

**SO YOU THINK  
YOU WANT TO START  
A NONPROFIT.....?**

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# SO YOU THINK YOU WANT TO START A NONPROFIT.....?

When one learns that they or a loved one has been diagnosed with a devastating disease, many feel hopeless and vulnerable. However, many turn this challenge into creating action. As their loved one's biggest advocates, they seek to improve their quality of life, by spreading awareness, encouraging research, and building much needed support networks.

Through this toolkit, you will come to understand that creating a non-profit organization is just one of the many ways that you can achieve any of these goals!

**Nonprofit organizations** (also known as not-for-profit organizations, 501(c)3 organizations, or tax-exempt organizations) positively contribute to our communities—both locally and globally.

Forming a nonprofit is not a decision to be taken lightly. It can be a daunting process, but this toolkit is here to help! From answering essential preliminary questions to exploring alternative options, this toolkit will help prepare you for this journey.

Please be sure to check out all of the toolkit's components (the FAQ section, short videos of expert knowledge, and bibliography of additional resources) in case you get stuck!



# QUESTIONS TO CONSIDER BEFORE YOU DECIDE

Before you decide if starting a nonprofit is the best avenue for you, we recommend answering a few important questions.

## 1. Is there a need?

Before embarking on this admirable and impactful decision, you should consider why you want to start a nonprofit. As mundane as this may seem, sometimes it is easy to get lost in the particulars of setting up a nonprofit, so one may forget about what inspired them to start a nonprofit in the first place.

After verbally recognizing the problem, you should reflect on the unique value(s) you can bring to successfully address the problem. Are there other organizations already meeting the need(s)? It would be disappointing to exhaust a lot of time and energy to only create something duplicative. Raising funds for a nonprofit isn't easy, so unless you are building an organization to address an unmet need, you may want to reconsider.

One patient advocate shares her experience on identifying the need to start a nonprofit and her organization's unique approach of addressing it:

*"When our son was diagnosed with Duchenne at the age of 5, we were told to go home and love our son. We were told that his muscles will die and not regenerate. Duchenne is a fatal childhood muscle disease that will always be with us since about half the cases are spontaneous mutations that can occur in any family.*

*CureDuchenne's mission is its name... to cure Duchenne. There was a void for a dedicated research organization that was focused on funding translational research for Duchenne. It was an easy decision to focus on research so we could hopefully save our son and all the other boys afflicted with this disease.*

*Since both my husband and I have business backgrounds, it made sense for us to work with biotech and pharmaceutical companies in order to build partnerships that would accelerate the speed of getting drugs to our kids. We did not want to duplicate efforts that other organizations were providing for patient care and parent support."*

— **Debra Miller**, Founder & CEO,  
*CureDuchenne*

## 2. What will be the nonprofit's mission— to support others affected by rare diseases, to fund research or both?

A fundamental ingredient to every successful nonprofit is a **mission statement** (Note: You may want to make it easy to comprehend, remember, and recite!).

## QUESTIONS TO CONSIDER BEFORE YOU DECIDE

Think of a mission statement as basically the statement of purpose, its reason for existing. It should explain the nonprofit's overarching goals and the paths to reach them. As a founder of a budding nonprofit, it is important to know what your goals will be.

It is advisable to know your mission statement *before* you start a nonprofit to add credibility, teach others about your organization, and receive funding/donations.

If you run into trouble while writing your mission statement, a great resource is Idealist (<http://www.idealists.org/info/Nonprofits/Gov1>). It provides details, showcasing the different approaches to writing a clear, purposeful mission statement.

### 3. Are there other nonprofits with similar missions?

What makes your approach different and unique from existing nonprofits? If your nonprofit's focus, mission, or cliental is identical to another nonprofit's, it calls into question your organization's relevance and necessity. Will it be able to compete with the already existing nonprofits for funding, support, and community?

To locate other nonprofits, use the **Active Organizations Search tool** on the National Center for Charitable Statistics website (<http://nccsweb.urban.org/PubApps/search.php>) as well as **Charity Navigator** (<http://www.charitynavigator.org/>).

It may be easier and more appropriate, in the case that a nonprofit with a similar mission does exist, to join its efforts (an alternative to starting your own nonprofit organization, which is detailed in the next section).

Working with an existing nonprofit organization may be difficult, however. One patient advocate gives advice on how to approach this alternative:

"I encourage others who are trying to collaborate with an established nonprofit to give it some time (at least a year) to see if it can be accomplished. The established nonprofit has probably been at it for a while, and major change like bringing in new people and new ideas can be intimidating, which can make the founders uneasy or defensive.

After about a year or longer of trying to work with an established group and feeling like you're getting nowhere, I think it would be time to go out on your own. But I recommend you let the other organization know what you are doing. In our case, we sent a formal letter to the other nonprofit, explaining what we were doing, how we hoped we would not be in competition, working together in our separate ways toward the common mission of finding a treatment or cure for our rare genetic disease."

— **Anonymous**, Secretary,  
*A Nonprofit Organization*

Additional insight in the Appendix showcases when partnering is not an option.

## QUESTIONS TO CONSIDER BEFORE YOU DECIDE

### 4.

#### **Have you thoroughly identified the economics behind your nonprofit? How will this nonprofit be a sustainable business?**

Nonprofit organizations, although usually not considered financially-motivated companies, are still businesses. They rely on in-kind and monetary support to survive—either in the form of volunteers, directed funds from companies, government grants, grants from other nonprofit organizations, or donations from individuals or corporations.

Note: many early stage nonprofits, like other businesses in their infancy, rely heavily on volunteers and/or staff members who are willing to commit to long, unpaid hours.

It is advisable to create a roadmap/chart that shows how your nonprofit will be able to sustain itself before setting out on the journey to create it. Likewise, it is also advisable to have someone involved with your organization that is already familiar with operating a business.

# ALTERNATIVES TO THE STANDARD 501(C)3 MODEL



Starting a nonprofit requires a lot of work, and an alternative may be more appropriate for you! In this section, alternatives to starting the standard 501(c)3 nonprofit organization are explained in more detail.

## Working for an Existing Nonprofit

If the idea of starting and managing a nonprofit seems too overwhelming, then that's okay! There are many nonprofits already in existence right now that you can join, collaborate with, or volunteer for!

Nonprofit organizations come in multiple forms. Some are 100% volunteer-operated (such as **Alstrom Angels** in Texas), which means they depend entirely on the generosity of volunteers to achieve their goals.

So instead of taking on the responsibility of managing your own nonprofit, a more supportive (yet highly valued) role as a volunteer for a nonprofit whose mission closely aligns with your own passions and cause may be a better fit for you.

This option allows more flexibility, while reducing potential liability. Inquire with a local nonprofit's Volunteer Coordinator to learn more about assuming this role.

## Engaging in a Local Chapter

In addition to heavily volunteer-operated nonprofits, there are also global, national

nonprofits that transcend just one specific location. These often rely on **local chapters** to reach many communities, spur support, and drive events.

This option, like being a part of a franchise in the business world, provides a sense of name-recognition for the public. You have less responsibility (but also less creativity) when it comes to marketing materials, logos, and causes. But you will also be a part of a bigger network, getting the added privilege of knowing that your efforts support a larger demographic and cause.

“The greatest strengths of being part of an established nonprofit organization are impact, benefit of organizational resources and credibility. When a new chapter is created, it is immediately able to utilize all of the resources of the Society and can participate in programs without having to “reinvent the wheel.” They are utilizing best practices drawn from national leadership and expertise. Additionally, their work “feeds up” to support National initiatives, thereby exponentially increasing the impact of their local efforts.

Finally, being part of a national organization means that you benefit from the credibility of the organization. In the case of HDSA, that means more than 40 years' worth of brand recognition and a track record of success, verified by independent auditors, which are important to donors.”

—Louise Vetter, CEO, Huntington's Disease Society of America

If you feel like starting a local chapter of a national nonprofit is a better option for you, consult first with a national nonprofit to gain permission. During your discussion, discuss the national organization's support structure for chapters to clearly gain an understanding about the expectations for each chapter.

## ALTERNATIVES TO THE STANDARD 501(C)3 MODEL

### Organizing Support through Online Social Media Tools

If your fundamental reason for starting a nonprofit is to offer support to others in similar situations as you or your loved ones, then starting a virtual support group through a social media site may be a viable alternative for you.

Those suffering from rare disease symptoms frequently benefit from joining or forming Facebook, Yahoo, Inspire, and Google groups that are dedicated to educating its members, providing support, and connecting individuals who oftentimes feel alone and powerless.

Options for forming a support group include:

- **Facebook** <http://www.facebook.com/help>
- **Inspire** <http://www.inspire.com>
- **Rare Connect**  
<https://www.rareconnect.org/en>
- **Google Groups**  
<https://groups.google.com>
- **Yahoo Groups** <http://groups.yahoo.com>
- **Patients Like Me**  
<http://www.patientslikeme.com>

One patient advocate lends advice and some thoughts to consider when using social media to support and enrich your rare disease community:

*“I would advise others who are considering this option to just “do it” because social media is both forgiving and gracious when dealing with healthcare. We learn as we grow, and we learn from our mistakes, knowing there is always someone to pick us up if we fall along the way.*

*But I would also prepare them for the commitment involved regarding time and energy. Your time becomes a daily commitment to advocacy work. If no one is posting on your site, then it is your responsibility to respond to that one person who is looking for answers, hope, direction or support.*

Once you expose yourself as a leader for your community, there are many demands that are imposed along with the demands you impose on yourself—due to the lack of information and resources available for these rare diseases.

*Many times I feel as though I have to be at 10 places at one time. It is not only learning the ropes as a support leader as much as learning social media in general. It is also important to be fearless, aggressive and—most importantly—ready to support all the other advocates on the journey. Without each other, we easily become lost.”*

— **Marianne Vennitti**, Co-Founder & Director, *Alliance for Cryoglobulinemia*

To read more about the benefits and challenges of using social media to build and invigorate your rare disease community, please turn to the Appendix for advice from Sharon Nissley, Co-Founder & Director of Communications, Klippel-Feil Syndrome Alliance.

But there are other ways to incorporate social media to meet your needs. If your goals are more short-term or self-seeking, such as raising funds for your child’s treatment or medical devices, then using online crowd-sourcing sites may be an appropriate option for you!

Crowd-sourcing sites are great avenues to raise awareness, gain support, and reach your goals. They enable you to create a free online fundraising page that can inspire others, raise finances, and hopefully reach your fundraising goals. Some helpful crowd-sourcing websites include:

- **RocketHub** [www.rockethub.com](http://www.rockethub.com)
- **IndieGoGo** [www.indiegogo.com](http://www.indiegogo.com)
- **WhenYouWish** [www.whenyouwish.com](http://www.whenyouwish.com)
- **Crowdrise** [www.crowdrise.com](http://www.crowdrise.com)
- **GiveForward** [www.giveforward.com](http://www.giveforward.com)



## ALTERNATIVES TO THE STANDARD 501(C)3 MODEL

### Finding a Fiscal Sponsor

It may be enlightening for some to learn that a nonprofit can exist **without** being designated as a 501(c)3 nonprofit organization!

An opportunity available for these non-501(c)3 nonprofits is **fiscal sponsorships**. When a non-501(c)3 nonprofit is sponsored by another nonprofit that is a 501(c)3 organization, money may be brought in originally through the 501(3) c nonprofit, but it is then funneled to the non-501(c)3 nonprofit (also known as the **Donor Directed Fund**), allowing the latter to use the funds for designated purposes.

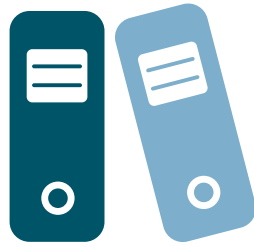
Some advantages to securing a fiscal sponsorship as an alternative to starting a 501(c)3 nonprofit are it usually takes considerably less time, the sponsoring organization provides support and usually handles much of the accounting work, start-up costs are minimal,

a separate board is unnecessary (as the sponsoring organization acts as the board).

If you are interested in establishing such a relationship, it is recommended on **Grant Space** [www.grantspace.org](http://www.grantspace.org) to: "Look for nonprofits whose missions are similar to yours. You might start with your current affiliations. Make a list of the professional societies, educational associations and institutions, religious organizations, social and recreational clubs, and other groups with which you are already associated, including employers."

Use the **Fiscal Sponsor Directory** <http://www.fiscalsponsordirectory.org> to search by state, service category or keyword for nonprofit fiscal sponsors. Profiles include eligibility requirements, fees, services, and types of projects supported. The site also provides statistics and resources on fiscal sponsorship.

# APPENDIX



## Working with an Existing Nonprofit—a Personal Account\*

I know that it is best to work with other organizations, if at all possible. We have been told that by patients, doctors, researchers and other medical professionals. However, my small group of friends and I did not feel like that was “do-able,” and therefore we went out on our own to form a new nonprofit.

Originally, my friends and I connected through an organization for our shared genetic disease. Many of us, our own family members and friends were donating to research for our disease. But we felt like we had little to no input or explanation on where the money went, how it was used and what benefit came of it. We also felt more could be done for awareness and education of our disease.

### When it Is Difficult to Connect

In addition, there were a number of incidents where we questioned the organization’s methodology. One such incident was when a friend and I had the idea to have an Awareness Day. Although there was already a special day for the Leukodystrophies in general, we wanted one specific to our rare disease. Unfortunately, this was not in accordance with the other organization.

We went ahead and set the date for the Awareness Day anyway, creating letter-sized awareness posters and other items that would be simple to share. We listed the already established organization as a place to go for more information regarding the disease. When these posters were made available to interested people online—most notably on Facebook—we were told to remove them immediately, as we had used the organization’s website address without permission and approval of the Board. This was puzzling, as we could have listed any number of other public websites (such as NORD or Wikipedia) as resources.

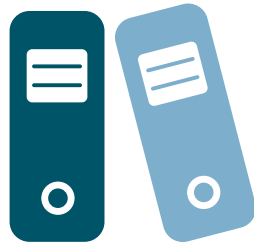
### Deciding to Start a New Organization

As time went on (this was over the course of about two years), we became more and more aware that we would not be able to do many of the things we felt would be good as far as awareness and education without jumping through major hoops.

I do hope that in the near future, our groups can work together, perhaps one taking on specific areas and letting the other group take on other areas, so that everyone is working toward the common goal of treatments and support for patients and their families.

*\*Given the nature of this personal account, the submitter requested to be kept anonymous.*

# APPENDIX



## Using Social Media as a Resource: Sharon Nissley, *KFSA*

### The Benefits of Using Social Media

Having a page or group is rewarding. You are helping others who may have found no other avenue for information, understanding, and community. You are creating needed change in peoples' lives, when things are lacking. This is so important.

You are also providing an active vessel to discuss and shed light on topics that help everyone feel a part of something bigger, something that takes action on a bigger scale. So many times a patient will write for the first time on our page and say, "I am so glad to know I am not alone after all this time!" This is a win. I know what alone with Klippel-Feil Syndrome is like.

You will also be helping people connect. This is very valuable for people looking for advice. The Facebook community is our vital link to the very people that we aim to work with, to empower ourselves as a community to bring forth change for KFS. Without this active way to communicate openly within our community, we would not have reached the people we have.

A page is public, so a larger audience sees your posts. It also puts information onto the walls of those who have "liked" the page, which helps spread information and awareness. This ability to share pulls people out of their shells and helps them see that their voices matter, that they can—and do—make a difference.

### Some Thoughts to Consider

Because the page is public, discussions tend to be not as personal, and people may limit what they post. Closed groups tend to have better ongoing input and discussions on a given topic.

Be clear on your page or group that you are not a doctor. On Facebook, I state that people must always seek medical advice before starting any treatment. On the MDJunction support group, I have the following statement posted under every discussion: I am not a doctor. I simply give information based on personal experience and knowledge I have gained while fighting Klippel-Feil Syndrome, Von Willebrand Disease, Ehlers-Danlos Syndrome, Cervical Dystonia and Vasculitis—five rare diseases. I hope to aim higher in fighting for awareness and treatment over a lifetime, for every one of us.

Sometimes people think that as a page or group leader, you have the disease and its answers all figured out when in fact you are just like everyone else, navigating things day by day, looking for solutions. As a page leader, you don't have to know everything. Often someone else has input and experience with a topic, so post the question to the group. This also helps the group connect and feel empowered. Because these diseases are rare, information may be lacking. You can provide resources and ask if others know anything. As a patient myself, I surely do not know half of what I would like to about Klippel-Feil Syndrome. However, I have provided links to information that is available and continue to build on that.

# RESOURCE GUIDE



## Crowd-Sourcing Sites

### **Crowdrise ([www.crowdrise.com](http://www.crowdrise.com)):**

This crowd-sourcing site lets users create fundraisers, explore events, and support various causes.

### **GiveForward ([www.giveforward.com](http://www.giveforward.com)):**

GiveForward is one of the easiest ways to support a loved one in need.

### **IndieGoGo ([www.indiegogo.com](http://www.indiegogo.com)):**

A funding platform, this site lets users create campaigns and raise funds.

### **RocketHub ([www.rockethub.com](http://www.rockethub.com)):**

RocketHub, a crowd-sourcing site, helps users raise money from around the world.

### **WhenYouWish ([www.whenyouwish.com](http://www.whenyouwish.com)):**

Instead of relying on government or banks, this network lets users discover and fund different projects.

## Locating Other Nonprofits

### **Charity Navigator ([www.charitynavigator.org](http://www.charitynavigator.org)):**

Charity Navigator evaluates thousands of large American charities. Use their various search tools to find nonprofit organizations near you, within the global sphere, that support an issue dear to your heart, or may be willing to support your efforts.

### **Fiscal Sponsor Directory ([www.fiscalsponsordirectory.org](http://www.fiscalsponsordirectory.org)):**

This resource connects community projects with fiscal sponsors, providing valuable information on securing fiscal sponsorships. If you are interested in finding a fiscal sponsor, this tool allows users to search by state, service category or keyword for nonprofit sponsors. The search results include eligibility requirements, fees, services, and types of projects supported.

### **National Center for Charitable Statistics (<http://nccsweb.urban.org/PubApps/search.php>):**

This helpful website provides data on nonprofit organizations. This direct link leads to the organization's Active Organization Tool that lets users search for organizations based on a variety of information.

# RESOURCE GUIDE



## Mission Statement Building Tools

### **Idealist (<http://www.idealist.org/info/Nonprofits/Gov1>):**

Idealist connects people, organizations, and resources together so everyone feels capable of reaching their philanthropic goals. This direct link specifies what a mission statement should encompass.

## Support Group Alternatives

### **Facebook (<http://www.facebook.com/help/>):**

Facebook, perhaps the most popular social media platform, reached over a billion monthly active users in September 2012. This site makes it easy for users to connect to others, especially through creating supportive community groups.

### **Google Groups (<https://groups.google.com>):**

Google Groups lets users participate in online discussions. Connected to Google's other features, this social media site allows users to keep things organized.

### **Inspire (<http://www.inspire.com>):**

Inspire connects patients, families, friends, caregivers, and health professionals, providing health and wellness support. This site allows you to connect with others who know what you're going through.

### **PatientsLikeMe (<http://www.patientslikeme.com/>):**



Users can join this registry to connect with others in similar situations. Access this site to read through others' stories, learn from their experiences, and share your own experiences with treatment.

### **Rare Connect (<https://www.rareconnect.org/en>):**

Hosted by trusted patient advocates, this is a place where rare disease patients can connect with others globally. Joining or forming a group through Rare Connect can help you provide support to others while learning from their experiences.

### **Yahoo Groups (<http://groups.yahoo.com/>):**

With millions of groups at your fingertips, it's easy to find the group that's best for you through this site. Establishing a group through Yahoo allows users to connect with a world of rare disease patients and parent advocates, inspiring and empowering others.



**LET OTHERS BENEFIT  
FROM YOUR KNOWLEDGE  
BY SHARING YOUR TIPS  
AND TRICKS!**

If you would like to contribute your experience or have a comment/suggestion, please enter it on the toolkit's online form.



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Global Genes Project  
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Lybba