):
Projected Revenue: _____
Projected Costs: _____
Projected Donation: _____

Publicity/Promotion (List all areas, ie., brochures, interviews, ads, etc.):

Please send completed form to the:
Alpha-1 Foundation
C/O Community Outreach
3300 Ponce de Leon Blvd
Coral Gables, Florida 33134

Event Organizer Signature: _____

Approved by: _____

Sample Event Budget Worksheet

Submitted by: <u>John Doe</u>	Event Date: <u>September 2, 2006</u>
Host City & State: <u>New York, NY</u>	Event Net Goal: <u>\$18,452.00</u>

Sponsorships	Name	Revenue
Title	<u>Local Car Dealer</u>	\$ <u>5,000.00</u>
Presenting	_____	\$ _____
Other	_____	\$ _____

Individual Tickets	<u>200</u> @ \$ <u>50.00</u> <i>Number of per \$ amount</i>	\$ <u>10,000.00</u>
---------------------------	--	---------------------

Tables	_____ @ \$ _____ <i>Number of per \$ amount</i>	\$ _____
---------------	--	----------

Profit Centers	Revenue
Ad Book	\$ _____
Live Auction	\$ _____
Silent Auction	\$ <u>5,000.00</u>
Raffle	\$ <u>2,000.00</u>
Contributions	\$ <u>2,500.00</u>
Other (Explain: _____)	\$ _____

TOTAL REVENUE:	\$ 24,500.00
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Inducement Information	Total Cost	Cost Per Person
Food/Drinks	\$ <u>4,000.00</u>	\$ <u>20.00</u>
Decorations	\$ <u>400.00</u>	\$ <u>2.00</u>
Venue Costs	\$ <u>300.00</u>	\$ <u>1.50</u>
Entertainment	\$ <u>500.00</u>	\$ <u>2.50</u>
Tax/License Fee	\$ <u>200.00</u>	\$ <u>1.00</u>
Other	\$ _____	\$ _____
TOTAL INDUCEMENTS:	\$ <u>5,400.00</u>	

Total Inducement Cost Per Person	\$ <u>27.00</u>
<i>(An inducement cost is a benefit received by a participant. To calculate the tax-deductible portion of a ticket, deduct the inducement cost from the total participation fee.)</i>	

Expense Information	Total Cost
Printing	\$ <u>400.00</u>
Postage	\$ <u>148.00</u>
Signage	\$ <u>100.00</u>
Other (Explain: _____)	\$ _____

Total Expenses	\$ <u>648.00</u>
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Total Costs (Inducements + Expenses)	\$ <u>6,048.00</u>
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Total Net Revenue	\$ <u>18,452.00</u>
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Building Friends for a Cure! Event Budget Worksheet

Submitted by: _____	Event Date: _____
Host City & State: _____	Event Net Goal: _____

Sponsorships	Name	Revenue
Title	_____	\$ _____
Presenting	_____	\$ _____
Other	_____	\$ _____

Individual Tickets	_____ @\$ _____ <i>Number of per \$ amount</i>	\$ _____
---------------------------	---	----------

Tables	_____ @\$ _____ <i>Number of per \$ amount</i>	\$ _____
---------------	---	----------

Profit Centers	Revenue
Ad Book	\$ _____
Live Auction	\$ _____
Silent Auction	\$ _____
Raffle	\$ _____
Contributions	\$ _____
Other (Explain: _____)	\$ _____

TOTAL REVENUE:	\$ _____
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Inducement Information	Total Cost	Cost Per Person
Food/Drinks	\$ _____	\$ _____
Decorations	\$ _____	\$ _____
Venue Costs	\$ _____	\$ _____
Entertainment	\$ _____	\$ _____
Tax/License Fee	\$ _____	\$ _____
Other	\$ _____	\$ _____
TOTAL INDUCEMENTS:	\$ _____	

Total Inducement Cost Per Person	\$ _____
<i>(An inducement cost is a benefit received by a participant. To calculate the tax-deductible portion of a ticket, deduct the inducement cost from the total participation fee.)</i>	

Expense Information	Total Cost
Printing	\$ _____
Postage	\$ _____
Signage	\$ _____
Other (Explain: _____)	\$ _____

Total Expenses	\$ _____
----------------	----------

Total Costs (Inducements + Expenses)	\$ _____
--------------------------------------	----------

Total Net Revenue	\$ _____
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Event Checklist – Building Friends for a Cure!

The following is a general list of things you may need for your event. While you go through your list think about which of these line items will incur expenses and which items you may be able to get underwritten.

Event Name	
Event Date	
Type of Event	
Start & End Time	
Location	
Venue	<input type="checkbox"/> Yes <input type="checkbox"/> No
Confirmed	

Room Arrangement

- | | | |
|---|--|---|
| <input type="checkbox"/> Conference | <input type="checkbox"/> Lecture | <input type="checkbox"/> Lectern |
| <input type="checkbox"/> Schoolroom | <input type="checkbox"/> Perimeter Seating | <input type="checkbox"/> Riser |
| <input type="checkbox"/> Herringbone | <input type="checkbox"/> Rounds of 6,8,10 | <input type="checkbox"/> Ropes/stanchions |
| <input type="checkbox"/> Hollow Square; U-Shape | <input type="checkbox"/> Head Table | <input type="checkbox"/> Tent |

Other Equipment

- | | | |
|--|--|---|
| <input type="checkbox"/> Blackboard | <input type="checkbox"/> Literature Table | <input type="checkbox"/> Registration Table |
| <input type="checkbox"/> Coat rack or coat check | <input type="checkbox"/> Message Board | <input type="checkbox"/> Telephone |
| <input type="checkbox"/> Easel | <input type="checkbox"/> Notepads and pencil | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Flip chart/markers | <input type="checkbox"/> Pointer | _____ |

Participants

- | | |
|--|---|
| <input type="checkbox"/> Invite List (A&B) | <input type="checkbox"/> Overnight accommodations |
| <input type="checkbox"/> Speakers | <input type="checkbox"/> Travel accommodations |
| <input type="checkbox"/> Panelists | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> VIPs | _____ |

Entertainment

- | | |
|---|--------------------------------------|
| <input type="checkbox"/> Live Music | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Recorded Music | _____ |

Special Needs

- | | |
|---|--------------------------------------|
| <input type="checkbox"/> Interpreter | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Wheelchair access | _____ |
| <input type="checkbox"/> Dietary restrictions | _____ |

Media Relations and Publicity

- | | |
|---|--|
| <input type="checkbox"/> Advertising | <input type="checkbox"/> Calendar alerts |
| <input type="checkbox"/> Media List | <input type="checkbox"/> Press room |
| <input type="checkbox"/> Photography | <input type="checkbox"/> Thank you letters |
| <input type="checkbox"/> Invoices | <input type="checkbox"/> Evaluation |
| <input type="checkbox"/> Press release(s) | <input type="checkbox"/> Other _____ |

Invitations, Letters, Programs

Save the Date Reminder

- Design Printing

Invitation, reply cards, envelopes

- Design Printing Calligraphy
 Labels Postage RSVP contact

Letters

- Compose Envelopes Letterhead
 Authorized signatures
 Postage RSVP Contact

Program

- Design Printing Distribute at event

Notes: _____

Other Printed Items

- Place cards Flyer
 Tent cards Tickets
 Seating chart Posters
 Labels Other: _____

Food & Beverages

Type of Meal

- Coffee break Breakfast Lunch Dinner Reception

Beverages

- Alcohol permit Bartender

Service

- Buffet Preset Served Other

Décor and Signage

- Balloons Banners Candles Directional Signs Centerpieces
 Flowers/Plants Lectern sign Meeting Kit (Office Supplies) Flag

Housekeeping

- Meeting and restrooms Grounds Clean-up crew
 Other: _____

Transportation

- Buses Valet Parking Security First-aid stations
 Other: _____

Recognition/Gift Items

- Awards Certificates Plaques Trophies
 Other: _____

Special Notes

Alpha -1 Foundation Check Request

**Alpha-1 Foundation
3300 Ponce de Leon Blvd
Coral Gables, Florida 33134**

**Building Friends For A Cure
Request for Check**

Date Submitted: ___/___/___

Date Required: ___/___/___

Payee: _____

Address: _____

Amount: \$ _____

Name of Event: _____

Charge to (Internal Use Only): _____

Check Number: _____

Check Date: _____

Date Mailed: _____

Requested By: _____ Approved By: _____

Email Address: _____

*Attach invoice or copy of Alpha-1 Foundation-approved contract.

*Confirmation of payment to vendor will be sent to person requesting check via email.

SPECIAL EVENT AGREEMENT

As a volunteer organizing an event to benefit the Alpha-1 Foundation, you will receive the following support:

- Use of the Alpha-1 Foundation's name. The name should appear as follows: "to benefit the Alpha-1 Foundation."
- A letter from the IRS with the Alpha-1 Foundation's federal tax identification number.
- The Alpha-1 Foundation will ask contacts in your region, state or city whether they want to help you with your efforts. Please note the list of constituents that will be provided have expressed an interest in helping you. Their names are provided for the sole purpose of Alpha-1 Foundation mailings and should not be shared with vendors or other organizations.
- Liability insurance coverage up to \$1 million for participants, volunteers and event location.
- Payment of approved event expenses. Prior to planning your event, the Alpha-1 Foundation requests that you submit a fundraising budget, which reflects the gross amount you plan to raise, expected expenses, and the expected net income of your event. We request that the cost of an event not exceed 25% of the gross income. An Alpha-1 Foundation person can work with you to determine an acceptable expense ratio for your event.
- A Community Outreach staff person will be assigned to serve as your main contact for the organization. The Alpha-1 Foundation has professional fundraisers on staff to advise you.

In order to receive the following support, the Alpha-1 Foundation requests that volunteers comply with the items listed below. It is important that volunteers comply with our policies as they protect the Foundation's corporate identity and reputation, ensure that it is in compliance with the IRS regulations and disclosure requirements, and assure that the Foundation is above reproach when looked upon by organizations such as the Better Business Bureau.

- Do NOT solicit donors listed in the Foundation's annual report by sending them a letter to financially support your event with a contribution or in-kind donation.
- The Alpha-1 Foundation's name must always be spelled-out. Please do not refer to the organization using the A1F abbreviation.
- Checks must be made payable to the Alpha-1 Foundation.
- The Alpha-1 Foundation accepts all major credit cards (AMEX, MasterCard, Visa and Discover). Staff can process the charges if you return the original signed form or copies of the signed form (RSVP card, flyer, etc.) directly to the Foundation. Each person's name, address, telephone number, credit card number, expiration date, signature and CVC code are needed in order to process the charge. All charges should be sent to the Alpha-1 Foundation in a timely manner so that the donor does not dispute the charge.
- Please refrain from using the Alpha-1 Foundation logo as graphic standards and identifiers may complicate your printing process. Simply use the name in
- full.

The following disclosure requirements are mandated: The IRS presumes that donations are not tax-deductible – the IRS requires taxpayers to prove that the amount they pay exceeds the fair market value of the food, entertainment, merchandise, or other goods and/or services that the donor receives. You should NOT state in the solicitation materials, catalogs, or tickets that the donor's payment is tax-deductible if the donor is receiving something of value in exchange for the contribution. The IRS is clamping down on organizations that do not follow disclosure requirements – A law enacted by Congress in 1993 establishes strict rules governing the sale of tickets for special events, the sale of auction items, and other situations where the donor is receiving something of value in return for his/her donation. **VIOLATIONS:** The penalties for violating these requirements can be severe. A charity may be assessed a penalty of \$10 per contribution, up to a maximum of \$5,000 per fundraising event.

- **Event Invitations:** When printing event invitations or any related materials where the price of the event is included state that “only a portion of the total price of this event is tax-deductible.” The Alpha-1 Foundation discloses on a printed acknowledgement what the donor receives. The donor is expected to keep this for his/her tax records. Prior to final printing of the invitation, it must be approved by a member of the Building Friends For A Cure Team. Please allow plenty of time for approval in case changes need to be made. A copy of the final invitation needs to be sent to the Alpha-1 Foundation for the general files.
- **Determining Inducement Costs:** If the costs of the food, entertainment, merchandise or other goods or services are equal to or greater than the cost of the ticket or amount of the contribution, then no portion of the contribution is deductible. If this is the case, you should state on the ticket, catalog, or other solicitation materials that the ticket price and/or donation is NOT tax-deductible. Inducement Costs are the retail value of the good or services to the donors. It is not the wholesale value or wholesale costs, nor is it affected by whether or not the charity received any of the goods or services as donations. The charity must provide the donor with a “good faith estimate” of the inducement costs of the goods or services, which were provided. The Alpha-1 Foundation will keep records of how the inducement costs were determined, and will issue an acknowledgment to the donor.
- **Program Books:** If you sell acknowledgments to individuals or corporations, the IRS requires that the acknowledgment NOT sell a service or item. For tax-deductibility, the individual or corporation may list their name and a congratulatory message. For example: *(Name of Company) salutes the Alpha-1 Foundation on its ongoing commitment to Alphas in (Name of City) and congratulates (your name) on a successful event.*
- **Deductibility and Charitable Auctions:** Regulations also clarify the legal procedures for charitable auctions. The regulations make clear that the charity must make a good faith estimate of the retail value of the items to be auctioned. Successful bidders must then be told that only the portion of their payment that exceeds the retail value is deductible as a charitable contribution. *Note: The Foundation recommends that you use bid contracts during your auction which lists the items, fair market value and winning bid. The donor signs the contract and provides payment at the event. He/She may use the contract as a receipt.*
- **No Deductibility of Raffle Tickets:** Payments for raffle tickets, lottery tickets, or door prize tickets are not tax-deductible.

- **When the Donor Refuses Items of Value at the Time of Contribution:**
The donor may deduct the full value of the charitable contribution by refusing the goods or services offered. The refusal must take place at the time of the contribution, such that the donor never exercises control over the goods or services. Merely not using the good or services provided is not enough.
- **Receipting:** Volunteers are required to give a receipt to a donor for auction items purchased at an event.
- **Acknowledgements:** The Foundation staff is responsible for handling all donor acknowledgements, which include tax-deductibility information. Volunteers should send personalized "thank you" letters to all participants.

Note that the Alpha-1 Foundation staff can assist you with following the above requirements so that you may focus on organizing your event.

Please initial and sign the following once you have read the Guidelines and Agreement.

_____ I have read and understand that I must comply with the items specified in this Special Events agreement and the Guidelines of the Building Friends for A Cure manual.

Name: _____

Signature: _____

Date: _____

WRITING LETTERS

By participating in a letter-writing campaign, you do not have to organize an event from beginning to end. Instead you can take action and make a difference right from your home. As part of the Foundation's friend-raising efforts, you can join others as they canvass the country with letters to request a donation on behalf of Alphas. Letter-writing campaigns are a fun and easy way to raise funds and awareness about Alpha-1 and are successful because **friends are asking friends to support them in their fundraising efforts**. The time and cost commitment is minimal on your part, but the benefit to the Foundation is remarkable!

Attached is a sample letter asking for support of the Alpha-1 Foundation. We encourage you to personalize yours to make it more relevant to your friends, family and colleagues. Remember that the best fundraising success stories come from people who are personally affected by Alpha-1. Below are some suggestions of content you can include:

- How it has affected you, your family, your friends, etc.
- Include the name of the Alpha-1 Foundation and its support of the Alpha-1 community.
- Your connection to the Foundation – as a volunteer, someone who has called the Foundation for information, etc.
- Ask for the donation. Remind them that the donation is tax-deductible. Let them know a donation form is enclosed for their convenience. This ensures that if they send a donation, you will receive an acknowledgement letter from the Alpha-1 Foundation confirming a donation was made in your name.

The Foundation staff is available to help you customize your letter and they are great editors as well. They are willing to review your letter for accuracy regarding Alpha-1 and the Foundation's mission. The Foundation will provide you with gift-giving envelopes for you to include with your letter.

Remember, your contact network may include friends, family, fellow parishioners, former and current colleagues and social groups. Before you start, be sure to make a list of contacts and addresses so that you can track how many people are being sent your letter. Work with the Foundation staff to measure your success rate.

Commemorative Gifts Program

You have little time but truly want to help! Our Commemorative Gifts Program provides a uniquely personal and deeply meaningful gift to create a lasting tribute to a friend or loved one. A Gift from the Heart can be given to celebrate a special person or occasion or memorialize someone special. Commemorative Gift Packages can be strategically placed in areas where people can pick them up or you can make a presentation to a group and ask them to contribute.

Sample Letter

Hi Everyone,

I just want let you know that I am participating in a national fundraiser for the Alpha-1 Foundation. As you may already know, I have a personal connection with Alpha-1 Antitrypsin Deficiency as I was born with it. Chances are most of you have heard me talk about it a time or two and how it has affected my life since I was diagnosed.

Alpha-1 Antitrypsin Deficiency, commonly referred to as Alpha-1, is one of the most common serious hereditary disorders in the world. A very low blood level of the protein alpha-1 antitrypsin, which normally is produced by the liver, characterizes the disease. One of the most important functions of this protein is to reach the lungs through the blood and protect them against harmful substances. In Alpha-1, a genetic defect impedes the liver from releasing the protein to the blood, leaving the lungs unprotected against smoking, pollution, infections or other dangerous inhaled substances. This is why people like me develop progressive lung destruction, typically manifested by shortness of breath, chronic cough and wheezing. The lung disease from Alpha-1 can result in disability and early death among affected persons, and is a major reason for lung transplantation.

Alpha-1 has affected me by dramatically slowing me down. Every task is made difficult and I tire so easily. Just going up and down the stairs is exhausting and it feels as I have walked a 5K marathon. I depend on oxygen a huge part of the time, vacationing is virtually impossible as there are still very tight rules and high fees related to air-travel with oxygen, and once a week I must I receive an infusion of human alpha-1 antitrypsin protein in my blood to help me manage the disease just a little longer.

At present, there is not a cure for Alpha-1 and on a daily basis I wonder what the future holds for me. Yet, my hopes are raised thanks to the scientific breakthroughs and advances made thanks to a wonderful organization, the Alpha-1 Foundation. The Foundation has not only been a great source of information for those of us affected but also has provided research grants, community education, detection initiatives and consumer advocacy across the country.

I'm sending you this letter not only to inform you about Alpha-1, but also to ask you to consider donating to the Alpha-1 Foundation now. Keep in mind that your donation is tax-deductible and that it certainly has an impact on helping the Alpha-1 Foundation find a cure for Alpha-1 Antitrypsin Deficiency.

If you wish, you can donate safely and securely online by visiting www.alpha1.org and click on the DONATE icon. Or, you can return the enclosed envelope with a check made to the Alpha-1 Foundation. Every little bit helps, whether it's \$10 or \$100.

I thank you for this opportunity to explain to you a little more about Alpha-1 and how it affects me. I also thank you for your support and ask for your prayers for my continued good health.

Thanks and warm wishes,

(Your name)

GETTING READY TO MAKE THE "ASK"

Here is some information on the basics of fundraising and techniques for becoming a top fundraiser. Even if you're a veteran, you're sure to find some new ideas. You can choose the one most comfortable for you, or use a combination of ideas. Whichever method you pick, don't delay putting it into practice. The sooner you start, the sooner you'll see your donations start to climb.

FACE-TO-FACE

Asking a potential donor face-to-face is the best way to raise money. We all know that it can be difficult to overcome your fear of how it feels to ask someone for a contribution. You may fear rejection or feel embarrassed and nervous. It is important to be confident when asking donors for support. Make sure to be fully prepared and the face-to-face request will be a breeze. Use the following topics and sources of information to build your confidence about asking a prospect to contribute to the Alpha-1 Foundation.

- **Remember you are not asking for the contribution for yourself; you are asking on behalf of the Alpha-1 Foundation.** Don't feel guilty or greedy, you are being generous! Your image will only be heightened because you are working for a good cause.
- **Educate your potential sponsor** so that they feel more comfortable about making a contribution.
- **Treat your request as an everyday conversation.** Don't start by apologizing! There is value in what you are saying. Build your request around your excitement and enthusiasm for participating in a special event that will help find a cure for Alpha-1. Share stories about why the event is important to you.
- Finally, **make the appeal personal.** Ultimately, your friends, family and co-workers will support you because you are doing the asking. And, don't forget about the times you have helped others by making a contribution or participating in an event for their cause. They will be happy to return the favor because you supported them in the past.

OVER THE PHONE

The telephone is an effective and direct way to reach out to your prospective donors, particularly those you do not see daily. Here are eight easy steps to raising donations over the phone:

- **Develop your list.** Determine who needs to hear your voice. Some of your friends and business contacts may be better suited to a letter requesting their support, but some need the personal approach.
- **Pick the best time to call.** Build a plan of who you will call and when – business contacts and vendors should be called during the day; family members and friends on evenings and weekends. Avoid the dinner hour and late-night calls.

- **Know what you're asking for before you ask.** Figure out ahead of time what you are going to request from your donor. Do you want them to purchase a ticket to the event, corporate table, donate an auction item? Be sure to start with the biggest ask then go down your list of other donor opportunities.
- **Go for it!** Once you make the call, explain that you have made a personal commitment to support the Alpha-1 Foundation. Here's the key statement, "I need your help to accomplish this. Will you make a donation or participate in the event?"
- **Silence is not a "no."** Don't feel like you have to ramble, fill in pauses or change the request or donation amount. They will respond when they have considered the contribution.
- **Thank them!** Regardless of the outcome of your call, thank them for their time, consideration and support. If you find someone that would like to help, but is unable to sponsor you, invite him or her to volunteer at your event.
- **Follow up with a written thank-you and return envelope.** This is a critical step to fulfilling your goal and keeping your donors satisfied. Personalize a thank-you letter with their name and the amount of the donation or type of support they agreed to on the phone. If they said "yes", but didn't say an amount, thank them for their generosity and let them know you appreciate whatever they are able to contribute. Including a return envelope will make fulfilling their donation very easy. Sponsors can make their tax-deductible checks payable to the Alpha-1 Foundation.
- **Have fun!** If you sound excited about your cause, it will be contagious!

SUCCESS TIPS

Once you've got the basics down, add your own ideas to really personalize your effort. Helpful topics and proven examples from a fund-raising expert are listed below.

What you can do:

- Start with easy targets – family and friends. Practice your techniques and build your confidence with a few trial runs. Then, go after the bigger marks.
- Where do you spend your money? Ask the manager of a local gas station, grocery store, coffee shop, hair salon, dry cleaner or restaurant to make a donation in return for your faithful patronage.
- Take advantage of peer pressure. Approach people in a group setting. Make a quick appeal before a business meeting, at a party or in the break room at lunch. Ask people to donate what they would spend on incidentals like movies, snack food, cocktails or dry cleaning for a week.
- Don't forget to contact people who have asked for your support in the past. They will be happy to support you in your fund-raising efforts.
- Keep your information (i.e. invitation, brochure, flyer) with you **ALWAYS!** You never know when you'll run into a potential sponsor, donor or volunteer. When you do, you'll be able to provide them with immediate information rather than a promise.
- Remember to use matching gifts. Many companies match their employee's donations to nonprofit organizations. If a donor's company is among them, they can double or triple donation dollars. Suggest to everyone that they speak to the Human Resources Departments.

Participant Mail-In Donation Form

Please complete this form and mail your collected donations to the address below (Please print clearly):

Name: _____

Address: _____

City/State/Zip: _____

Name of Fundraiser: _____

Home Phone: _____ Work Phone: _____

of checks in this package: _____ Total donations in this package: \$ _____

Are you expecting to receive any more donations? Yes _____ No _____

If yes, please indicate how much more money you plan to turn in: \$ _____

Please mail this form along with donations to:

Alpha-1 Foundation
3300 Ponce de Leon Blvd
Coral Gables, Florida 33134
ATT: Development

- Please include a list of in-kind donors that you would like the Alpha-1 Foundation to also acknowledge. Be sure to include name and address for each contact person and a description of their involvement in your event.

MANAGING OUTREACH & AWARENESS

The Alpha-1 Foundation depends on you to educate your community about Alpha-1 Antitrypsin Deficiency. Whether distributing information to a medical professional or talking with your congressional representative about important legislation that will direct funds to Alpha-1 research, you make a difference.

The Foundation is focusing outreach and awareness on:

- Local Awareness Campaigns
- Local Government Advocacy
- Outreach to the Media (see section on **Getting Publicity**)

Local Awareness Campaign:

Ask your local civic and community groups (Kiwanis, Jaycees, Rotary Clubs, etc.) to let you speak at one of their monthly meetings. The Foundation staff will be happy to provide you with some key statements and a power point presentation. In addition, you should distribute information packages at all these meetings; just be sure to ask the Foundation to mail you packages at least two weeks in advance.

Local Government Advocacy:

The Alpha-1 Foundation monitors issues of interest for the Alpha-1 community and takes action on a national basis. It is imperative that you assist the Foundation in communicating such information to your local government. The Foundation staff will be happy to provide you with sample letters and collateral materials when needed.

Outreach to the Media:

As Alphas you have stories to tell. By sharing your personal experiences with members of the press, you are not only helping to raise mass awareness, you are also helping others get information on the value of early detection. Remember, no one can speak of the challenges of living with Alpha-1 better than you can.

GETTING PUBLICITY

Once you have decided to pursue a media story, you should learn the basics of media relations. If you need help from the professionals, contact the Communications Manager for the Alpha-1 Foundation, at (877) 228-7321, ext. 273.

These are some of the most common questions asked about the art of media relations. They may help you as you contact editors and reporters in your hometown:

IS SOLICITING PUBLICITY OR MEDIA COVERAGE BEST LEFT TO THE PROFESSIONALS?

Professionals definitely have a role in helping with publicity through press releases, media strategy and organized pitches. However, you have a compelling story the professionals cannot match, if you are willing to share it.

WHY WOULD THE MEDIA LISTEN TO ME?

Journalists love a good "people" story, especially a story about a local person.

BUT THE MEDIA IS SO BIG AND I DON'T KNOW IF ...

Approaching the media can be intimidating but remember they are people too, and they are always looking for good human-interest stories. If you get brushed off, don't take it personally and try again. Realize that editors receive an overwhelming number of phone calls and the response, in many cases, will depend on whether you are calling at the right time.

WHICH MEDIA ORGANIZATION SHOULD I APPROACH?

There is no hard and fast rule. Local and community newspapers as well as television and radio stations are good places to begin for local human-interest stories. Before you make your pitch, it's a good idea to find out who the editor, health reporter or assignment editor is so you can write or ask to speak directly to them. When in doubt, start small: try your local community weekly newspaper. The staff is likely to be receptive, and this will help build your confidence.

WHY NOW? WHY NOT WAIT?

Every day another person is diagnosed with Alpha-1 Antitrypsin Deficiency, beginning the lifelong quest of understanding and fighting Alpha-1. Promoting awareness today will connect individuals and their families with the organizations that will help them on this journey. They will be able to access information, education and support. Awareness also can help raise funds that will bring us one step closer to fulfilling the common mission of finding a cure for Alpha-1 while improving the life of those affected with it.

HOW DO I GET STARTED?

Contact the Communications Manager at the Alpha-1 Foundation at (877) 228-7321, ext. 273 today. You'll get answers to any questions you may have.

WHAT CAN I DO IF THEY ASK ME FOR INFORMATION I DO NOT KNOW?

Because the Alpha-1 Association and the Foundation are the only national organizations of their kind helping people with Alpha-1, they are good references for press wanting additional quotes or information. Staff members of both organizations can answer the more difficult questions. In addition, both the Alpha-1 Foundation and the Alpha-1 Association truly appreciate the coverage, as it is another step in educating people about the help that they can receive.

BUILDING A MEDIA LIST

Where do you send a press release and to whom to do you send it? An up-to-date list of your local media with the right contact person can be helpful when you begin any outreach to the media.

Here are some suggestions for building a media list:

FOLLOW THE MEDIA

Read your local newspaper and watch news broadcasts that cover health-related issues. Take note of who wrote the article or reported on the news and add these reporters to your list.

CONTACT YOUR LOCAL MEDIA

Call your newspapers, radio and TV stations and ask for the appropriate contact person, address, phone, fax and email information. You will want to know who covers health, medicine, or other pertinent topics. Your list should include reporters as well as editors.

SHARE A LIST

Ask public relations and news media professionals to help you with your media list. You can also ask other groups in your community to share their lists and experiences. Once people know the reason for your interest, they will most likely help you.

RESEARCH MEDIA DIRECTORIES

Conduct a search on the Internet. You may want to look under "media in (your hometown)." The library will often have a copy of resources such as Burrelle's Media Directories, Bacon's Media Directories, and News Media Yellow Book, among others.

PROVIDE SIGN-IN SHEETS

When you have an awareness event or a fundraiser that attracts the media, have the media sign-in when they attend. Now you have their names on file for future usage.

ASK THE MEDIA TO FILL OUT A "FAX BACK"

Consider sending out a form for the media to complete their contact information. This is also a good way to receive requests from the media for more information.

NOTE: Developing a media list takes time and it should be updated periodically. You will have better results in your outreach to media if you have a good up-to-date list to start.

PITCHING A STORY TO THE PRESS

The news media are in constant search for story ideas. Each media outlet must fill their print space or airtime every day and operate under tight deadlines. You are the resource on Alpha-1 and your story may be just what they need. Following these tips will help improve your chances of getting Alpha-1 covered by the media:

ESTABLISH A RELATIONSHIP WITH JOURNALISTS

Find out who the media are in your area and which ones report on medical/health or lifestyle issues. Follow their column or show. Offer yourself as a resource for the media. Don't be afraid or timid. Remember, journalists need your ideas. To get your foot in the door, you may want to call them first and let them know that you will be sending them some time-sensitive materials on Alpha-1. Now you have connected the Alpha-1 issue with a name and face. You have become a resource for the journalist.

PRESENT YOUR ISSUE IN A NEWSWORTHY WAY

Try to match up your activities with the most appropriate media. If you have a good visual story, you may want to contact your local TV station. You can enhance your chances of being picked up by the local media by the way you present your event. Make it interesting and exciting; something new.

BE PERSISTENT

Contact journalists throughout the year with information on newsworthy items. This can be in the form of a press release or a follow-up phone call. Just remember that if the journalist does not run your story now, it does not mean that they never will.

KEEP YOUR PITCHES SHORT

Get to the point quickly with any contact you may have with the media. Know your key messages to share with the media before you contact them.

SET A TIMEFRAME

There are certain times when your story may be more relevant. If there is an event being held in your hometown, if a hospital is holding a health fair, or if a national awareness month or day has been proclaimed. The more time we give a reporter to plan, the better. Try to get a press release out at least two weeks before you would like to have your news covered. This will give you enough time to follow up.

WRITING A PRESS RELEASE

Press releases are a powerful tool to get your message out to the media, whether it's general Alpha-1 awareness efforts or to promote a specific event. But there is a certain way to draft a press release and certain items that the media expect to see in a press release.

Overall, the press release is like a pyramid with the quick summary points first and more information following in the order of importance.

FORMATTING

- Keep the release to one page.
- Use 8 ½ x 11 white paper.
- Leave margins of at least 1" on each side of the page.
- Address the release envelope to a specific person by name.
- Give contact name, company or organization name, and telephone number so you can be easily reached for further information. Make sure you list a person who is easily accessible.
- Keep your release to about 5 short paragraphs. The media will call you if they need more information.

HEADLINE

- Give a descriptive phrase that gives the reader a quick summary of the release.

FIRST PARAGRAPH

- Give the key facts about your news. This is where you have to grab the reporter's attention!
- Give the "who, what, why, when, where, and how."

SECOND AND THIRD PARAGRAPHS

- Include important information that expands on your news.
- Include more background facts and figures.
- Include a quote; personal ones always work well.

FOURTH AND FIFTH PARAGRAPHS

- Expand on any other information relevant to the story.
- Wrap-up with general information on Alpha-1.

ESTABLISH THE END

- Editors and reporters look for a "###" or a "-30-" at the end of the release signifying its end.

Note: There is also a shortened version of a press release called a *media advisory* that is helpful to use a few weeks in advance of your awareness activity. A media advisory is usually just bulleted information on "who, what, why, when, where, and how," followed by your contact information and either a "###" or a "-30-".

PRESS RELEASE SAMPLE

Contact:
Communications Manager
Tel: (305) 567-9888 ext. 273

Miami Lakes resident affected by rare genetic condition holds ice cream fundraiser for a cure

Join your community and support the Alpha-1 Foundation Saturday, Sept. 12 at the “Get the Scoop on Alpha-1” ice cream social. Enjoy an ice cream sundae while learning more about the condition to help promote awareness and raise money for much needed research to find a cure.

Alpha-1 Antitrypsin Deficiency, or Alpha-1, is a genetic condition that is estimated to affect about 1 in every 2,500 Americans. It is a deficiency that results in serious lung disease in adults and/or liver disease at any age. Intravenous treatments that slow down the deterioration of the lungs and liver are available, but currently, there is no cure. Those affected by the condition (“Alphas”) typically require supplemental oxygen, sometimes 24/7, and may eventually need lung or liver transplants.

Insert information about yourself HERE. Consider explaining why you are involved and what finding a cure means to you. Example:

Local resident, Alpha, and host of “Get the Scoop,” Laura Mason was diagnosed in 2008. “It took me four years of chronic bronchitis and inexplicable lung disease to figure out what was wrong with me.” Like many Alphas, Mason had been misdiagnosed with asthma. Finally in 2008, a blood test confirmed she had Alpha-1.

“The Alpha-1 community is working diligently to raise awareness and find a cure. This ice cream social is my small part in helping us get there,” says Mason.

The event will be held at the Miami Lakes Community Center, 2358 NW 86th St., Miami Lakes, FL 33014. Anyone is welcome to come and create their perfect Haagen Dazs ice cream sundae with a \$10 donation at the entrance. Raffle tickets will also be sold for a donation of \$2.

###

About the Alpha-1 Foundation:

The mission of the Alpha-1 Foundation is to provide the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency. For more information, please visit: www.alpha1.org.

CONDUCTING INTERVIEWS

The media tend to like stories that are local and are relevant to the community. So it is important to present your personal story.

Here are some general tips that are applicable to any media interview:

- Always return reporters' calls immediately.
- Do your homework. Know where your facts come from – Alpha-1 Foundation, etc.
- Anticipate hostile or difficult questions and rehearse your answers.
- Don't get put on the defensive; never speak "off the record".
- Pick three or four points you want to get across and practice working on them (see **INFORMATION YOU CAN USE**).
- Try to speak in layman's terms or offer a brief explanation of terminology.
- Respect deadlines. Ask what their deadline is. Reporters often need to arrange an interview within a few days, so try to be flexible.

For *print* interviews:

- Expect quotes to be edited. Even if the reporter writes your whole quote, his or her editor may cut it down due to space limitations.
- Ask for clarification of a question if you need it.
- Always avoid the phrase "no comment". If you are not aware of something or do not know the answer to a particular question, just be honest. Tell them where they can get the information – Alpha-1 Foundation, a physician, etc.

For *radio* interviews:

- Rehearse what you will speak about. During the interview take a few moments to think before you speak.
- Do not fill the dead air with "ums" and "wells" and don't be afraid of silence.
- Be aware of the microphone, but don't speak directly into it. Microphones can easily pick-up voices that are reasonably close.
- Know when you are on and off the air. The microphone might still be on while the segment is ending.
- Avoid sounding monotone by using intonation and inflection in your voice.
- Check your voice by practicing speaking at a normal volume. There is no need to speak loudly.

For *television* interviews:

- Dress appropriately and conservatively – business attire is best!
- Wear minimal and/or plain accessories.
- Speak naturally; gesture as you would in a normal conversation.
- If make-up is offered, don't turn it down.
- Sit on the chair's edge and lean forward slightly; keep your hands relaxed on your lap.
- Cross your ankles not your legs.
- Smile when you speak.

INFORMATION YOU CAN USE

In addition to sharing your personal story, you want to share the following:

WHAT IS ALPHA-1?

Alpha-1 Antitrypsin Deficiency (Alpha-1) is a hereditary disorder that most commonly shows up as emphysema or chronic obstructive pulmonary disease (COPD) and/or a chronic liver disease (neonatal hepatitis, cirrhosis, liver cancer). There is a lack of a protein in the blood called AAT (alpha-1 antitrypsin) that is produced by the liver. The main function of AAT is to protect the lungs from inflammation caused by infection and inhaled irritants such as tobacco smoke. The low level of AAT in the blood occurs because the AAT is abnormal and cannot be released from the liver at the normal rate. This leads to a build up of abnormal AAT in the liver that can cause liver disease.

WHAT ARE THE COMMON SYMPTOMS OF ALPHA-1?

- Shortness of breath
- Wheezing
- Chronic cough and sputum (phlegm) production
- Recurring chest colds
- Eyes and skin turning yellow (jaundice)
- Swelling of the abdomen (ascites)
- Gastrointestinal bleeding (from large veins in the esophagus or stomach)

WHO SHOULD BE TESTED FOR ALPHA-1?

- Everyone with emphysema, chronic obstructive pulmonary disease (COPD), chronic bronchitis, or asthma that is incompletely reversible after aggressive treatment
- Individuals with bronchiectasis
- Newborns, children, and adults with unexplained liver disease
- Individuals with a family history of liver disease
- Relatives or partners of a person diagnosed with Alpha-1

WHAT IS INVOLVED IN TESTING FOR ALPHA-1?

- Testing is performed by blood tests or a mouth swab test

WHY SHOULD I BE TESTED?

- There are treatments and preventive measures that may slow the progression of lung disease and help you take better control of your health status.
- Being hereditary, Alpha-1 can be passed on to your children. It should be considered when making decisions about having children (reproduction) and it is something to discuss with your children.

LIVER AFFECTED ALPHA-1 ANTITRYPSIN DEFICIENT INDIVIDUALS

How is Liver Disease Related to Alpha-1?

In Children:

Alpha-1 Antitrypsin Deficiency is one of the leading genetic causes of liver transplantation in children. Newborns and infants with the severe deficiency may be jaundiced and have liver failure, requiring transplantation at a very early age. Children may have the following symptoms: neonatal cholestasis (neonatal hepatitis syndrome); symptoms or sign of jaundice; abdominal distention; pruritis ("itching"), poor feeding, poor weight gain, or enlargement of the liver or spleen.

In Adults:

Alpha-1 is the leading cause of non-alcoholic cirrhosis, and a "co-factor" in other forms of liver disease. Even those diagnosed predominantly with lung complications due to Alpha-1 can show signs of liver damage as well.

Diagnosis: Diagnosis is determined by phenotype blood test. A liver biopsy is not required for the diagnosis but may be needed in some patients to evaluate the degree of liver injury or the role of other health problems in the development of liver disease.

What to Do Once a Diagnosis is Confirmed?

Currently there is no treatment for children with liver disease that may have Alpha-1. However the disease can be managed if diagnosed. Management includes preventing other chronic liver diseases and treatment of infection and inflammation due to Alpha-1. As a parent, doctors may advise you to quit smoking and to actively prevent your child's exposure to second hand smoke or other harmful environmental exposures.

ALPHA-1 FAST FACTS

- **Alpha-1 Antitrypsin Deficiency (Alpha-1) is one of the most common serious hereditary disorders in the world** and can result in life-threatening lung or liver disease.

The most common signs and symptoms of Alpha-1 are:

- Family history of lung disease or liver disease	- Recurring respiratory infections
- Shortness of breath or awareness of one's breathing	- Rapid deterioration of lung function without a history of significant smoking
- Decreased exercise tolerance	-Unexplained liver problems
- Non-responsive asthma or year-round allergies	- Elevated liver enzymes

Alpha-1 has been **identified in virtually all populations**. An estimated **100,000** Americans and a similar number in Europe have the deficiency.

- Alpha-1 is **widely under diagnosed and misdiagnosed**.
 - Less than 10% of those predicted to have Alpha-1 have been diagnosed -- it often takes an average of three doctors and seven years from the time symptoms first appear before proper diagnosis is made.
- An **estimated 20 million people in the U.S. are undetected carriers** of an abnormal gene that causes Alpha-1 and may pass the gene on to their children.
 - Alpha-1 carriers may be at risk for lung and/or liver disease.
- Alpha-1 **can lead to lung destruction** and is often misdiagnosed as asthma or smoking-related **Chronic Obstructive Pulmonary Disease (COPD)**.
 - Lung disease is the most frequent cause of disability and early death among affected persons—striking in the prime of life—and a major reason for lung transplants.
- Alpha-1 **can lead to liver failure** in childhood, making it a major cause of liver transplantation in children. It may also **cause progressive liver damage** in adults, often going undetected until reaching a critical, life-threatening stage.
- The **World Health Organization (WHO)**, the **American Thoracic Society** and the **European Respiratory Society** recommend that all individuals with **COPD** be tested for Alpha-1—an estimated 10 million Americans.
 - Alpha-1 can be detected by a simple blood test or the new mouth swab test.

**20 Steps to a Successful
"SOCIAL" FUNDRAISING EVENT
TO BENEFIT
THE ALPHA-1 FOUNDATION**

1. Give yourself lots of time to plan and organize - at least 9 months.
2. Identify a cause, a theme (a cocktail reception, a luncheon, a inner), a specific use of the funds with a local connect. Remember "people give to people".
3. Determine your budget: develop a project plan and budget - sign off by the Alpha-1 Foundation Development Office.
4. Early in the process you need to form a "committed" committee who can act as advisors, cheer leaders and share the work. Consider a junior committee for worker bees. The local high school has a service club which can help.
5. Target preferred dates and check for conflicts in your town and your organization: religious holidays, mother's day, father's day, and family events such as your nephew's graduation from whatever.
6. Identify a master of ceremonies and honoree who is complementary to the main cause.
7. Find a venue, a photographer, music, and printer/mailer.
8. Solicit corporate sponsors and figure out a connection.
9. Approach local merchants for auction items.
10. Devote some real time to preparing a mailing list (your Christmas card list, school list, church list, etc), and each committee member should be able to contribute - expect about a 10+/-% return, don't take personally.
11. Personal calls/notes to participants who will be key donors to your ticket and silent auction sales.
12. Send out "save the date" cards, four (4) to five (5) months before the event. This will also help cleaning up your mailing list.
13. Design invitations, with the view of who your audience is.
14. Mail invitations two (2) months before event. It is critical to write personal hand-written notes and that is where your committee comes back into play as each should take responsibly for this.
15. Use the internet social networking fundraising tools. Have junior committee set-up event on Facebook and Firstgiving.
16. Make follow-up calls/emails to those on the invite list.
17. PR before and after event such as signs in local stores, newspapers, radio stations, etc.
18. Select and distribute photos.
19. Thank you notes. Have a long term follow-up plan.
20. Schedule a meeting to follow-up with your committee on what you learned for your event and what can be improved for the next year.

SAMPLE OF SPONSORSHIP LEVELS

***Note:** For corporate sponsorships target big companies in your local area that you frequent. If you will be requesting sponsorships from major industry partners of the Alpha-1 Foundation, please submit your request to the Community Outreach. We will submit the request on your behalf.

Event Name

Fundraiser to benefit Alpha-1 Foundation

“Location”

Date

CORPORATE SPONSOR LEVELS

- \$15,000 Title Sponsor** - a full page advertisement in the event program, 30 tickets for this event, a recognition plaque, a corporate sponsor listing in the front of event program, a group donor listing on sign board at this event, and recognition on all flyers and brochures.
- \$10,000 Platinum Sponsor** – a full page advertisement in the event program, 20 tickets for this event, a corporate sponsor listing in front of event program, a group donor listing on sign board at this event.
- \$5,000 Gold Sponsor** - a full page advertisement in the event program, 10 tickets for this event, a recognition plaque, a corporate sponsor listing in front of event program, a group donor listing on sign board at this event.
- \$2,500 Silver Sponsor** - a full page advertisement in the event program, 4 tickets for this event, a recognition plaque, a corporate sponsor listing in front of event program, a group donor listing on sign board at this event.
- \$1,500 Bronze Sponsor** - a full page advertisement in the event program, 2 tickets for this event, a recognition plaque, a corporate sponsor listing in front of event program, a group donor listing on sign board at this event.
- \$1,000 Table Sponsor** - your business or individual name listed in the event program and 6 tickets for this event (6 persons/table)
- \$500 Business Friend** - a one-half page ad in the event program.
- \$250 Friend** - your name listed in this event program and one ticket for this event
- \$100 Business Listing** - a business card advertisement in the event program

**For more information, please contact
*Name and Phone***

SAMPLE OF A SPONSORSHIP REQUEST LETTER

Date

Name
Organization
Address
City, State, Zip Code

Dear Mr. Name,

I would like to enlist your support of the Alpha-1 Foundation's ongoing efforts in continuing its mission to providing leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1).

Alpha-1 is a hereditary condition that is passed from parents to their children through genes. This condition may result in serious lung disease in adults and/or liver disease in infant, children and adults.

I would like to request a charitable contribution in the amount of \$_____ to sponsor our **EVENT NAME** to be held at VENUE NAME, VENUE CITY, VENUE STATE on EVENT DATE. This is a fundraiser that will benefit the Alpha-1 Foundation. We expect to have approximately ___ guests. They will include Alpha-1 patients, family members, caregivers, physicians, nurses, medical professionals and many other prominent figures in the Alpha-1 community.

We would be extremely grateful if you would support the Foundation's work.

Please make your check payable to:

The Alpha-1 Foundation
3300 Ponce de Leon Blvd.
Coral Gables, FL 33134

On memo of check note
"FUNDRAISING CHAIR NAME Fundraiser"

We appreciate your support in the past and look forward to your continued commitment.

Sincerely,

FUNDRAISING CHAIR NAME
Fundraising Chairperson
NAME OF EVENT

Cc: Angela McBride
Director of Corporate Relations & Community Engagement
Alpha-1 Foundation

SAMPLE OF A SILENT AUCTION REQUEST LETTER

Date

Name

Title

Company Name

Address

City, State Zip Code

Ms. Name:

I would like to enlist your support of the ongoing efforts in continuing its mission to providing leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1).

Alpha-1 is a hereditary condition that is passed from parents to their children through genes. This condition may result in serious lung disease in adults and/or liver disease in infant, children and adults.

We would be extremely grateful if you would support the Foundation's work by providing us with a donated item of your choosing, to be used as part of our exciting silent auction in conjunction with **EVENT NAME** fundraiser to be held at VENUE NAME, VENUE CITY, VENUE STATE on EVENT DATE. This is an excellent opportunity for your company to demonstrate your desire to help our community.

Monies raised from this event will enable the Alpha-1 Foundation to support its mission.

Thank you for your thoughtful consideration of this request. If you should have any questions or would like to arrange for pick up, please feel free to call me at (XXX) XXX-XXXX or e-mail me at [EMAIL ADDRESS](#). I would be happy to work with you on identifying other ways we could recognize your company's participation in this event. I look forward to hearing from you.

Sincerely,

EVENT NAME Silent Auction Committee



Take Action and Make a Difference
It's Up To **You!**

THANK YOU
Alpha-1 Foundation
305..567.9888 ext. 233
amcbride@alpha1.org

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