



RARE TOOLKITS

# Building a Foundation and Your Future





Most likely you have a need for this **Building a Foundation and Your Future** toolkit because you or a loved one has a rare disease. 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 make the road to advocacy for your rare disease more manageable.

We know, all too well, that a lack of information and support for people living with rare diseases can lead to feelings of depression, anxiety, and isolation. This is common, but you are not alone. Fortunately, rare advocates see these challenges as opportunities to take control and many fill the void with support, knowledge, and advocacy.

While we believe you will benefit from reading all of the material in this toolkit, we don't want to overwhelm you. 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. ■

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 *Paper and pen indicate an interactive exercise*



# Founding Fathers and Mothers

Passionate fathers, mothers and others are founding rare nonprofit organizations around the globe. But like runners in a marathon, each founder is running their own race. Therefore, it is important to resist measuring the success of your foundation against the success of other founders.

Experienced founders advise that, regardless of your motivation and mission, managing a nonprofit is comparable to running a small business. If a new founder can execute the steps for foundation building from the perspective of owning a business, the process may feel more familiar.

### Just Do It!

While Nike's "just do it," tagline helps the company sell a gazillion pairs of running shoes, the experienced runner knows the "doing it" part is preceded by mental and physical preparation. Whether you are just starting a nonprofit or you are an experienced founder with the goal to take your foundation to the next level, being prepared with good resources and pacing yourself can make it easier to get to the next mile marker.

Here are some highly recommended next steps for a founder to consider between mile markers:

### State of Mind

- Be honest about where you are mentally, emotionally, and physically as it relates to taking on the responsibilities necessary to fulfill your foundation's short-term and long-term goals.
- Be candid with your family about what you believe is the best mission and vision for the foundation. (It helps to know they'll be cheering for you.)
- Beyond your passion for starting a foundation, are you prepared to be the leader of your foundation?
- Do you need to reevaluate your foundation's mission, vision, or strategic plan before you take the next step?

### Self-Check Interactive: Take Me to Your Leader!

Being a good leader is a benefit to your family, patient community, volunteers, and the many other partnerships a founder has. Social science suggests some people are born with the personality traits that make them "natural born leaders". Maybe you're a natural born leader—maybe not; in either case there are many ways you can improve your leadership skills to benefit your organization.

Put a check ✓ mark next to the traits that you believe best reflect your leadership style:

- Micromanaging
- Effective delegator
- Fair negotiator
- Flexible
- Good communicator
- Good listener
- My way or the highway
- Natural problem-solver
- Generally optimistic
- Patient
- Transparent

Forbes magazine lists the following personal qualities of effective leaders. Put a check ✓ mark next to the qualities you want to improve:

- Confidence
- Creativity
- Enthusiasm
- Honesty
- Humility
- Ethical

List three people whose style of leadership you admire and can emulate.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

Use your responses to this self-check guide to evaluate your leadership skills and to make improvements where necessary.



### Patient Community Needs: Leaders

Filled with passion to move forward on starting a foundation, a new founder may be unaware of founders on the path ahead of him. He may not know that these leaders are already meeting the needs of the same or similar patient communities.

Co-founder and President of the Global Foundation for Peroxisomal Disorders, Melissa Bryce Gamble advises, "Make sure your nonprofit meets a current unmet need. Before you begin all the hard work needed to create a nonprofit from scratch, ask yourself this question: What unmet need will I fulfill? In the nonprofit world, we can't afford to duplicate efforts. The resources are limited, so work to partner with whomever you can to get your goal accomplished." (From the article "Business Perspective with Melissa Bryce Gamble: Use This Checklist to Start Your Nonprofit," published by tulsaworld.com.)

### Expert Tips!

Experienced founders suggest these tips for addressing the needs of the patient community:

- Founders do not have to have a strategic plan in place to understand the unmet needs of a patient community—ask people what they need.
- Have honest conversations and share your story with others in your rare community. Sharing these stories opens the door for collaboration between community members to address their needs.
- When the needs of the community are understood, the founder's role is to connect with leaders in the rare disease space and relay those needs to people who can help the community.
- If there is an organization doing what you are doing, instead of reinventing the wheel by yourself, think about partnering with them.
- Mirror your passion and mission to the reality of what is really needed in the patient community.
- Don't start a nonprofit if there is an existing organization making rapid progress. Rare diseases are similar. When a treatment is discovered for one of them the door will open to discover treatments for many others. ■



## Lacing Up: Starting a Nonprofit

Buying a new pair of running shoes when preparing for a marathon is a practical, but optional, expenditure. The same is true for founding a nonprofit; but in addition to optional expenditures (having a post office box), there are practical expenditures (again--having a post office box) to consider. New founders need enough funds in advance of incorporating to cover startup costs and operational expenses.

### Basic Business Startup Expenses

- Articles of Incorporation application
- Register corporate name
- Legal assistance
- Accounting assistance
- IRS Form 1023, 501(c)(3) status application
- Basic liability insurance coverage for directors and officers
- Nonprofit mailing permit from US Postal Service
- Post office box
- PR/marketing materials
- Individual state(s) charitable solicitation registration
- Website
- Home office expenses

Soliciting money from donors to pay for startup expenses prior to incorporation does not offer a tax benefit for the donor or the founder. Therefore, it is common for a founder to use: personal savings, credit cards, investments, retirement funds, family loans, second mortgages, and other personal finances to start a nonprofit.

### Expert Tips!

Three rare foundation experts share their insights on startup resources:

*Meredith Cagle*

Senior Director of Patient Engagement, Global Genes

*"Find a fiscal sponsor. A fiscal sponsor can allow a founder to fundraise under the sponsor's nonprofit status until the sponsored organization receives nonprofit approval. A fiscal sponsor may also be willing to assist a new founder with startup costs."*

*Melissa Bryce Gamble*

Co-founder and President of the Global Foundation for Peroxisomal Disorders

*"Government grants for starting a nonprofit, if they exist at all, are minimal. Therefore, the funds to start a nonprofit generally come from the founder and the initial board members."*

*Luke Rosen*

Founder KIF1A.org

*"It saves time and money to have somebody on your team who knows the short-cuts. Find the best clinical social worker you can. Ask this person to help you navigate the rare disease space and to direct you to other people for guidance."*

Based on a number of factors, location being one of them, the costs of business expenses can differ greatly. Also, depending on your foundation's mission, some cost may be optional. Internal Revenue Service (IRS) applications and filing fees can vary by hundreds of dollars as explained in this IRS.org instruction for filing tax-exemption Form 1023 or Form 1023-EZ to get tax-exempt 501(c)(3) status.

### IRS Form 1023/Form 1023-EZ Fees

*"The amount of the user fee depends on the applying organization's average annual gross receipts. If the organization's average annual gross receipts have exceeded or will exceed \$10,000 annually over a four-year period, the fee is \$850. If gross receipts have not exceeded or will not exceed \$10,000 annually over a four-year period, the user fee is \$400. An applicant must certify its gross receipts in Part XI. If the organization is eligible to submit Form 1023-EZ, the user fee is \$275."*

*[The fees listed in this IRS instruction were current when this toolkit was published. Please visit IRS.org for updates or changes.]*

*(See the Example Forms section at the end of this toolkit for additional information on filing IRS Form 1023.)*

## State Your Case: State Laws

State laws govern nonprofit status with the IRS. An organization receives nonprofit status by filing Articles of Incorporation with its state's Secretary of State office. It must be noted that nonprofit status is not required to apply for federal tax-exemption. And, having nonprofit status does not guarantee that an organization will receive a federal tax-exemption.

### Time-Saver Tip!

Articles of Incorporation applications differ somewhat by state. But, having answers to these commonly asked questions on applications in advance of starting the application may save you some time:

- ✓ The corporation's name
- ✓ The corporation's business address
- ✓ The name and address of your corporation's registered agent
- ✓ The corporation's purpose/mission
- ✓ The corporation's duration
- ✓ Information regarding the number of (if any) shares and classes of stock the corporation is authorized to issue
- ✓ The names and addresses of the incorporators (or of the initial officers or directors)
- ✓ One or more incorporator signatures

In addition to providing information to apply for Articles of Incorporation your state may also require the following:

- ✓ File Articles of Incorporation at the county level
- ✓ Publish your incorporation filing in a local newspaper(s)
- ✓ Adhere to laws for soliciting and receiving donations from other states
- ✓ Register with a state agency before soliciting the state's residents for contributions
- ✓ File periodic financial reports with states you solicit contributions from

*(See the Example Forms section at the end of this toolkit for an example of the Articles of Incorporation directive from the Illinois Secretary of State.)*

## Out of State Charitable Solicitations

To determine what state(s) you may be required to register to solicit charitable contributions or hold assets subject to a charitable trust, the IRS suggests checking the National Association of State Charity Officials website.

After the Secretary of State's office reviews and accepts the submitted Articles of Incorporation, and agrees the name of the corporation is acceptable and available, the corporation becomes legal. Acceptance of the Articles by the Secretary of State should be considered a contract between the incorporator(s) and the state.

## The Feds and IRS 501(c)(3) Status

Next, you'll need to cooperate with the federal government to get tax-exempt, IRS, 501(c)(3) status for your foundation. Organizations described in IRS section 501(c)(3) are commonly referred to as charitable organizations and fall into one of three primary categories:

1. public charities
2. private foundations
3. private operating foundations

Organizations described in section 501(c)(3), other than testing for public safety organizations, are eligible to receive tax-deductible monetary contributions in accordance with IRS code section 170. ■

## The Name Game: Naming a Foundation

Naming a foundation may be one of the most important decisions a founder will make. As with any organization, over time, its name becomes synonymous with its identity. In her book "Designing Brand Identity," Alina Wheeler identifies some of the major categories for types of brand names.

Here are five of those brand name categories with pros and cons for using them to name an organization.

### 1. Founder

Pros: The chances of another brand in your industry having the same name are slim.  
Cons: If there is bad press about the founder, it may negatively affect the organization.

### 2. Descriptive

Pros: Immediately conveys your purpose. (The American Heart Association)  
Cons: Using a specific feature of your organization in your name may not accurately represent the organization's mission in the future.

### 3. Fabricated

Pros: Because of their uniqueness fabricated names stand out and may invoke curiosity about a brand.  
Cons: It does not readily identify the organization's purpose.

### 4. Creative spelling

Pros: It may be easier to get a website domain name with an unusual spelling of a common word.  
Cons: There's the risk of people misspelling the name in print and in online searches.

### 5. Numeric

Pros: The story behind a word and a number can make for a memorable name.  
Cons: It might be hard to secure a website domain if the name only has a couple of numbers. Long numeric names may be difficult for people to remember.

*"The name of your new brand will usually be with you forever. Once a name has been selected and implemented, it is an expensive and disruptive undertaking to go through the process of changing that name, which is why it is so important to get it right the first time."*

FABIAN GEYRHALTER, AUTHOR, "HOW TO LAUNCH A BRAND"



# The Longest Mile: Incorporation to Tax-Exemption

The process from Articles of Incorporation to IRS tax-exempt 501(c)(3) status may feel like the longest mile a new founder has to run, and depending on the circumstances, it may well be. The good news is a founder doesn't have to run this mile with a blindfold on. A business tax attorney, IRS.gov, your state's government website, online legal sites, and other nonprofit founders and leaders (some of whom generously contributed to this toolkit) are resources that can make the process less taxing.

Listed are the basic steps for nonprofit incorporation and applying for IRS, 501(c)(3) status:

1. Obtain an Employer Identification Number (EIN). Similar to a Social Security Number, an EIN is the equivalent of your corporation's federal ID number. The IRS form for obtaining this number is SS-4.
2. Apply for your state's Articles of Incorporation through its website.
3. File IRS Form 1023. Assuming your documents pass muster the first time out, this form is the final step in obtaining your tax-exempt 501(c)(3) status.
4. Go fishing! The turnaround time for completion of review of the IRS Form 1023 is normally about 2 months; but it may take up to six months depending on the office its being processed through.

*(See the Example Forms section at the end of this toolkit for more information about applying for an EIN.)*



## Time-Saver Tip!

Most organizations seeking exemption from federal income tax under section 501(c)(3) are required to complete and submit an application. However, the following types of organizations may be considered tax exempt under section 501(c)(3) even if they do not file Form 1023 or Form 1023-EZ.

- Churches, including synagogues, temples, and mosques.
- Integrated auxiliaries of churches and conventions or associations of churches.
- Any organization that has gross receipts in each taxable year of normally not more than \$5,000.

## Run on Purpose: Mission Statement

From the New Year's resolution runner (you know who you are) to the marathoner who greets every sunrise on a running path, they are both on a mission. And while starting a nonprofit is a different type of endeavor, the founder of a nonprofit is also on a mission.

The founder's mission should define the organization and give it focus. A good mission statement should, ideally, convey the purpose of the organization in a memorable way. And if those reasons aren't motivation enough to create a mission statement—this might be: a mission statement is required on the IRS Form 1023, tax-exemption application.

*(See the Example Forms section at the end of this toolkit for more information about applying for an EIN.)*

## 10-to-Know: IRS 501(c)(3) Status

1. State law governs nonprofit status, which is determined by an organization's Articles of Incorporation or trust documents.
2. Federal law governs tax-exempt status.
3. Entities that can seek 501(c)(3) determination from the IRS include corporations, trusts, community chests, limited liability corporations, and unincorporated associations.
4. The overwhelming majority of 501(c)(3) organizations are nonprofit corporations.
5. To be tax-exempt under section 501(c)(3) of the Internal Revenue Code, an organization must be organized and operated exclusively for exempt purposes set forth in section 501(c)(3).
6. None of the earnings of a 501(c)(3) may inure to any private shareholder or individual. Most tax-exempt organizations are required to file an annual tax return 990-series form.
7. To qualify for 501(c)(3) status, the organization must be a corporation, community chest, fund, articles of association, or a foundation.
8. A trust is a fund or foundation and will qualify for 501(c)(3) status. Individuals or partnerships won't qualify for 501(c)(3) status.
9. If an organization engages in an excess benefit transaction with a person who has substantial influence over the organization, an excise tax may be imposed on the person and any organization managers agreeing to the transaction.
10. Section 501(c)(3) organizations are restricted in how much political and legislative (lobbying) activities they may conduct.

## IRS Tip!

Do not include Social Security numbers on publicly disclosed IRS forms. The IRS is required to disclose approved exemption applications and information returns; exempt organizations should not include Social Security numbers on these forms. Documents subject to disclosure include supporting documents filed with the form, and correspondence with the IRS about the filing.

## Expert Tips!

Use these expert tips to create a mission statement:

**Clearly** communicate the intent of the organization

**Avoid** an overuse of words and jargon

**Be** clear and concise

**Keep** the statement to one or two sentences (about 15 words)

**Be** direct and get to the point

**Create** a tagline if the mission statement is more than 15 words (the tagline should reflect the mission statement)

## Examples of Popular Mission Statements:

**American Diabetes Association:** To prevent and cure diabetes and to improve the lives of all people affected by diabetes.

**American Heart Association:** To build healthier lives, free of cardiovascular diseases and stroke.

**Leukemia & Lymphoma Society:** Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

**Make-A-Wish:** We grant the wishes of children with life-threatening medical conditions to enrich the human experience with hope, strength and joy.

**Susan G Komen for the Cure:** Fighting every minute of every day to finish what we started and achieve our vision of a world without breast cancer.

## Examples of Popular Taglines:

**United State Forest Service:** Give a hoot, don't pollute!

**United Negro College Fund:** A mind is a terrible thing to waste

**Drunk Driving Prevention:** Friends don't let friends drive drunk

**Pennsylvania Breast Cancer Coalition:** Finding a cure now...so our daughters don't have to

**National Crime Prevention Council:** Take a bite out of crime ■



# Create a Path: Strategic Planning

After celebrating the nonprofit's incorporation, a new founder has a must-do list that includes: holding the initial meeting of shareholders and directors; adopting bylaws; and appointing officers. With all of these to-dos properly documented, the business of creating a strategic plan can begin. A good strategic plan creates a path for achieving the nonprofit's short-term and the long-term goals starting with its:

**Mission:** the fundamental business of the organization (the work it does).

**Vision:** the impact the organization will have in the world because of its work.

**Values:** the essential tenets that drive organizational behavior and decision-making.

### Why Strategic Planning?

The founder needs to formulate a cohesive strategic plan, even if its yet to be published, that can be shared with board members, volunteers, staff, donors, and advocate partners. Even a small



Graphic courtesy of:  
Child Neurology Foundation and McKinley Advisors

organization needs to know what the founder's destination is and what path the founder is creating to get there. For the new founder, it may be easier to think of strategic planning like an exercise and not a document. Do an internal and external assessment exercise of your organization.

### Assess:

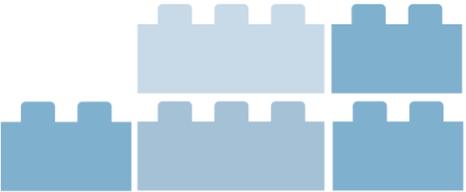
- Financial resources
- Patient community needs
- Staff/volunteers
- Fundraising strategies
- Other foundations with similar missions
- Collaborations/partnerships
- The organization's next step(s)

### Plans and Process

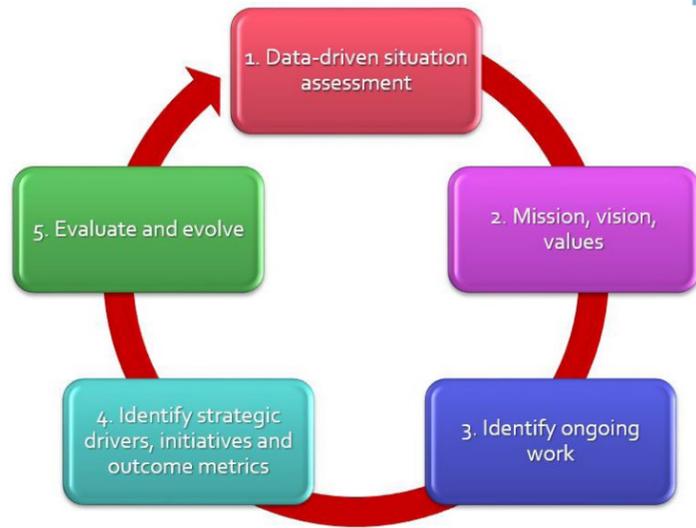
While, the idea of creating a strategic plan may bring up feelings of angst and uncertainty, the process should not be equated with a dentist appointment. Strategic plans generally prescribe to a three-year or five-year plan model. Based on different variables (staffing, funds, goals) a three-year plan may be more

practical than a five-year strategic plan. And a new founder may feel excited to have a strategic plan that covers the next 90 days!

A five-year strategic plan is most often presented in the for-profit industry to investors, but is it the preferred option for nonprofits? Amy Miller, Executive Director of the Child Neurology Foundation, offers this counsel, "While, a five-year strategic plan gives an organization time to get traction on its goals and to show deliverables to donors, board members, collaborators, and the public, it's not necessarily the best option for healthcare and advocacy nonprofits. Because the landscape in the healthcare space is constantly changing, the recommendation is to create a three-year strategic plan. Additionally, depending on the nonprofit's mission, it can be difficult to forecast the relevancy of some trends over a five-year period of time."



# The Strategic Planning Process



Graphic courtesy of: Child Neurology Foundation and McKinley Advisors

## Expert Insight!

- Strategic planning is a good tool for avoiding duplicity of efforts by other nonprofits.
- Be open to collaboration with other organizations to get the most from available funding resources.
- A good strategic plan holds the organization accountable to its mission and vision.
- For new or established organizations, a strategic plan is the vehicle for sharing with staff, board members, advocate leaders, donors, and other partnerships how the nonprofit plans to fulfill its mission.
- Board members should help to set the strategy; the staff's role is to help execute the strategic plan.
- A strategic plan can provide insight on: what the organization should start doing; keep doing; or stop doing.
- A strategic plan shows organizational stability, transparency, and helps to control chaos. ■

[See the Example Forms section at the end of this toolkit for the Child Neurology Foundation's Strategic Drivers graphic.]



## On Your Mark: Laying the Foundation

With a working strategic plan the founder has a blueprint for laying a foundation for the nonprofit to build upon. There's money to raise; board members, volunteers, and staff to recruit; and a patient community to serve; so use the best building materials available.

### Fundraising Matters

Even large organizations with sophisticated development practices are constantly working and innovating ways to succeed at fundraising. Yes, some organizations receive large grants from benefactors like the Ford Foundation; but the reality is most nonprofits are funded by lots of small donors. A founder must constantly think of ways to raise money and generate revenue to cover basic overhead costs and programs to fund the mission.

### Donor Class

The good news is, research shows individual giving is driven by societal responsibility, self-image and a vested interest in a cause. People are also more likely to support a specific health related charity when they know someone who has the health condition or who succumbed to it.

It is best to reach out to these supporters first. They are in the nonprofit's primary network and they have a personal, mutual connection with the cause. In addition to being monetary donors, they may also become advocates, volunteers, employees, board members and/or connections to additional sources of financial support.

It is important for founders 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 transparency, good financial stewardship, and results. ■

## The Long View: Vision Statement

In addition to having a clearly defined mission statement, the organization is served well by having a vision statement. Ideally, the vision statement is one-sentence that describes the long-term desired outcome of the organization's mission.

### Expert Tip!

Use these expert tips to create a vision statement:

**Be** clear and concise about the vision (outcome) you want to achieve

**Aim** for a vision statement that is inspirational

**Create** a statement that is memorable

**Keep** the vision statement to one or two sentences (about 15 words)

### Examples of popular vision statements:

**Alzheimer's Association:** A world without Alzheimer's

**Oxfam:** A just world without poverty

**National Multiple Sclerosis Society:** A World Free of MS

**Special Olympics:** To transform communities by inspiring people throughout the world to open their minds, accept and include people with intellectual disabilities, and thereby anyone who is perceived different.

Download the Global Genes: "Finding Your Fundraising Strategy" toolkit for more expert insights on successful fundraising.



# Relay Race: Building a Board

Running a nonprofit, even a small one, is generally a team sport; akin to passing the baton to the next runner in a relay race. And board members can be some of the team's most valuable players in a variety of ways. Their individual expertise in marketing, science, finance and other areas can be vital to keeping the mission of the organization on course.

## Recruiting Board Members

All aboard—not so fast! Do not underestimate the importance of finding good board members. The prudent founder knows that not everyone who wants to support the organization will be a good fit for the board.

The board of directors is responsible for governing the organization. The board's duties of care are to set the strategy of the organization. Additionally, they should ensure that the mechanics of how the strategy is executed is: efficient, ethical, and financially responsible.

In his book, "The Power of Strategic Alignment," Dennis C. Miller says, "Good nonprofit boards evaluate their CEO, while great nonprofit boards evaluate themselves." He points out that, "The overwhelming reason most nonprofit organizations fail is the result of not adequately addressing their internal issues and not because of their response to the changing environmental landscape of the sector. An organization needs to honestly address both challenges, internal and external, in order to be in strategic alignment."

Occasionally, the line between management and oversight by the board may be blurred. But a toe or two over the line by board members does not have to lead to conflict. Being a good leader and making sure the team is aligned with the organization's current goals and how to achieve them, can minimize your possibility of having these issues with board members:

- Founder's syndrome
- Lack of trust in the CEO/founder
- Stale programs
- Bored board members
- Overreaching into how the strategic plan is executed

When recruiting board members the founder needs to know that potential members are on board and aligned with the mission of the organization. When the board is complete, ideally it is made up of members who are committed and passionate about the mission; and who also bring valuable skills to the table.

***"Overall, a board of directors ensures a mission based, strategic direction. The board makes sure the organization has goals and it supports the organization in achieving those goals."***

- MEREDITH CAGLE, SENIOR DIRECTOR OF PATIENT ENGAGEMENT, GLOBAL GENES

## Recruiting Board Members Tips!

**Recruit** co-founders, parents, caregivers, advocates, and social service providers inside the patient community.

**Invite** medical providers, pharmaceutical representatives, and others in the healthcare space to join the board.

**Look** beyond the patient community. Teachers, social activists, religious leaders, and other professionals like lawyers and accountants make good board members.

**Be** clear with potential board members about how they can contribute to the mission.

**Ask** them. Many people want to serve on nonprofit boards; founders just have to ask them.

## Types of Boards

Board members should consider the extent to which their involvement in operational activities versus strategic matters may handicap or benefit the organization. The board may consider formally defining the roles of the board and management as it relates to operational and strategic activities.

### Operational board

Members of operational boards/working boards are actively involved in the operation of the organization. Board members may offer leadership in specific areas like human resources; do bookkeeping; staff fundraising events; and provide other administrative assistance that helps the organization to operate.

### Strategic board

As the name suggests, the duties of a strategic board encompass oversight over the organization's strategic plans to fulfill its mission and vision. A strategic board has input in items like: expanding the geographical scope of the organization, new goals, additional services, budget approvals, increased research and development, investments, hiring a new CEO, and issues that affect the organization's stakeholders.

## Board Responsibility

### Fiscal responsibility

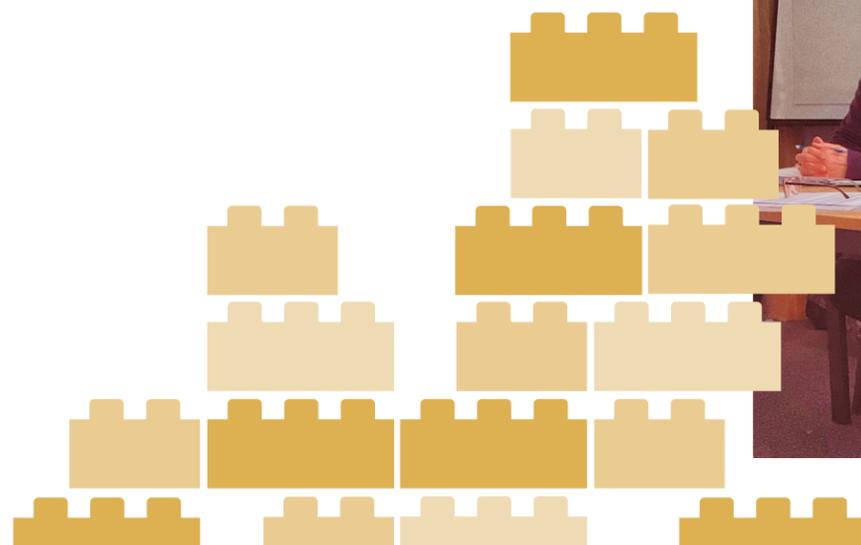
Fiscal oversight is a critical part of the board's role. The board is charged with ensuring the organization has a chief financial officer or someone with similar responsibilities (accountant, bookkeeper, or an accounting firm). This person should work with the board on developing a budget and other financial plans. Monitoring and ensuring the integrity of the organization's record keeping process and other financial reporting are also the responsibility of the board.

### Give/get board

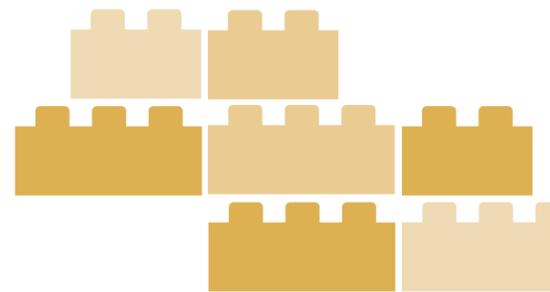
In exchange for being on an organization's board, give/get board members agree to donate (give) a determined amount of money to the organization annually. The money can come from the member's pocket or from the pockets of others (get) by way of personal fundraising. Some of the benefits of board membership: resume builder, prestige, advocacy opportunities, and other incentives can make a give/get board a viable fundraising tool for a nonprofit.

### Pro bono work and expertise

Pro bono (for free) work done by board members from a variety of professions can save an organization a substantial amount of money over time. The pro bono accountant can do the math on how much money his expertise and that of other pro bono board members is not costing the organization annually. It is in the financial interest of the founder to recruit pro bono board members from the legal, technical, accounting, marketing, medical, and pharmaceutical industries. ■



# People Power: Volunteers and Staff



More than any other resource, nonprofits are fueled by people power. Volunteers are an important part of the nonprofit sector; and over two-fifths of public charities rely on dedicated volunteers for help. In the early days of the organization, work done by paid employees is often done for free by the founder's family, volunteers and pro bono board members.

As the organization grows the need for more hands on deck increases, which means actively recruiting volunteers and eventually hiring staff. Fortunately, with pro bono work, statistics show an increase in volunteering and people who want to work for nonprofits. To minimize turnover and time consuming HR issues, it is important to bring on volunteers and staff members who are on board with the mission and the vision of the organization. ■



# Building a Community

Like a marathon course, winding its way through 26.2 miles of a city's neighborhoods, the nonprofit landscape is also very diverse. Approximately 1.41 million nonprofit organizations were registered with the IRS in 2013, an increase of 2.8 percent from 2003. Members of the rare community are included in these numbers.

Luke Rosen recently founded KIF1A.org, a rare nonprofit; and he shares this insight about community building, "When we started the foundation, we knew of 26 children throughout the world who were diagnosed. Our doctor encouraged us to organize a family meeting with the other 25 families, which is how we first connected. When you sit around a table looking at other parents going through the same uncertainty, there is no other choice than to band together. Have a family meeting, that is the first step to building a nonprofit community."

## Expert Tips!

Luke Rosen recommends these additional tips for community building:

- Share every mile of your journey with the public
- Use social media
- Create a private and public Facebook page (Facebook recently waived its nonprofit donation fees!)
- Reply in a timely manner to correspondence regarding the organization
- Use the foundation's story to expand interest in the scientific community for finding a cure ■



# Sky's the Limit: The Road Ahead

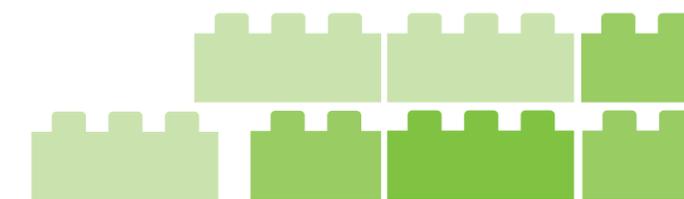
Nonprofit organizations include everything from soup kitchens to large foundations with millions of dollars in assets—evidence that the sky is the limit! Some nonprofits have a mission to feed the poor daily, while others are advocating for rare disease solutions like clinical trials, treatments and cures.

There are many ways to advance the mission of a nonprofit starting with having a healthy organization. Translation, a nonprofit needs a strategic plan; an engaged and educated board; credibility; good financial standing; and actively doing work that reflects the organization's mission statement.

## Long-term plans for a nonprofit include:

- **Adding advisory boards;** as the organization grows and/or tweaks its mission, the need for additional advisory boards is likely. If fundraising efforts suddenly bring in millions of dollars (to God's ears), it may be time to add a financial board. If the mission shifts its focus to research instead of healthcare advocacy, adding a medical board may be practical.
- **Research and development,** and being aware of trends in the healthcare space, without losing focus (don't get distracted by every new marketing idea) of the mission are critical for growth. Conferences, public events, and industry partnerships are all vehicles for sharing the nonprofit tenets of advocacy, education, and legislation.

- **A willingness to change,** when necessary, is also important to growth. Experts recommend that the organization's mission statement should be revisited every three years. And a smart founder with an equally smart board of directors will adjust the mission, if doing so supports the organization's vision for years to come. ■



# The Finish Line: Outcomes

As you build your foundation it is important to remember that growth and success comes in many forms; and getting there is different for each founder. Hopefully, the suggestions, tips, and knowledge of other rare founders, industry experts, and resources included in this toolkit will help you run your best foundation building race! ■

**Articles of Incorporation** are called a Certificate of Incorporation in some states. This is the document that must be filed with an appropriate government agency, generally the office of the Secretary of State, if the owners of a business want it to be given legal recognition as a corporation.

**Association** or a group that has formed an ongoing organization around a common purpose or interest is not a legally established corporation or a partnership. To make this distinction the term “unincorporated association” is often used.

**Board of Directors** are shareholders of a corporation who direct/oversee the corporation. Since many corporations have only one or two shareholders, states require only one or two directors to serve on the corporation’s board.

**Charity** is usually a corporation established under state guidelines that requires IRS approval in order for contributions to it to be deductible from gross income by donors.

**Corporation** is an organization formed with state governmental approval to act as an artificial person to carry on business or other activities. A corporation can sue or be sued. It can issue shares of stocks (unless it is a nonprofit) to raise funds to start a business or increase its capital.

**Endowment** is a transfer, generally as a gift of money or property to a charity, college, or other institution for a particular purpose.

**Founder’s Syndrome/Founderitis** one or more founders maintain disproportionate power and influence following the effective initial establishment of the project, leading to a wide range of problems for the organization.

**IRS code 501(c) (3)** offers nonprofits tax-exemption status under the section 501(c)(3) of the Internal Revenue Code. An organization must be organized and operated exclusively for exempt purposes set forth in section 501(c)(3), and none of its earnings may inure to any private shareholder or individual.

**IRS 990 Form** most tax-exempt organizations are required to file an annual [tax] return. Which [990-series] form an organization must file generally depends on its financial activity.

**Mission Statement** is a written declaration of an organization’s central purpose that generally remains the same over time.

**Nonprofit/Not-For-Profits** are organizations that are tax-exempt under Internal Revenue Code Section 501(c)(3) because they qualify for the status of “public charities” formed to provide “public benefit.” Nonprofit status is governed by state law, and is determined by an organization’s articles of incorporation or trust documents

**Private Foundation** is a non-governmental entity that is established as a nonprofit corporation or a charitable trust. The primary purpose of a private foundation is to give grants to organizations, institutions, or individuals for medical research, education, and other charitable purposes.

**Pro Bono** is to provide a free service (often legal work or other expertise) for a person, group, or philanthropic cause.

**Strategic Plans** provide the details of how a business/organization will achieve a future result.

**Tag Line** is a memorable catch phrase that sums up the tone and premise of a product, service, or purpose.

**Vision Statement** is a description of what an organization aspires to accomplish long-term.

Shown is the directive on Articles of Incorporation from the Office of the Illinois Secretary of State website. This example is representative of the tone and content on other state websites. Check your state’s website for their specific Articles of Incorporation instructions and forms.

## From the Office of the Illinois Secretary of State

### Articles of Incorporation

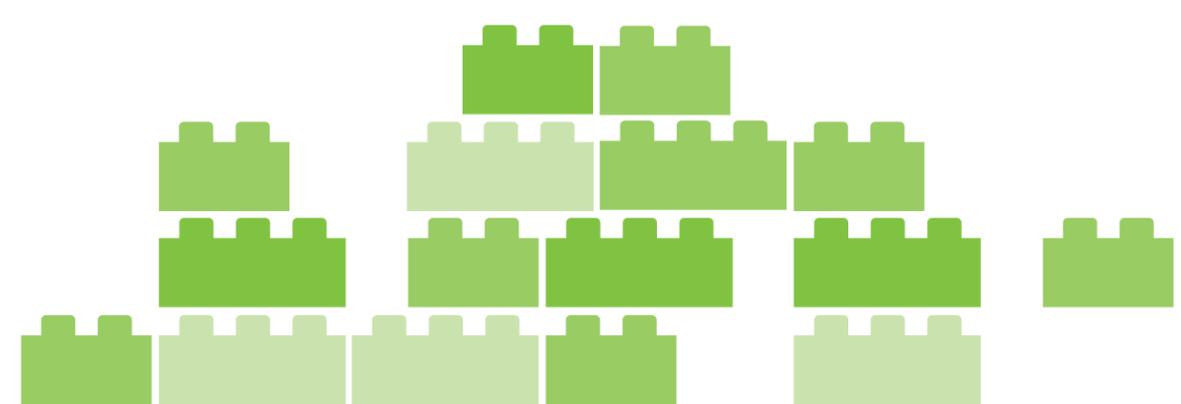
The Articles of Incorporation is a legal document through which a corporation is formed. This document is sometimes referred to as the “charter.” Regardless of your future tax-exempt status, you must complete and submit two (2) identical copies of the Articles of Incorporation, Form NP-102.10, with at least one copy being the original. All the interrogatories must be answered. Please type or print all responses.

### Tax-Exempt Status

Not all not-for-profit corporations are tax-exempt. Before you take any action, you should decide whether you wish to apply for federal income tax-exempt status (e.g., 501(c) (3) status). Only certain kinds of charities, schools, churches, research institutes, clubs, etc. fall into that category. The words “athletic,” “benevolent,” “eleemosynary,” and “social” are not acceptable as purposes if a corporation is going to apply for 501(c) (3) status.

Should you decide to apply you will use either Form 1023 or Form 1024. However, you must be incorporated before the IRS will consider your application as a Not-for-Profit Corporation. [An organization does not have to be incorporated to apply for exempt status.] Incorporation does not guarantee federal tax exemption, but if you wish to apply for that status your Articles of Incorporation may have to be written with the IRS regulations in mind.

To find out if your corporation may qualify for a tax break, obtain and read IRS Publication 557: How to Apply for and Retain Exempt Status for Your Organization.



## IRS Employer Identification Number (EIN) Form

### Step 1: Determine Your Eligibility

You may apply for an EIN online if your principal business is located in the United States or U.S. Territories.

The person applying online must have a valid Taxpayer Identification Number (SSN, ITIN, EIN).

You are limited to one EIN per responsible party per day.

### Step 2: Understand the Online Application

You must complete this application in one session, as you will not be able to save and return at a later time.

Your session will expire after 15 minutes of inactivity, and you will need to start over.

### Step 3: Submit Your Application

After all validations are done you will get your EIN immediately upon completion. You can then download, save, and print your EIN confirmation notice.

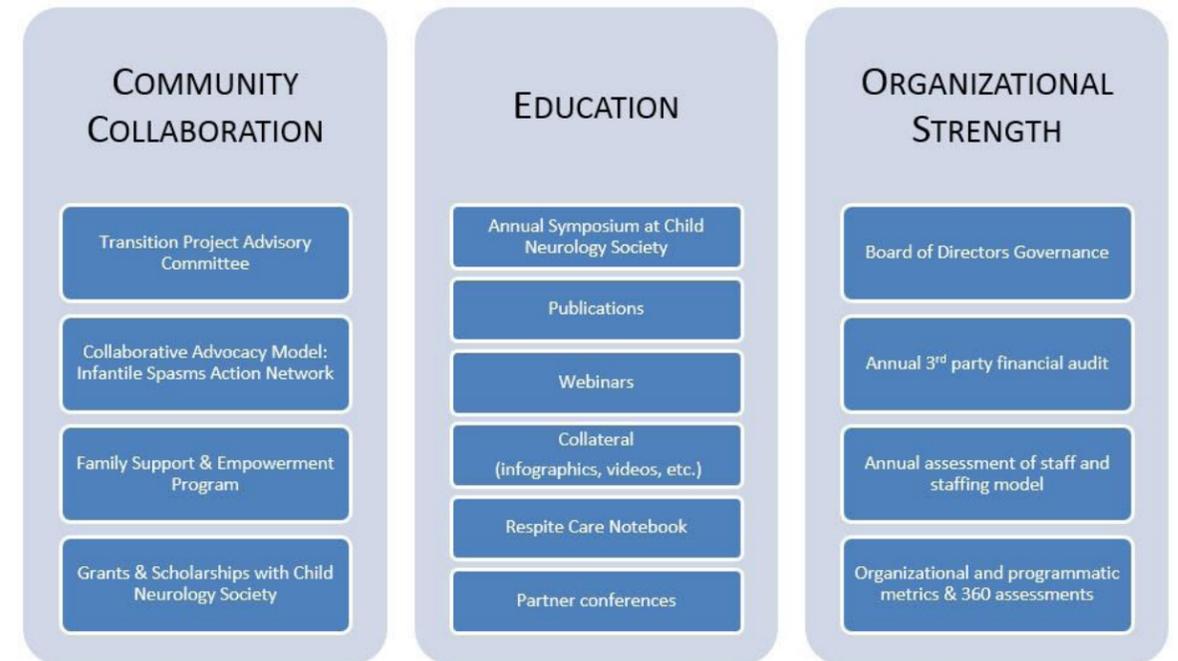
## IRS Form 1023

### Part II Organizational Structure

You must be a corporation (including a limited liability company), an unincorporated association, or a trust to be tax exempt. (See instructions.) **DO NOT file this form unless you can check "Yes" on lines 1, 2, 3, or 4.**

1. Are you a **corporation**? If "Yes," attach a copy of your articles of incorporation showing **certification of filing** with the appropriate state agency. Include copies of any amendments to your articles and be sure they also show state filing certification.
2. Are you a **limited liability company** (LLC)? If "Yes," attach a copy of your articles of organization showing certification of filing with the appropriate state agency. Also, if you adopted an operating agreement, attach a copy. Include copies of any amendments to your articles and be sure they show state filing certification. Refer to the instructions for circumstances when an LLC should not file its own exemption application.
3. Are you an **unincorporated association**? If "Yes," attach a copy of your articles of association, constitution, or other similar organizing document that is dated and includes at least two signatures. Include signed and dated copies of any amendments.
- 4a. Are you a **trust**? If "Yes," attach a signed and dated copy of your trust agreement. Include signed and dated copies of any amendments.
- 4b. Have you been funded? If "No," explain how you are formed without anything of value placed in trust.
5. Have you adopted **bylaws**? If "Yes," attach a current copy showing date of adoption. If "No," explain how your officers, directors, or trustees are selected.

## CNF STRATEGIC DRIVERS: 2017-2021



Graphic courtesy of: Child Neurology Foundation

**CNF mission statement:** To serve as a collaborative center of education and support for children and their families living with neurologic conditions.

**CNF vision statement:** A world in which all children affected by neurologic conditions reach their full potential.

## Resource Guide

Internal Revenue Service: [IRS.gov](https://www.irs.gov)

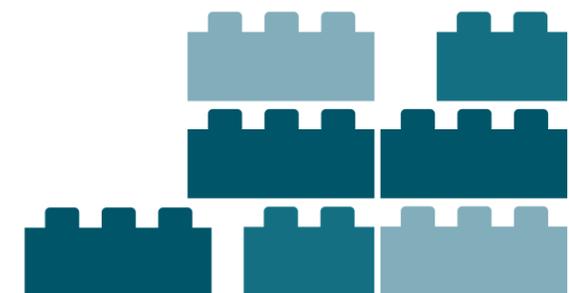
National Council of Nonprofits: [councilofnonprofits.org](https://www.councilofnonprofits.org)

The Guide to Not-for-profit Governance: [pbpatl.org](https://www.pbpatl.org)

"Designing Brand Identity," author, Alina Wheeler

"How to Launch a Brand," author, Fabian Geyrhalter

"The Power of Strategic Alignment: A Guide to Energizing Leadership and Maximizing Potential in Today's Nonprofit Organizations," author, Dennis C. Miller



# 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

# Contributors

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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)

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If you are interested in contributing to a future toolkit topic, please email:  
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JUNE 2018 