

## RARE TOOLKITS

# Finding your Fundraising Strategy







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Thank you for including us on your journey! Most likely you have a need for this toolkit, Finding your Fundraising Strategy, because you or a loved one has a rare disease and you want to make some kind of change. As you prepare to use the tools in this kit, we want you to know that you are not alone. We are in this together. It is our hope that the personal stories, resources, tips, and suggestions for self-reflection in this guide will be the path to making change for your rare disease more manageable.

While we believe you will benefit from reading all of the material in this toolkit, we don't want to overwhelm you. The articles do not have to be read in order. We've included a table of contents to make it convenient for you to find the information you are most interested in at this time.

We know, all too well, that there is a huge need for more research, support, education and awareness in the rare community. Having the support of a large group of dedicated individuals is a good start; but to really bring about change, rare patient organizations need financial resources. The articles, tools and rare patient experiences included in this toolkit can help you maximize your fundraising potential! ■

-  *Paper and pen indicate an interactive exercise*
-  *These little glasses indicate a bulleted list of tips and information*





# Under the Big Top!: Fundraising Overview

Like a world-class circus, successful fundraising includes a variety of talent, magic, and tightrope risk taking. And even if you are included in the estimated 12 percent of U.S. adults who have coulrophobia (a fear of clowns), you can still enjoy being the ringmaster in charge of your group's Big Top fundraising tent.

**Fundraising:** also known as development, is the art of seeking financial support for a charity, cause or business venture.

This toolkit serves as a companion to the Global Genes 5 Essential Tips and Tools for Effective Fundraising toolkit. And whether this is your first rodeo with fundraising or you're an experienced cowhand, we think you will find the tools in this kit useful for raising money for your rare cause or for any other project.

Nonprofits often depend on fundraising, also known as development, to cover certain expenses, programs, activities, services, and to support their staff. Some organizations rely heavily on in-person fundraising events, while others prefer soliciting

online or by mail. It is important to know which development tactics are best suited to your goals, resources, and capabilities. Proven strategies for raising money for disabled veterans may not be the best approach for your rare cause.

The articles in this toolkit are a good starting point for understanding what it takes to craft and execute a successful fundraising strategy. There are different types of fundraising. As an advocate you should also be aware of how to overcome some of the specific challenges of fundraising for rare causes.

## The Amazing Flying Advocates

High-flying acrobatic acts are circus mainstays because they sell lots of tickets and salty peanuts. Fundraising is, likewise, a mainstay of nonprofit organizations because of the many options it offers for turning salty peanuts into sweet cash. It is also one of the most valuable and popular tools at your disposal for disseminating your message and getting people in your tent.

Knowing how to effectively use a combination of fundraising tactics can help you determine the most

practical and expedient way to raise the funds you need to reach your goals and objectives. And, while there may be times when fundraising feels like you're swinging on a trapeze bar without a safety net, it should be an ongoing focus of your group's efforts.

## 60 Tips and Tricks

- It is typical for fundraising to be used for securing resources to enhance operations, programs, and facilities or to start functioning as an organization.
- Fundraising is not a get-rich-quick tool; it is a long-term strategy that requires patience and attention.
- Ideally, the money in your fundraising piggy bank should not solely be used for making payroll or for keeping the lights on.
- Fundraising or the lack thereof, can greatly impact the level of success you'll have advocating for your cause.

Creating a fundraising development plan means building and developing long-term relationships with donors. It also means creating a catalyst for continuous funding through marketing strategies and tactics. Development is a process that involves cultivation, solicitation, donor recognition, and all forms of direct marketing. ■







# Goal Mine and Expectations

## Welcome Ladies and Germs!

Maybe it's been 20 years since you raised money for a scouting badge or for the high school debate team. You sold chocolate bars to classmates, your parent's coworkers (mostly), and to shoppers outside the Piggly Wiggly Superstore. These activities provide a basic understanding of fundraising; but selling candy bars (not including the ones you ate and had to pay for with your allowance) are likely not enough experience for your current fundraising endeavor.

***"Life is like a box of chocolates, you never know what you're gonna get."***  
FORREST GUMP'S MAMA

Therefore, if you have minimal fundraising experience or none at all, it's okay if you are not ready or able to undertake a big fundraising development strategy. The first time out you don't have to step into the ring with a lion that missed lunch. Right now it's more important to focus on long-term goals. Which may mean starting with a much smaller strategy, like sending an email blast that asks donors to support your RARE Pennies for Postage campaign.

## Team Spirit! Event Planning for Fundraisers

Event planning is much easier and more likely to be successful with a committee who can help you to recruit participants and manage details. The first thing I suggest is for fundraisers to form a team. To expand your reach, ask people from different social circles: family, friends, co-workers, and neighbors to help you. People are far more likely to support an event when they know the person asking them. The more people making "asks," the more people who are likely to support the event.

Next, have a meeting to determine the type of event that team members feel they can comfortably ask their contacts to support. When team members are comfortable with the ask, it makes it easy for them to invite prospective donors.

Discuss with the team:

- What price point are they comfortable asking their contacts to pay?
- Who is their audience based on?
- Who they know?
- What types of activities would appeal to them?

It is often good to have a few ideas to start with after the first meeting; and then narrow down after research into interest and costs to answer the ultimate questions:

1. How many people will need to support the event to make it profitable?
2. Is your team certain they can surpass that amount by enough to make their efforts worthwhile?

Once the event is set, the team needs to ask, ask, ask! Social media is a great way to invite many people at one time and should always be used heavily, but personal asks are also essential as they are more effective. While most people who support events do so because they are asked to by someone they know, the group coordinator should contact local media and highlight her story. A community coming together to support someone with a rare disease is far more engaging than event details.

At the event, your story and the mission of the charity should be front and center. You'll also want to educate attendees, encourage additional donations to raffles and auctions at the event, and secure donor support for the future. Get attendees' email addresses so you can thank them for their support after the event and to keep them in the loop about future endeavors.

Understanding what resources you currently have available is helpful in determining realistic and achievable goals. A good place to start in your fundraising journey is to first assess your organization and the current donor list.

## 60 Tips and Tricks

When creating your organizational goals consider the following:

1. The size of your organization.
2. Amount of staff and volunteers.
3. Who are you trying to reach?
4. What are you trying to accomplish?

Drive a calendar:

- Print out a year-long calendar.
- Start wherever you are. Regardless of your fiscal year, remember your supporters live in a calendar year, so take that perspective into consideration.
- Mark any major events- conferences, meetings, banquets, and galas on the calendar.
- Include things that take a lot of pre-planning like printing and shipping, save-the-date postcards, etc.
- Add any consistent emails or newsletters you put out: a quarterly newsletter, a monthly alert.
- Back out of these milestone events with preparation milestones, but more importantly communication milestones.
- Look across the board and see if there are holes.

When you are done, you should have a calendar of the major things that will dominate your schedule for the year. Be careful of scheduling a lot of content or too many events in the beginning of the year. The calendar will show if you are only sending out communications around the holidays. Make adjustments where there are gaps in your output during the year and where you are overwhelming yourself.

Whether you're wading into the shallow end of the fundraising pool for the first time or you're an experienced fundraiser preparing for your next high-dive, persistence pays off! The foundation of successful fundraising is establishing goals and managing expectations. Master these and you're on your way to becoming a fundraising Olympian. ■

***"Start with the budget and then back into a development plan. How much money do I need to raise? What tactics should I use to do that? Establish a monthly calendar of things to be done in order to reach your goals. Review and revise development plan as needed."***

JOAN LAWRENCE, DIRECTOR OF DEVELOPMENT  
NATIONAL TAY-SACHS & ALLIED DISEASES  
ASSOCIATION (NTSAD)

*"It only seems impossible, until it's done."*

-NELSON MANDELA







## MVP: Relationship Building

You may (really) be the smartest person in the room at work, at home, or at game night with the in-laws, but in the world of fundraising it's not what you know, it's who you know! You need to be your team's most valuable player (MVP) of relationship building. Now, in addition to using your big brain for winning charades, you can use it to develop a network of loyal supporters for your organization.

The size of your organization has a direct relationship with the number of connections in your network. Rare disease communities are typically small to begin with, which is why it is even more important to constantly build and nurture your network through awareness and education.

People in your network may know a rare disease patient or they may know donors who prefer supporting smaller causes. Some fundraising efforts will yield many one-time donors, which is great; but the ultimate goal is to turn those donors into repeat supporters. Remember, your best prospects for donations are people who have given in the past!

### Tips and Tricks: What Works with Rare

**Challenge:** Don't think –

- Acquisition

**Solution:** Do think –

- Retention
- Develop stewardship protocols
- Create a donor database

A donor database management system can help grow your organization. This software helps you to create donor profiles. You will know who's donating, how much, when, and other personal details that make it easy for you to build successful donor relationships. Do your research; donor management systems come with different features and at different prices. Even if your current supporter roster is small, it may be worth the investment to get a system that will accommodate your long-term donor growth.

### Gifted! Why People Give

Individual giving is made through donations, supporting events, and other fundraising activities. The National Center for Charitable Statistics reports that individuals represent the majority of contributions at over 70 percent of total giving. In a recent annual report, Giving USA estimated that Americans donated over \$258 billion in 2014. These reports confirm (much to the delight of fundraisers) that individuals are continuing to donate to organizations.

Post this list as a reminder to why people give:

- People give to people, in support of causes.
- People give because they want to. They do not give because they are forced to.
- There may be several motivating factors, but ultimately people give because it is something they desire to do.
- People give money to make a change for the good.
- People give to opportunity, not needs.
- People give to a vision, not a budget.
- People will give because they are presented with an opportunity to achieve something—not because you need the money.

It's not enough to communicate the need for more money—one must demonstrate a compelling reason. Generally speaking, if there is no relationship, there is no donation.

An organization must demonstrate why it is important for people to give. It must show that the gift will support the good the organization is doing. They won't give simply because you have been around a long time. In asking for a gift, your strategy should reflect that motivation.

### Tips and Tricks

- Make it easy for donors to give.
- Allow them to donate with: cash, check, direct debit, credit or debit cards, shares, property and other assets and by setting up charitable and living trusts.
- Be willing to accept donations by: phone, snail mail, bank transfer, and most conveniently online.

Information that's helpful to know about donors and prospects:

- Employment and educational history.
- Family and social ties.
- Volunteering, board service and charitable giving issues of interest.
- Things they have in common with you or with someone else in your organization.
- Political, fraternal, civic, and religious affiliations.

### It Takes Two: Partnerships

If you've had a kernel of success in romantic courtships, you know one date rarely leads to old school, going steady. Romantic relationships, generally, require a bit of courting and personal gamesmanship before couples are willing to be exclusive to each other. And, so it is with building relationships with donors, a little hand-holding can keep them feeling confident, passionate and committed to your cause.

### Tips and Tricks

Donor stewardship:

- Appreciation
- Acknowledgment

The long-term success of these partnerships is accomplished through relationship building, making connections, and sharing the stories of your community. It is mission critical and worth the effort to get your network emotionally and financially invested in the stories of the people inside your community; the organization that represents them; and the programs that will help fund your community's causes. ■





## Magic Acts: Types of Fundraising

Magicians and illusionists have breathed new life into magic and are riding a wave of popularity with audiences of all ages. These emerging sleight of hand performers know that pulling Thumper the rabbit out of hat on a stage is different than doing up close street magic, or performing for a television audience.

Likewise, it is important to understand the basic types of fundraising and how to use them to mesmerize your donors. Success often requires a combination of fundraising sources, tactics, and sometimes (literally) a good magic act. Individual donors will be the foundation of your fundraising efforts and are often times one of the easiest groups to solicit.

### Individual Donors

Anyone who has ever dropped money into a Salvation Army kettle, church collection plate, or sent a donation at zero-dark-thirty to a charity on television is an individual donor. And it has become the norm for politicians to boast about how many small donations their campaigns are receiving from individual donors versus acquiring big bucks from special interest groups.

Social media feeds are filled with heartwarming stories about massive numbers of individual donations to everything from endangered honeybees to helping victims of natural disasters. Ultimately, fundraising and individual giving are two sides of the same coin you'll likely drop into the red kettle this holiday season.

***“The most basic truth of fundraising is that people give to people they care about. Start with your closes connections to create your circle of influence. People who care will donate and they will also provide you with other warm leads and connections.”***

KRISZTINA QUICK, STATEWIDE DIRECTOR OF  
SIGNATURE EVENTS (CA)  
AMERICAN LUNG ASSOCIATION

### Events

Let's get this play Chess-for-Charity party started! Events are activities or campaigns that raise money for an organization or cause. Events run the gamut

from: a formal dinner for 200 well-mannered guests, a golf tournament for corporate bigwigs, silent auctions, annual telethons (the discontinued—granddaddy of them all, Jerry Lewis's MDA Labor Day Telethon), and other activities big and small. It is common for some organizations to have an annual signature gala or event.

Many organizations plan and sponsor the same events around the country annually. These annual events are an excellent way to involve your entire community, regardless of where your organization is located. And as they attract larger numbers of participants, they generate local and national publicity across multiple locations.

### Online

Fundraising has found a new and welcoming home online. It makes it easy for people to share their stories and to create campaigns for one-time donations or for recurring contributions. Online giving is having a dramatic impact on donations because it expands the way organizations solicit and secure donations. Online fundraising simplifies the process for organizations by making it much easier to

launch appeals and for donors to give online. Online platforms also make it possible for people with and without fundraising experience to collaborate and to take action on charitable, political, social, cultural, artistic, and less traditional causes like building homes for carpenter ants. They facilitate both team and individual fundraising and provide campaign management tools. Online giving offers organizations a small risk, high reward option.

### Corporations

Corporate giving may consist of both cash and in-kind donations. Many corporations donate a percentage of annual profits to one or more causes. Charitable giving by corporations represents 5 percent of annual giving. Some corporations handle giving internally while others establish foundations to manage their efforts. Many smaller, local businesses are also willing to support local causes and organizations.

Corporate giving comes in many forms. Larger firms often publish corporate giving profiles. These profiles make it easy to know which corporations support your type of cause.



### Sponsorships

National and local businesses often seek out sponsorship opportunities in the communities their customers live in. Different than a monetary donation, in exchange for public promotion, business sponsorships pay for a nonprofit's specific needs, project, or an event. Sponsorships are a win-win for the sponsor and the sponsored.

While the sponsor gets name recognition and possibly new customers; the sponsored gets new baseball uniforms with "Mary's Yarn Barn" on them. Sponsors also get tax benefits, because their sponsorship cost is considered a donation.

### Gift Horse

Listed are some of the more popular types of corporate giving programs.

### Matching Gift Programs

Some companies support their employees by providing matching dollars, generally up to a maximum amount. Ask everyone you know if the company they work for offers a matching gift program. If so, you'll receive double the amount donated (up to the matching max) by employees. Donors like these programs because it often impacts the local community and it is a positive representation of their employer.

### In-Kind Donations

Companies may not be willing to or able to make a monetary contribution to your cause, but are willing to support you with their manufacturing operations or purchasing power. To maximize in-kind donations:

- Make a wish list of things your organization wants or needs such as equipment for ongoing operations or for a specific project or event.
- Keep the wish list current and post it on your website.
- Use social media and other communications to make appeals for items on the list.



### Private Foundation

A private foundation can be established by an individual, by a family or by a business for philanthropic purposes. Most have a mandate that determines who and what they will and will not support. Most often the money is given via grants. Charitable trusts may also be administered through a foundation.

There are nearly 100,000 private foundation grants in the U.S. Some of the more notable and larger foundations are:

- The Ford Foundation
- The J. Paul Getty Trust
- The Bill and Melinda Gates Foundation

### Government Grants

The U.S. government also offers grant programs. These grants are available to support small businesses, minorities, women, research projects, community development, nonprofits and more. Information about government grants is available on a variety of state and federal websites. The websites generally provide information on available grants, deadlines, and application requirements.

The grant process is linear. It includes creating the funding opportunity, applying, making award decisions, and successfully implementing the award.

The specific actions along the linear lifecycle of a grant are grouped into three main phases:

1. Pre-award phase
2. Award phase
3. Post award phase

Some of the most common government grants include:

- Federal grants: A federal grant is one of many different forms of federal financial assistance provided by the U.S. government. Federal grants are available to eligible recipients to fund ideas, projects, and public services that stimulate the economy. Individuals, organizations, municipalities, businesses, and other entities can apply for federal grants.
- State and municipal grants: The requirements may not be as stringent or difficult as applying for a federal grant. And it may be easier to be recognized by the grantor, if the project will provide a solution to a known need in the community. ■





# Dollars to Doughnuts: Individual Donors

It is best to reach out to individual donors first. They are in your primary network and they have a personal, mutual connection with your cause. In addition to being monetary donors, they may also become advocates, volunteers, and/or connections to additional sources of support.

It is important to nurture donor relationships by sharing information that is useful or of interest to them. It is equally important to justify their investment of money and time by regularly demonstrating your financial stewardship and results. ■

***“Be able to demonstrate that your organization is transparent, responsible and doing good things.”***

JEAN CAMPBELL, PRINCIPAL  
JF CAMPBELL CONSULTANTS, LLC

## Tips and Tricks

### Fundraising Principle (LAI)

#### Linkage

- Who are you connected to?
- Who are your constituents connected to?
- Where is your cause known?
- Who cares about your cause already?
- Who has an interest in a cure and treatment for your disease?

#### Ability

- Capacity to give

#### Interest

- Who has shown an interest in your cause?
- Who is participating in events?
- Who is attending webinars?
- Who comments on your cause specific, social media postings?



## Self-check Interactive: You Know Who?

If you’re new to fundraising you may be surprised at how many of the listed linkages are in your immediate circle. Place a check mark next to the potential donor linkages you already have.

### Organizer Linkages

#### 1. Who are you connected to?

- ☐ My family/in-laws & outlaws
- ☐ Friends
- ☐ Church
- ☐ Co-workers
- ☐ RARE support groupers
- ☐ My doctor
- ☐ Local and state representatives
- ☐ Community/neighborhood action group
- ☐ PTA board and parents
- ☐ Social media contacts
- ☐ College chums
- ☐ Library staff
- ☐ Restaurants that I frequent
- ☐ Dry cleaners and carwash crew
- ☐ Newspaper delivery person
- ☐ Pharmacy staff
- ☐ Postal delivery person
- ☐ Sorority, fraternity, and other service organizations

#### 2. Who are your connections connected to?

- ☐ Family to other family/jobs/friends
- ☐ RARE supporters to their families & friends/medical people/jobs/neighbors
- ☐ My doctor to other docs/drug sales reps/his staff
- ☐ Legislative representatives to other politicians/family/constituents
- ☐ Retail biz people to their other customers/families/friends
- ☐ Social media friends to their other friends/followers

#### 3. Who cares about your cause?

- ☐ Me and my family
- ☐ Other rare advocates, patients and their families, doctors, researchers
- ☐ Pharmaceutical companies
- ☐ Legislatures

#### 4. Who has an interest in your cause and in finding a treatment?

- ☐ Me and my family
- ☐ My doctor
- ☐ Other patients

### Linkage Success Tips

- Constantly build and nurture your network.
- Use social media and email marketing to foster engagement and interest.
- Communicate your accomplishments and progress.
- Make it easy for individuals to help you by providing tools and information they can use.
- Say thank you!





## Fundraising Jackpot: Events

What happens at the Las Vegas Night fundraiser in the basement of your church will likely not stay there! Events are a popular fundraising tool because they allow people to have a good time, while raising money for a good cause. And a successful event can substantially add to your coffers. Events also have the added benefit of generating publicity for your organization and an opportunity for your supporters to gather for a common cause.

Depending on your goals, a return on your event investment can be difficult to justify. Even small events take time to plan and often have expenses that have to be paid in advance of realizing event revenue. Therefore, it's very important to be realistic about your goals, both financial and otherwise before planning an event.

### Tips and Tricks: What Works with Rare

**Challenge:** Don't think – less successful

- Large, expensive event like black-tie dinners

**Solution:** Do think – more successful

- Grassroots and peer-to-peer (P2P) fundraising

Use peer-to-peer fundraising. Ask your connections to host their own small events such as a wine and cheese reception or individual yard sales. The National Tay-Sachs & Allied Diseases Association (NTSAD) helps families throughout the country with individual fundraising efforts. They support everything from lemonade stands at youth sports games to larger community based events. NTSAD helps by promoting an event on their website, setting up a donor page, providing information to distribute at events and offering giveaways such as tee-shirts. They also facilitate peer-to-peer connections by introducing families to other advocates who have planned similar events.

***“Events require a lot of time, energy and work. Make sure you plan an event that is reflective of your organization and within your means to do. Small local or regional events may work better than a large one.”***

JEAN CAMPBELL, PRINCIPAL  
JF CAMPBELL CONSULTANTS, LLC

### Planning: Place Your Bets

Before you roll the dice on an event, minimize the financial risk by setting a fundraising goal. Events are labor intensive, so you will also need to consider your manpower resources. You'll want to have a plan for achieving your fundraising goal and a timeline for event planning activities.

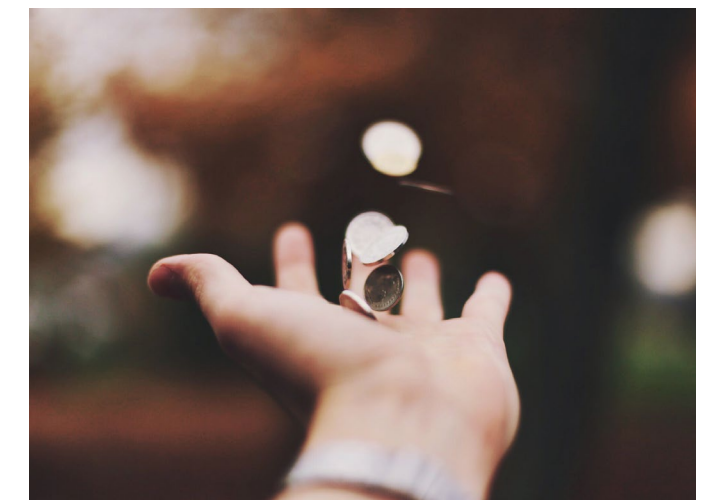
Funds can be generated through ticket sales, auctions, merchandise sales and more. You will need to establish a budget for: marketing, the venue, refreshments, entertainment, security (if necessary), and other expenses. It is always a good idea to have a contingency fund (about 15 percent) for unforeseen expenses.

Event fundraisers are often organized by a committee of volunteers working in tandem with the organizational staff. There is no shortage of work to be done or decisions to be made. The possibilities are endless. Gathering information and making decisions that allow you to achieve your goals is important.

Think carefully about the size of your event; larger events don't necessarily yield a big monetary return. Whether it is a black-tie gala or a bike-a-thon, you

want attendees and participants who will not only show up, but who will also help you to raise funds.

To be hugely successful, nonprofits seldom have enough volunteers to do everything they want to do and need to do. Volunteers are as critical to your success as money is. Your community may participate in a Volunteer Match incentive. This resource allows you to post a request for anything—from a website designer to someone who will answer the phone a couple of days a week.





Volunteers provide real value: free manpower, expertise, expanded networking and more. Millions of Americans donate their time and talent to causes.

Listed are some of the many places volunteers are available:

- High schools that have community outreach requirements for students.
- Colleges where students are seeking internship opportunities.
- Greek letter and National Pan-Hellenic fraternities and sororities that are service-based organizations generally require members to fulfill social service activities on and off campus.
- National and local youth organizations.
- Senior centers.
- Veterans' groups.
- Religious groups.

### Event Essentials

Even in a small town getting the word out about an event can take more effort and money in advance than you anticipate. Listed are considerations for planning an event.

1. Where will it be held?
2. Will it be formal or casual?
3. Will there be refreshments?
4. Will there be entertainment?
5. Should you charge general admission or have a VIP ticket with special perks such as a pre-reception to meet a celebrity or other notable person?

#### Event Success Tips:

- Establish a fundraising goal.
- Have sufficient staff and volunteer manpower.
- Use social media and email marketing to publicize the event.
- Have your event listed in community calendars (a 3 to 6-month lead time is often required).
- Be prepared to cover pre-event costs.
- Deliver an event that people will enjoy.
- Follow-up with letters of appreciation and results within 30 days.
- Debrief your staff and volunteers for future event planning.

***"Fundraising for rare diseases is difficult because there are not a lot of people who are affected by a specific rare disease. There is no government funding and it is hard to find grants. Patients and their families are tapped out with medical expenses. You have to create and nurture a local, passionate, volunteer donor base."***

CYNDI FRANK, GAUCHER ADVOCATE

### Event Day: Winner takes All!

Go big or go home! On the day of the event you have to believe that you and your team have planned an event that reflects well on your organization. Smile and be prepared for donors to have feedback about your event. Wealthy donors may expect a first class gala; while more modest donors may think the money should have been used to reach your goals. The truth is you will never please everyone.

Regardless of how much planning goes into your event, the unexpected can happen. Hurricanes, earthquakes, platters of spoiled (really smelly) broccoli, and many other things that you can't control. Even with the best contingency plan, you can't prepare for every possibility. What you can do is select an event manager who has a calm demeanor, excellent organizational skills, and the ability to improvise when things get spoiled.

### After-Party

After the event, thank your volunteers and attendees, cash in your chips, and share the results. Attendees appreciate knowing how much money was raised and how the donations will be used. Let donors know \$10,000 will send 100 kids to camp or \$50,000 will be invested in drug research. The more information you provide the more successful your relationships with your donors will be. You should also ask attendees to do a short online survey to get their valuable feedback. Use this information and observations from your staff and volunteers to improve on the next event. ■



## Internet Sensation: Online

Yes, you may be the next internet charity challenge sensation! Cultivating individual support has been greatly aided by social media. In the recent past, smaller nonprofits were restricted by expensive promotional costs or by the media coverage they could get for free. Those days are in the fundraising rearview mirror. The web has changed everything to do with connecting to potential supporters.

Online social media allows organizations to build a case for their mission, share personal stories and beat the drum 24/7 with little to no expense. More importantly, social media can keep people engaged, informed, and interested in your cause.

Online giving platforms also make it very easy for you to organize an event, register participants, fundraise, sell tickets, host auctions and more. You can create and sell merchandise with your organization's logo and slogan, sell a product and receive a percentage of the sales profits; or allow supporters to have all of their purchases credited to your organization.

Crowdfunding websites allow organizations to post specific projects or needs and to acquire small amounts of support from many individuals via the

internet. Other options include businesses that make charitable donations when someone agrees to watch their online commercial or they donate a percentage of sales from products purchased. With new development strategies always on the horizon, the possibilities for online fundraising continue to evolve.

Email marketing is another low-cost effective way to keep in touch online. It can be used for fundraising appeals, sending a newsletter, program updates, event promotion, and sharing news about research development. There are several email marketing programs available that can help you to easily format and distribute compelling communications.

### Success Tips:

- Explore all of the platforms and options to best determine which ones meet your needs.
- Have a solid description of your organization's mission and activities and a clearly defined goal for the campaign.
- Be certain to have your Tax ID listed.
- Don't forget to link your organization's ratings or certificates. ■





## Double Vision : Matching Gifts

Fortunately, it is not unusual for large businesses to participate in corporate matching gift programs. Although, corporations offer these programs, they are likely not listed at the front of the employee human resources manual (just saying!). Which means on a 3-legged stool two legs are missing, the employee/donor and the fundraiser. In the end everyone benefits when donors get to double their dollars to the causes they support. The company and the employees get recognized for their generosity and fundraisers get closer to reaching their financial goals.

Maybe you live in a college town where many of your donors work for the university; or in a company town where most of the people work for a few large corporations. In these situations, getting access to information you can share with donors on how to participate in a matching gift program will likely be easier. In a larger environment you may have to contact each corporation's human resources department and request the information. In either case the effort you put into educating donors about corporate matching gift programs can pay off smartly for your cause. Giving donors the information they

need to submit corporate gift match requests not only saves them time, but also increases the odds of them following through on the donation.

### Success Tips:

- Make your wish list.
- Leverage your network of individual donors to make contacts.
- Make a list of both large and small local corporate donors and programs.
- Get your organization listed in planned giving campaigns.

Don't overlook the value of time, expertise and materials. ■

### Tips and Tricks

Strategies to increase fundraising from matching gift programs:

- Research the company's matching gift program online (if possible).
- Send potential donors company specific guidelines and forms for matching gifts (when possible).
- Appeal to donors to ask human resources or other employees about the company's gift matching program.
- Thank donors and companies for their matching gifts.

***"Don't be afraid to tell your personal story. You never know where your next donation may come from. Ask people for donations. Ask them where they work, where their spouses and friends work, if they know anyone in a family foundation, or work for an employer with a matching gifts program."***

JOAN LAWRENCE, DIRECTOR OF DEVELOPMENT  
NATIONAL TAY-SACHS & ALLIED DISEASES  
ASSOCIATION (NTSAD)





## In It to Win It!: Grants

Grant applications, like chickens, also have feathers that require plucking! First, you'll need to find grants that meet your needs and then you'll have to allow time to work on the applications. If you are just starting out, it helps to have committed volunteers you can rely on to assist you with the process.

Often times, there is a short window of opportunity from announcement to award; six to eight weeks is common. This may be time that you can ill afford. As you grow, it may be worth the investment to employ or contract with someone who has specialized expertise in securing grants or other fundraising efforts.

Organizations can benefit from the expertise of a Certified Fund Raising Executive (CFRE) and/or a Grant Professional Certified (GPE). While hiring a professional grant writer may increase your chances of success, you should know that grant writing is a specialized skill that can have a price tag of \$5,000 to \$10,000.

Like contestants who are "in-it-to-win-it" on a TV talent show, there are many other nonprofit organizations and small businesses competing for and receiving federal grants. To increase your odds of receiving a federal grant take into consideration the following:

- Federal grant programs have very specific requirements and your application must tick all of the boxes.
- Larger grants generally require three to five years of demonstrated success and metrics of proof.
- Finding programs that fund rare disease organizations may be challenging.

### Tips and Tricks: What Works with Rare

**Challenge:** Getting corporate sponsorships can be more challenging for rare causes.

**Solution:** Ask where your families work and where they are known.

**Challenge:** Receiving grant support can be more challenging for rare causes.

**Solution:** Ask where you have linkages.

**Challenge:** Disease is unknown or doesn't impact large numbers of people.

**Solution:** Put a face on the cause by giving constituents tools to share their stories.

Although there are trillions of government grant dollars awarded annually, there are other funding options. Grantwatch.com is one of many websites that gives paid subscribers access to a variety of government and non-government grants. Small nonprofits are able to find funding opportunities amongst thousands of unique and current grants. The site claims to have the largest detailed listing of the newest nonprofit grants and grants for government agencies, small businesses and individuals.

Ultimately, getting a grant or donation can be a real boost to your finances and fundraising morale; therefore applying for them should be part of your long-term strategy.

### Success Tips:

- Determine how much time you have available to invest in researching grant programs, writing and submitting applications.
- Have demonstrated proof and quantifiable metrics to support your request.
- Be prepared to accept rejection.
- Cultivate expertise in grant writing.
- Explore state and municipal grant programs.
- Don't force a square peg into a round hole.

### Grants: Expand Your Efforts

The grant process is about building relationships. If possible, get a meeting with the grant administrator to make the person familiar with you and your project. And, even if you don't get the grant the first time, continue to apply to keep them aware of your project.

Listed are answers to commonly asked questions about the grant application process.

1. Is there a significant benefit to hiring a professional grant writer to do the application?

When an organization doesn't have the experience or human resource to write the grants it makes sense to hire a professional grant writer. The organization can also tap into the professional writer's knowledge, skills and connections to the grant world.

2. What are the 3 most common mistakes people make in applying for grants?

1. Submitting a grant application without a prior relationship with the grant administrator.
2. Not fully addressing the questions in the application.
3. Mismatched application.

3. What are the 3 most common reasons a grant is not approved?

1. Competition from other applicants.
2. Not enough experience in managing grants.
3. No relationship with the grant administrator.

4. If possible, what things can someone do to increase the odds of receiving a grant?

The professional grant writer can be more valuable if she can research the right-fit grant opportunities, and establish a relationship with the grant administrator before submitting the grant. You can increase the odds of receiving a grant significantly this way.

***"Apply for grants. They are an excellent way to get money in the door. Explore community grants from large companies like Target and Walmart that have programs to give locally."***

CYNDI FRANK, GAUCHER ADVOCATE





## Fundraising Conclusion: Strike Up the Band

As a nonprofit generating funds that can sufficiently support your operational expenses and allows you to make an impact will be a primary activity and one that requires creativity, perseverance and hard work.

There is no magic bullet. Each organization must find the best mix of donors and fundraising tactics that works for them and allows them to generate money. Even larger organizations with sophisticated development practices are constantly working and innovating to succeed in a competitive and difficult fundraising environment.

Undoubtedly, most organizations would like to receive lots of large cash donations; but the reality is you will likely have to cobble together a strategy that helps you reach your financial and organizational goals in small increments. You must constantly ask yourself what you can do to raise money and generate revenue to cover basic overhead costs and programs.

Where there's money there are tax laws. It is essential that you know and abide by federal and state tax

laws. You may have to register in individual states if you are receiving donations. You should also pay close attention to charity watchdog groups. People may check before making donations to make sure you are legitimate, fiscally sound and doing what you say you will do with the funds you raise.

If you are just starting out, use this toolkit to brainstorm both your needs and the needs of your prospects. If you are more established look at what other organizations of similar size are doing and adopt best practices.

Fundraising is both art and science and it is continually evolving. The resources included here are by no means comprehensive. Continue to add new acts that will educate and engage the donors under your fundraising Big Top tent. Utilize websites, books and other resources that are dedicated to nonprofit fundraising in order to help build a winning fundraising strategy for your RARE cause. ■



# Resource Guide

## General Fundraising Resources

Association of Fundraising Professionals (AFP)

<http://www.afpnet.org>

AFP's nearly 30,000 individual and organizational members raise over \$100 billion annually, equivalent to one-third of all charitable giving in North America and millions more around the world.

Giving USA

<http://givingusa.org>

Government Grant USA

<https://www.usa.gov/grants>

Global Genes Fundraising Toolkit

<https://globalgenes.org/toolkits/5-essential-tips-tools-for-effective-fundraising/introduction>

Global Genes Webinar

<https://globalgenes.org/rare-webinar-effective-fundraising>

Grantmatch

<http://www.grantmatch.com/>

Free Management Library

<http://managementhelp.org/nonprofitfundraising/index.htm>

The Library contains a wide variety of resources on various elements of fundraising.

National Association of State Charity Officials (NASCO)

<http://www.impactfoundry.org/resource/national-association-state-charity-officials>

An association of state offices charged with the oversight of charitable organizations and charitable solicitation in the United States. The requirements and procedures for forming charitable organizations differ from state to state, as do the registration and filing requirements for organizations that conduct charitable activities or solicit charitable contributions.

National Center for Charitable Statistics (NCCS)

<http://www.nccs.urban.org>

The national clearinghouse for information on non-profits in the U.S. Their mission is to develop and disseminate high quality data on nonprofit organizations and their activities for use in research on the relationship between the nonprofit sector, government, commercial sector and society.

National Council of Non-Profits

<https://www.councilofnonprofits.org>

The National Council of Nonprofits advocates for America's charitable nonprofits through its network of State Associations and 25,000-plus members. As the nation's largest network of nonprofits, they help nonprofits achieve greater collective impact in local communities by identifying emerging trends, sharing proven practices, and promoting solutions that benefit charitable nonprofits and the communities they serve. They curate and maintain resources on fundraising.

National Philanthropic Trust

<http://www.nptrust.org>

National Philanthropic Trust (NPT) is a public charity dedicated to providing philanthropic expertise to donors, foundations and financial institutions, enabling them to realize their philanthropic aspirations.

Network for Good

<http://www.networkforgood.com>

Network for Good is a hybrid organization—a nonprofit-owned for-profit. Network for Good's nonprofit donor-advised fund uses the Internet and mobile technology to securely and efficiently distribute thousands of donations from donors to their favorite charities each year. Their website includes a fundraising library.

OneOC

<https://www.oneoc.org>

The Fundraising Authority

<http://www.thefundraisingauthority.com>

Provides information, counsel and professional tools on how to raise money for organizations of all sizes.

Volunteer Match

<https://www.volunteermatch.org>

## Management System Resources

Bloomerang

<https://bloomerang.co>

Raiser's Edge

<http://bit.ly/Raisers-Edge-NXT>

## Online Donor Resources

Classy

<https://www.classy.org/tour/all-in-one-fundraising>

Crowdrise

<https://www.crowdrise.com>

Donor Drive

<http://www.donordrive.com>

First Giving

<http://www.firstgiving.com>

GoFundMe

<https://www.gofundme.com>

Razoo

<https://www.razoo.com>





# Welcome to Something Bigger!

You are a part of something bigger—THE RARE COMMUNITY! Building connections within your specific disease community is absolutely the most vital part of your efforts. Members will tell you that the depth of the connection they feel with others in their rare disease community is hard to describe. There is an innate sense of closeness and empathy that comes with a rare disease diagnosis.

Like we said in the beginning you are not alone. You are part of an estimated 30 million Americans and 350 million people worldwide that are affected by a rare disease. While the diseases and the symptoms may be different, people in the rare community often share the same challenges and fight for the same changes. This is a powerful thing! Rare is everywhere and is frankly not-so-rare.

*"It's not in the stars  
to hold our destiny,  
but in ourselves."*

- WILLIAM SHAKESPEARE



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## Let's Stay Connected!

Global Genes is invested in collecting and then sharing best practices and lessons learned as well as devoted to celebrating successes of the rare disease community.

Submit questions, feedback and your action steps here:  
[www.globalgenes.org/toolkitfeedback](http://www.globalgenes.org/toolkitfeedback)

Follow us @globalgenes



If you are interested in contributing to a future toolkit topic, please email:  
[advocacy@globalgenes.org](mailto:advocacy@globalgenes.org).

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FEBRUARY 2017 