

STARTING A NEW NON-PROFIT ORGANIZATION FOR A RARE DISORDER

Most voluntary health agencies for specific diseases are started by people who are affected by the ailment, their relatives, or friends. The need to create a charitable organization is often apparent: Public attention and research dollars are generally aimed at diseases that are highly publicized; raising substantial money for research is usually not possible if donors cannot get a tax deduction for their gifts; if the efforts of individuals and families go uncoordinated, it is much more difficult to make progress than if all interested parties work together for the same cause. Incorporation of a non-profit organization is the logical remedy to solve these problems.

On the other hand, the success of any charity is based on its creditability. Because of highly publicized scandals, the public's trust in charities is not automatic. Non-profits must constantly work at earning and keeping the public's trust. It is therefore important to understand the technical aspects of creating and sustaining a non-profit organization, decide what its mission and programs will be, and develop adequate governance that ensures each donated dollar will be spent for the benefit of the organization's constituents.

- **What do you want the organization to accomplish?**

The organization should have a concise mission statement that describes why the organization exists; "The XYZ Society is dedicated to education and research for XYZ disease." Or, "The XYZ Society is dedicated to the diagnosis, treatment, and cure of XYZ disease." The statement can be used in printed materials, repeated in newsletters, on your Website, and inserted in letters that you write. If the organization does not intend to fund research, and will focus on education or social services, your mission statement should reflect those limitations.

- **Programs**

Once you decide on the mission statement, determine which programs your organization will administer to implement your mission. Programs must be relevant to your mission: e.g., if your mission is limited to education and research on a specific disease, the organization cannot arbitrarily create a program to save wildlife in a rain forest.

Define your programs in terms of what you want them to accomplish in future years, and not in terms of your immediate financial constraints. For example, your education program may have several different audiences (e.g., affected patients and families, the general public, health policy-makers such as politicians, practicing physicians, researchers, etc.), so you can outline how you intend to reach these audiences (e.g., pamphlets, newsletters, public service announcements, Website, exhibits at medical conventions, visiting academic researchers and the National Institutes of Health, etc.). You may realistically believe that you will not have enough money to do all of these things immediately, but you can keep your “wish list” of program goals and implement them slowly.

- **Governance**

The governance of a charity is the most important element for earning and maintaining public trust. Each year, your IRS 990 forms and a list of your board of directors will be on the Internet so potential donors and charity-monitoring groups can see who is responsible for the corporation. As a general rule of thumb, a non-profit corporation should have no less than five people on its board of directors, and more than 25 may hinder the decision-making work of the board. Members of the board

should not be from the same family, although legally there is no prohibition against this. However, the success of a 501(c) 3 charity depends on financial support that is received from the general public, and the public wants to be assured that unbiased people with a passion for the agency's mission will govern the agency. If several members of one family are on the board, they may be suspect of having too much influence over the conduct of the corporation.

A Board of Directors should reflect democracy in that they are elected, geographically dispersed, come from different areas of society and represent the various constituencies with your disease. They may be patients, parents, business people, professionals, other relatives, friends, etc. Do not insert language into your bylaws that limit the composition of your board to people affected by the disease, parents, etc. You should be looking for candidates with particular skills (e.g., accountants, lawyers, etc.) rather than people with a particular relationship to the disease.

- **Bylaws**

These and other issues can be addressed in your bylaws. The most important single legal instrument of your organization will be bylaws that explain how your organization will be governed, who will elect the board of directors, how long terms will be, who will be a "member," how you will guard against conflict-of-interest and discrimination, etc. It is not a good idea to give the board of directors' sole power to elect the board of directors (themselves). It is always wise to have your "members" elect the board.

Governance of non-profit corporations is very different than for-profit corporations, so it is important to develop bylaws that conform to the non-profit sector. If you are not sensitive to these differences, your bylaws may disqualify your organization from

certain fundraising campaigns, and give you a low rating from charity watchdog groups. In many cases, a low rating from a charity watchdog group will disqualify you from corporate and foundation grants, and you will have to change your bylaws many times to come into conformance. NORD has sample bylaws you may use in modeling your own.

Remember that a 501(c) 3 corporation is a “voluntary” agency that is governed by “volunteers.” Therefore, members of the board of directors cannot be compensated. However, expenses that are directly related to their work on the board can be reimbursed.

- **The “Corporate” Aspect**

When you decide to create a non-profit voluntary health agency, you recognize there is a need to create a corporation that is a business regulated by the Internal Revenue Service (IRS). As a business, you will eventually hire staff, you will hold fundraising events, you will have to submit reports to the government (federal and states), and do all the necessary things that other corporations are required to do (e.g., you will need insurance, including coverage for your fundraising events in case someone gets hurt).

“Non-profit” does not mean that you cannot earn a profit. If you do not bring in more money than you spend, you will not be in business very long. The non-profit label simply means that any profit your organization earns must be spent solely for the public’s benefit. Individuals are not allowed to benefit financially from the revenues of a charity, but society must benefit in order for you to maintain your tax exemption.

The tax exemption your organization receives from the IRS is a subsidy from taxpayers. In return for this gift, each charity must devote its revenues to meeting the

needs of society (within the context of your mission). The government relies on charities to provide programs and services that the government does not provide, or to supplement government social services. Thus charities play a very big role in American society. But in return for the government's tax exemption, non-profits must devote their resources to the public's betterment.

Non-profits are required to have a great degree of transparency to ensure the public that their donations are spent for an appropriate charitable purpose. To this end, non-profits with revenues over \$25,000 per year are required to file an IRS 990 form. When any member of the public requests a copy of the 990, you are required to send it to them. Additionally, the 990 will be posted on certain Websites that monitor charities.

In general, members of the public will want to know how much of each donated dollar will be spent by your agency on programs, and how much on fundraising and administration. Your goal should be to spend less than 25 percent of each donated dollar on fundraising and administration combined. The remainder should be spent on programs.

- **Research**

Most voluntary health agencies are incorporated to raise money for research because founders of the organization want to find a cure for the disease. But cures are not found overnight, and realistically people must be prepared to work many years before a medical breakthrough can be expected.

People with no scientific training should not decide which research grants should be funded. Your organization should create a Medical Advisory Committee (MAC) that

will review grant applications and give them a score. They would then advise the board of directors which of the highest scoring grants should be funded. This process of scientists reviewing scientific proposals is called “peer review.”

Even if you do not have enough money to fund grants, there is much you can do to “encourage” increased research. Get in touch with the National Institutes of Health (NIH) and find out which NIH scientists are responsible for research on your disease, or related diseases. Then do a Medline computer search and locate scientists at academic institutions who are doing research on your disease or related disorders. Contact those researchers, and stay in touch with them to keep them interested.

If you fund research grants, make sure your agreement with the grantee requires periodic “Progress Reports.” Funding a grant does not guarantee the research will be done, so someone at your organization should monitor progress. Do not expect overnight discoveries because each grant may bring you incremental advancements that may not result in a new treatment or cure until years later. A good goal for your research program could be to fund small “seed money” grants that enable scientists to generate data that can later be used to apply for larger government-funded grants, or to fund “fellowships” that enable young scientists to do research on your disease so they can later build a career in your field of medicine.

When you award a research grant, have the grantee sign an agreement stating that if they publish journal articles about their research they will mention in the article that your agency funded it. This will help your organization to become better known in the research community.

- **Research Vs. Services Vs. Education**

There is often an internal struggle in new organizations over the percentage of assets that should be devoted to research, and the percentage devoted to education or services. Our best advice is not to put all of your eggs in one basket. While you continue to work toward a cure, education will continue to get people diagnosed, and after they are diagnosed they will need other services: Children many need special education services, adults may need help getting Social Security Disability, or help educating their health insurer. There is so much to do and always too few resources to do it all!

Prioritize, prioritize, and prioritize. In determining priorities, your Board of Directors should engage in healthy dialogue. What is most important and least important? If you need more resources, how much do you need? How can you get enough resources? Most leaders of voluntary health agencies will tell you they will never have enough resources to do everything that should be done. It is simply the nature of serving medically disenfranchised populations.

Concerned families who reached out to other volunteers and built a non-profit corporation governed by people who care passionately about the organization's mission, was the impetus that started most charities for rare diseases. With time and experience, the organization moved out of a volunteer's home and into an office with hired staff. They built credibility with a prestigious Medical Advisory Committee who helped them to succeed. But success was not overnight. It took years of planning and hard work. They had to first find the cause of the disease, fund the scientists who broadened the understanding of the ailment, and then came treatments, but they are still looking for the cure.

NORD is here to help those committed volunteers who are willing to build a rare disease charity and start a journey on the long path to a cure. An ancient Chinese

proverb tells us, "Hope is like a road in the country. There never was a road, but when many people walk together a road comes into existence." Voluntary health organizations are many people who are walking together.