STARTING A NONPROFIT: THE FIRST STEP
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Starting a nonprofit is no simple task, and there are many steps that should be taken to ensure your budding organization’s survival. This toolkit hopes to streamline the initial steps in an easily comprehensible and compact format. From completing all of the required paperwork to establishing internal structure, these instructions will help prepare you for this journey.

Please be sure to check out all of the toolkits’s components (the FAQ section, short video of interviews with experts, and bibliography of additional resources) in case you get stuck!
WHERE TO BEGIN? WHAT PAPERWORK...?

This is potentially the biggest operational hurdle you will face, but don’t get discouraged. We will help you navigate through the process! Also, make sure to watch the accompanying interviews that feature expert advice from others.

**Fulfilling State Requirements**

It is recommended to be fully prepared before embarking on securing nonprofit status. So it’s helpful to have a 1-2 page synopsis of your nonprofit’s goals and the processes by which you hope to attain them. Also, make sure to write a list of all your resources (contacts, financial, etc.).

Each state has specific requirements, and they differ greatly by state. Find direct information regarding your state by going to http://usa.gov and searching “State Filings for Nonprofits. But there are some similarities that this section will touch upon. Often, a department within the Secretary of State’s office handles the nonprofit incorporation, and these offices can mail informational packets on the incorporation process. Instructions that guide individuals through the process and sample templates are also available on their websites. To find your Secretary of State, visit here: http://www.fec.gov/pubrec/cfsdd/cfsdd.shtml.

One patient advocate elaborates on this process:

“...the hardest thing to understand and deal with is the fundraising and filing that is needed from state-to-state. It is daunting and easy to mess up on. I am still learning, and I have much more to understand, but the rules for funding, accounting and taxes are the most intimidating to people when they start their organization, especially if they are small or trying to do it all on their own (the case for many rare disease organizations).

I used LegalZoom (http://www.legalzoom.com/) to do our Articles of Incorporation, our 1023 for the IRS 501(c)3 process and the state filing for tax exempt status. It was the easiest and most inexpensive way for us to do this, and they gave excellent help. It was approved fast without issues, through the expedited process with the IRS. I also looked to the National Organization for Rare Disorders (NORD) (http://www.rarediseases.org/patient-orgs/build-an-org) and found the information helpful.

I have e-filed to renew the Articles of Incorporation for years, but I had not looked back at the details in a long time. Things evolve in the process, especially when developing the Bylaws and doing the 1023 filing for IRS tax exempt status.”

— Karen Durrant, President & Founder, The NOMID Alliance

Incorporating has several benefits, including limiting personal liability and allowing the nonprofit to apply for tax exemption from the Internal Revenue Service (a topic explored later in this section).
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But in order to incorporate your nonprofit organization, one important legal document you may have to prepare is an Article of Incorporation (or in some states, a Certificate of Incorporation). This document verifies the organization’s name and its existence. And it is essential to note within it that no part of the organization’s assets will benefit its members. In order for it to be complete, signatures must be obtained from all Incorporators while in the presence of a notary. Once this has been filed with a state government, the organization becomes a legal entity.

In addition, bylaws of how the organization will be managed have to be created. These explain important procedures, detailing how directors are elected and their length of service, other positions within the organization and their duties, the frequency of meetings, etc. Please note that bylaws are determined by each state. Read a checklist of all the vital components of bylaws here: http://www.blueavocado.org/content/bylaws-checklist

While submitting these documents to a state government, one may have to pay appropriate fees.

Fulfilling Federal Requirements

After the corporate filling offices return a copy of your filed articles, you can submit your federal 501(c)3 tax exemption application to the IRS. This is known as the IRS Form 1023, Application for Recognition of Exemption. Please note that it can take 3 to 12 months for the IRS to return its decision, and it is best to file within 27 months after the date of your incorporation. Read the IRS application instructions here: Go to http://www.irs.gov and search “Application for Recognition of Exemption.” Once your application has been received by the IRS, it will be reviewed and either approved, denied, or placed on hold while the IRS gathers more information. To read instructions on filling out the proper forms, please access the IRS Publication 557, Tax-Exempt Status for Your Organization: http://www.irs.gov/pub/irs-pdf/p557.pdf. The IRS also has a help line: 1-877-829-5500.

Although it may seem daunting, others have traveled this road before you. One patient advocate reflects on her experience filing her federal 501(c)3 exemption application to the IRS:

“Our 501(c)3 process was very clean and simple. It took us 5 weeks from the time we submitted our 1023 application until our tax-exempt status was approved.

The biggest obstacle is people underestimate the amount of work that needs to be done beforehand. All the paperwork needs to be completely in order when you submit it because the IRS will kick back your form to you if they have any questions or discrepancies. If you have everything prepared in complete detail, the quicker you will get your paperwork through.”

— Carrie Ostrea, Executive Director, Little Miss Hannah Foundation

Another patient advocate shares her experience of filing with the IRS, explaining how she believes her organization was quickly approved:

“The entire process of filing and then getting the confirmation letter to become a legal 501(c)3 with the IRS can take anywhere between 12-18 months. I was fortunate because I filed in November and was approved the following April—that is rare in itself. I think I was approved so quickly because I answered honestly and exactly to the point. I would advise others to try to
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keep it short, sweet, and simple. The IRS doesn’t want long, drawn-out explanations.”

— Susan Noble, Founder & President, Epilepsy Warriors Foundation

States vary in regards to tax-exempt status. Some states require a separate application to get state tax exemption; some states are satisfied with your federal tax-exempt status, while others will request a copy of your IRS approval letter (also known as a determination letter). To find out what your state requires, contact your state tax agency: http://www.taxadmin.org/fta/link/default.php.

Fundraising by State

Once you receive tax-exempt status from the federal government, many states and localities will require its nonprofits to register with the Charities Registration Bureau of the state/localities where you plan on fundraising. If you anticipate fundraising in multiple states, you may need to register in each state. One patient advocate explains what her organization did to secure fundraising capabilities:

“Cure JM Foundation is registered with the Department of Charitable Solicitations in every state where fundraisers are held. This department is generally part of the Attorney General’s office or the Secretary of State. The registration process can vary by state, but typically requires an initial report of finances and governance along with annual financial reporting.

In terms of requirements, I always make sure we have the appropriate permits, insurance, licenses and approvals needed for any fundraising event. This will vary with the type of event and the location.

Each state has different rules regarding raffles and anything that could be interpreted as “gambling,” such as Monte Carlo events. Most states require a gaming license from the state’s Charitable Gaming Department.”

— Shari Hume, Co-Founder & Vice President of Marketing, Cure JM Foundation

State rules are summarized in http://www.multistatefiling.org. The state-by state index will give you a sense of whether you need to talk to your local charity-oversight officials before starting a campaign. Another great tool is the National Association of State Charity Officials. This collection of state offices regulates charitable organizations and charitable solicitation in the United States: http://www.nasconet.org/documents/u-s-charity-offices/

In addition to your state, your city may also require you to have a solicitation license before you can begin fundraising.

Finding Quality Assistance

It’s important when filling out these forms to seek guidance from experts—not just your friends who may be less familiar in these areas. There are lawyers and accountants who have direct experience working with nonprofits. They can be found through your state’s bar association, the Better Business Bureau, searches for experts in tax-exempt organization (or nonprofit) law, or references from other nonprofit owners.

The Better Business Bureau (http://www.bbb.org/) is a nonprofit organization that collects and offers free business reliability reviews. It also alerts the public of potential scams.
Global Genes Rare Toolkits

Bringing Rare Disease to Capitol Hill: Advocating for Your Cause

Creating Organizational Structure

Nonprofits are rarely produced by a single-minded visionary, and your chances of success increase with support from others. Assistance can come in many forms, paid or nonpaid.

Building a Board of Directors

Think of the Board of Directors as the governing body of your nonprofit organization. Usually filled with volunteer members, this is an essential component (and legal requirement) of most nonprofits. Arranged in the organization’s bylaws and often contingent upon state laws, a nonprofit’s Board of Directors meets as often as once a month and as rare as once every quarter.

“As a new nonprofit, if you have developed a ‘working board’ (meaning one that doesn’t just advise but also helps with tactical execution), it should meet once a month by phone for 1 hour. This allows board members to share what they have been working on, while hearing updates from the others.

Another thought to consider is hosting an annual in-person ‘board retreat’ to bring all of the board members together for a half or full day. As the nonprofit becomes older and more well-established, it is appropriate to host board meetings once a quarter (with 1 of them as an in-person meeting or board retreat).”

— Nicole Boice, President & Founder, Global Genes | RARE Project

Unlike a for-profit’s corresponding body, a nonprofit’s Board of Directors is often more entrenched in the organization’s operations: fundraising, managing, etc. It also monitors the organization’s fiscal management, reviewing and approving the annual budget and verifying that the nonprofit’s money is being effectively and efficiently utilized. Please note that the latter must also be weighed against the pledges to donors.

In addition, the Board of Directors frequently reevaluates how well the organization is fulfilling its mission: reviewing plans for major programs and ensuring that the nonprofit’s values are considered before proceeding with every action. Board members also support the organization in the community, conveying its mission to raise awareness and funds.

The minimum number of board members depends on which state your nonprofit is incorporated in. A minimum is typically 3 members, and if larger, it is recommended to build your board slowly and carefully. It would be a big mistake to not properly integrate new members through orientations, training sessions, and evaluations. Doing this can ensure the long-term success of any board!

When recruiting board members, it is important to represent varied talents and backgrounds to stimulate growth. Ask yourself if they have relevant skills:

- Legal
- Financial
- Marketing
- Public relations
- Philanthropic
- Entrepreneurial/Business

A good board member brings unique abilities and perspectives. Refer to the “3 W’s”: Work, Wisdom, and Wealth.
They should provide at least 2 of the 3 to be desirable candidates for your Board of Directors. What else is vital? An active interest in the organization! It also helps if the board member is connected in the community, represents your constituency, and truly hopes to see your organization succeed!

A good resource for boards is BoardSource (https://boardsource.org/eweb); it offers online advice, printed materials, periodicals, and other tools. BoardSource is a membership organization with many free resources for members.

Assembling a Staff Team

When starting your nonprofit, you may not know immediately how many staff members and volunteers it will need. But a great way to begin is by creating a list of positions that you believe are necessary, including their duties: managerial, administrative, functional, etc. Staff can facilitate everything from operations to development, so the board can concentrate on its own responsibilities.

A great way to simplify it is by combining complementary activities and matching these lists to designated positions. For example, answering phones, filing paperwork, and managing office supplies could all be delegated to an Office Manager.

When deciding whether these positions should be paid or not, it is wise to consider if they would be a daily necessity. Will these positions cover activities that happen habitually, weekly, annually, etc.? If a position is ongoing, you expect the person to commit to a specific amount of daily time and/or if their services are specialized, it may be a good idea to make it a paid position.

Many nonprofit founders ponder how much employees should be compensated, so it can be wise to browse and assess current job openings for nonprofits to better understand the hiring environment. Salaries for similar positions can vary, depending on geography, the organization’s size, the position’s responsibilities, and the specific candidate’s qualifications.


Another thought to consider is if this team of paid staff should be salaried (with benefits) or contactors (with no employee taxes, benefits, etc.). The latter is great for new organizations as providing benefits can be costly.

Securing Dedicated Volunteers

Many nonprofits rely on the generosity of unpaid volunteers for many of their programs, activities, and efforts, so the importance of their services cannot be stressed enough! Since most nonprofits are very small, many are purely sustained by the energy and tenacity of a small group of volunteer supporters.

Volunteers can be utilized in a variety of modes. They can deliver direct services; participate in events, fundraisers, or activities; educate the community on your mission and goals; distribute marketing materials; sell memberships, tickets, or goods; as well as a multitude of other tasks!

First, make sure your volunteers align well with your organization. Assess all potential volunteers’ goals, interests, and skills to save you time and energy in advance. Imagine the time you may waste finding, selecting, and training an unwanted volunteer!
“Sometimes the best volunteers are your closest friends and family. Often times they are the first to jump on board and rally behind your cause. These are by far some of the best, most passionate and most reliable volunteers. However, use caution when enlisting them and be very purposeful as to HOW you use them.

For example, you might be hosting a benefit dinner, and your family and friends are anxious to help. Of course, you never want to turn down help! But you also don’t want your best, most passionate supporters to feel like they are work horses and are only at your event to work. This is especially true if you need to enlist volunteers multiple times a year, regardless of the reason, purpose, or event.”

— Cassie Johnston, Co-Founder, Alström Angels

Once attained, it may be a struggle keeping them! So try to make volunteering for your organization fun. Consider providing food or beverages for them, and make sure they are not overwhelmed. Do they have heavy workloads? Is the work being evenly distributed amongst the volunteers or does one have more responsibilities than all of the others? It is crucial that they don’t feel crushed with work.

Most importantly though is that their charitable efforts (both great and small) are recognized. Volunteer recognition is one of the most effective ways of retaining good volunteers. A few examples are highlighting their efforts in a newsletter, media releases, staff meetings or events (like an all-volunteer exclusive dinner or a Volunteer Appreciation Day). To read a more detailed guide on retaining volunteers from Cassie Johnston, Co-Founder, Alström Angels, turn to the Appendix.

Idealist (www.idealist.org) and Volunteer-Match (www.volunteermatch.com) are great sources for volunteers. Upload short job descriptions to generate interest in your organization!

Another great resource is A Volunteer’s Bill of Rights and Responsibilities.

Go to http://www.Idealist.org and search “Volunteer’s Bill of Rights and Responsibilities”, which outlines what volunteers are entitled to.

### Considering Consultants

A consultant is a professional who provides expert, specialized advice on either a terminal or ongoing basis. There are many types of consultants, and several can be beneficial for your organization: marketing/social media, web design/information technology, accounting, legal (especially in tax law), event planning and management.

Nonprofit consultants can advise you on how to obtain grants, manage budget, improve your organization’s image, and communicate with the public. A consultant can sometimes better assist a nonprofit’s situation because, as an outsider, he/she can provide an objective view.

Consultants are best when approached on a project or limited basis. Consider how often you plan on communicating with this expert for advice. Will you need their guidance on a monthly, weekly, or daily basis, and are the tasks time consuming?

The [Association of Consultants to Nonprofits](http://www.acnconsult.org/) helps connect consultants to nonprofit organizations as well as provide both with useful tools.
How to Retain Volunteers and Show your Appreciation: Cassie Johnston, Alström Angels

We like to use a 3-step approach to strengthen the relationship between our organization and our volunteers: Recognize, Promote to Leadership, and Appreciate.

Recognize

Show your volunteers that you know how much time they have committed to your organization and recognize that commitment. Many organizations will use newsletters and emails to recognize their volunteers. While this is fine, we encourage you to take this recognition one step further.

Create a “benchmark” of logged volunteer hours to recognize the individual as exceptional. Give this benchmark a name: Star Volunteer, Honor Volunteer, etc. Once your volunteers reach this benchmark, recognize that achievement in your newsletters and emails. We also recommend you provide these exceptional volunteers with a status symbol: a lapel pin, ribbon, or special shirt to wear that signifies their achievement. This status symbol can be worn at all volunteer opportunities to showcase their accomplishment of becoming an exceptional volunteer.

Here is an example:
Once our volunteers reach 15 logged hours at our organization, Alström Angels, they become an “Angel Volunteer,” and we present them with an angel lapel pin to wear at our events and volunteer opportunities. In our newsletters and emails, we list all volunteers, but give special recognition to our Angel Volunteers.

Promote to Leadership

Everyone loves to get promotions and be recognized as a leader within their organization/business. Volunteers are no exception! So promote your volunteers to team leader as their roles become more substantial. A team leader is a volunteer that is knowledgeable about your organization; passionate about your mission; and able to help train, motivate, and recruit more volunteers. As your volunteer base grows, this could be a valuable method to keep everyone involved, organized, and informed about your organization’s needs. The most important gain that comes out of this method is your team leaders’ ownership of the success or failure of their teams. They become personally vested in the involvement of their team members.

There are several different criteria you can use to determine who would make a good team leader. Here are the measures we use:

After an Angel Volunteer logs at least 30 total volunteer hours with our organization, they are eligible to become a team leader. Then we look at the volunteer’s overall passion for our mission and understanding of the inner workings of our organization. We also look at their past track record: How reliable are they? Do they naturally take the lead on tasks? Do others look up to them?
Appreciate

Appreciate, appreciate, appreciate your volunteers!! We can’t emphasis this enough! After all, they are the fuel that allows our organizations to do the amazing things we do on shoe-string budgets. And the more you appreciate your volunteers, the more they will be refueled for the next task or event.

The possibilities are endless as to showing your volunteers how much you appreciate the time and effort they have given to your organization. We like to host an annual Volunteers’ Luncheon where we shower them with praises and awards. Every single volunteer is recognized at the Luncheon, including Angel Volunteers and Team Leaders.

Additionally, we give out special awards to individual volunteers and teams. Here are some examples:

- **Outstanding Commitment Award** – The individual who volunteered the most hours
- **Exceptional Team Award** – The team that volunteered the most collective hours
- **Extraordinary Heart Award** – An individual whose passion for our mission and commitment to deliver that mission is unparalleled
- **Extra Mile Award** – An individual who always goes above and beyond what was asked of him/her without exception
- **Guardian Angel Award** – An individual whose overall commitment to our organization and passion for our mission has made a difference in the lives of others

Another way we like to remind our volunteers how special they are is by sending them a birthday card. This is a very easy, low-cost way to make a huge gesture of appreciation for the special people who make our organization run. Because this is so impactful, we recommend implementing birthday cards as a minimum standard for volunteer appreciation.
Acquiring and Retaining Volunteers

A Volunteer’s Bill of Rights and Responsibilities (Go to http://www.Idealist.org and search “Volunteer’s Bill of Rights and Responsibilities.”): This article outlines what volunteers are entitled to. When new and unsure of how to properly retain volunteers, this guide outlines what volunteers should receive for their efforts and contributions to your organization’s cause.

Idealist (www.idealist.org):
Idealist connects people, organizations, and resources together, so everyone feels capable of reaching their philanthropic goals. Use this site to upload short job descriptions to generate interest in your organization and recruit dedicated volunteers.

VolunteerMatch (www.volunteermatch.com):
VolunteerMatch is a great source to find volunteers and generate interest in organizations. Like Idealist, this site can be used to upload job descriptions for vacant volunteer positions.

Building a Board of Directors

BoardSource (https://boardsource.org/eweb):
BoardSource is a membership organization that offers online advice, printed materials, periodicals, and other tools. A 501(c)3 organization itself, BoardSource is a tool that offers advice to boards so they can reach their goals in relation to their missions, financial positions, and strategic directions.

Determining Staff Members’ Compensation

The Economic Research Institute allows users to search through compensation data from nonprofits by job title and geographic location. When pondering the amount your employees should be adequately compensated, it is wise to assess the hiring environment. Refer to similar positions within the area to get a better understanding of the climate through this resource.

Finding Consultants

Association of Consultants to Nonprofits (http://www.acnconsult.org/):
This association connects consultants to nonprofit organizations. When considering adding consultants to your team, this site can help you identify ample new additions.
Fundraising Resources

National Association of State Charity Officials (http://www.nasconet.org/documents/u-s-charity-offices/):
Just as the requirements and procedures for forming charitable organizations differ from state to state, so does the registration and filing requirements for organizations that conduct charitable activities or solicit charitable contributions. Use this collection of state charity offices to learn what is needed for your specific state.

Gaining Nonprofit Status

Blue Avocado (www.blueavocado.org/content/bylaws-checklist):
A magazine of American nonprofits, Blue Avocado provides practical information for nonprofits, including all of the components for the bylaws. This resource provides a checklist of all the vital components of the bylaws.

This directory lists Secretaries of States. Often, a department within the Secretary of State’s office handles the nonprofit incorporation, so browse their websites to find instructions on this process and sample templates.

Federation of Tax Administrators (www.taxadmin.org/fta/link/default.php):
Each state has different requirements for rewarding tax-exempt status. To learn what your state requires, use this directory of state tax agencies.

This resource supplies the instructions for filling out the IRS Publication 557, Tax-Exempt Status for Your Organization.

US Government Official Web Portal
(Go to http://usa.gov and search for “State Filings for Nonprofits”):
This web portal provides trusted, timely, and valuable government information and services to the public. Use this direct link to learn of each individual state’s specific requirements for securing nonprofit status.
RESOURCE GUIDE

Seeking Guidance from Experts

The Better Business Bureau (www.bbb.org):
This nonprofit organization collects and offers free business reliability reviews. When filling out these forms for your emerging nonprofit, it is important to consult experts. Read reviews on the possible experts you wish to consult through this resource.
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