Supporting Sarcoma Advocacy Organizations

An ESUN Editorial by Bruce Shriver, PhD

Overview

This editorial presents criteria for you to use to help determine which sarcoma advocacy organizations (SAOs) to support with your donations and your volunteer time. It is a long editorial that I hope you find it worthwhile reading in its entirety. Here is the short version:

What's important to you? There are many, many ways to support and assist sarcoma patients, caregivers and survivors and to further sarcoma research and clinical trials. You should explore what SAOs are doing and decide what matters to you.

Learn as much as you can about various SAOs. It's important to understand what their mission and goals are, how they are organized, how they operate, and how they use your money. Some SAOs do a better job than others in (a) defining and executing the programs you are interested in; (b) using independent peer-review to ensure the scientific and clinical quality of research that they fund; (c) controlling their costs; and (d) being transparent and accountable to the donors and the sarcoma community.

Select the SAOs you'll support with your donations and volunteer time and revisit these decisions occasionally. Based on your analysis, you'll select the initial set of SAOs to support. Since organizational missions, programs, staff, volunteers and accomplishments change over time, I encourage you to reassess your selection every few years.

Now let's proceed with a more detailed exploration of these areas.

An Introduction to SAOs

From the onset, it is important to realize that many SAOs focus on a specific sarcoma, such as Ewing’s sarcoma, liposarcoma or leiomyosarcoma. Other SAOs focus on a group of sarcomas, such as "pediatric sarcomas" or "young adult sarcomas." Finally, other SAOs deal with all sarcomas and age groups.

Editor's Note: Bruce has more than a decade of experience in sarcoma advocacy. As a founder of Liddy Shriver Sarcoma Initiative, he has worked with dozens of sarcoma advocacy organizations from around the world to assist and advocate for sarcoma patients and families and to fund sarcoma research. As the Initiative's role in sarcoma advocacy comes to a close in 2015, Bruce hopes to help advocates make the most of their important role in sarcoma care and research.
Additionally, some SAOs direct their efforts to benefit specific institutions, investigators, research projects, clinical trial studies, or some combination of these, whereas other SAOs do not make any such commitments or restrictions.

A variety of different legal structures are used to form SAOs, e.g., Private Family Foundations, tax-exempt nonprofit organizations (e.g., a 501c3 organization in the United States or a Registered Charity in the UK), Donor Advised Funds, and Collective Giving Funds, whether or not an SAO is "all volunteer" or a "combination of paid staff and volunteers." Each of these legal structures has its own public disclosure requirements.

Finally, some SAOs limit their activities to a particular country, a region within a country, a group of countries, or have no such limitations and function internationally.

**What do SAOs do?**

There are a wide variety of ways in which various SAOs spend their time and resources; for example, an SAO might:

1. Focus on increasing public awareness of sarcomas, e.g., by publishing and distributing pamphlets, booklets or other literature and providing information and speakers to the media, hospitals, and event organizers.
2. Provide information to sarcoma families and medical professionals, e.g., articles on websites, podcasts on topics of interest, education forums, and videos of sarcoma specialists addressing critical issues in sarcoma treatments.
3. Conduct surveys and report on them to the sarcoma community and the media.
4. Gather patient specific information to be of use to sarcoma oncologists and researchers and provide information relevant to participation in tissue banks, genomic and kindred studies, and organ donation programs.
5. Provide a forum, chat room or similar mechanism for sarcoma patients, caregivers, and survivors to interact with one another, e.g., posting and answering questions about treatment regimens, side effects and clinical trials and, in general, any issue of concern. Such resources often include social networking environments like Facebook and Twitter. Occasionally sarcoma physicians, nurses and researchers also participate in these discussions.
6. Provide an online resource for sarcoma families to post photos as well as an on-going account of their sarcoma journey in the form of blogs, essays, or videos to honor those still under treatment or those who have lost their life to sarcoma.
7. Help sarcoma families financially:
   a. Pay travel and lodging costs to obtain treatment at a sarcoma center, or the costs of obtaining a second opinion, or the costs of chemotherapy drugs or special tests.
b. Provide scholarships and other education-related expense support for sarcoma patients survivors to continue their education.
d. Provide "hospitality houses" which offer temporary housing to caregivers and patients while in treatment at a medical facility far from home.

8. Visit sarcoma patients in a hospital or home setting to make their experience more tolerable, often bringing small gifts, entertainers, magicians, etc. to brighten their day.

9. Provide general referral and assistance functions:
   a. Put sarcoma patients and families in contact with one another
   b. Provide information regarding sarcoma centers, second opinions, and treatment options
   c. Provide counseling services to members of a sarcoma family
   d. Help caregivers by helping with transportation to/from treatments, shopping, house cleaning, babysitting, etc.

10. Lobby appropriate federal and state agencies regarding public policy, legislative and regulatory issues, e.g., to increase funding for sarcoma research and clinical trials, or to pass laws providing access to treatments for these rare cancers.

11. Send representatives to observe and report on lectures, presentations and poster sessions at relevant sarcoma conferences and workshops, e.g. the Connective Tissue Oncology Society (CTOS) and American Society of Clinical Oncology (ASCO) meetings.

12. Have an annual gala/event/retreat/meeting which brings together patients, physicians, friends and family, and potential donors to (a) review the accomplishments of the past year and the challenges which lie ahead and to (b) raise funds. At some of these events, selected patients, physicians and donors are given public recognition and awards for their contributions to the sarcoma community.

13. Organize fund raising events and programs with media involvement aimed at helping support the above activities and the administrative and infrastructure costs of the SAO (personnel, location, insurance, travel, communications, etc.).

14. Fund sarcoma research, e.g., basic science research, translational research, clinical trials studies, or a combination of these. Such financial support can be given independently or in collaboration with other SAOs.

Of course, each of these efforts takes people, time and money to bring them to fruition.

**What would you like to support?**

Few, if any, SAOs, attempt or have the resources do everything in the above list. Many, as you would suspect, focus on a small number of goals and programs. It is no surprise that some SAOs do a better job than others in
defining and executing their programs. So, it may turn out that if you'd like to focus on helping sarcoma families with their financial burden and sponsoring sarcoma research and promoting laws that provide patient access to treatments for sarcomas, you may wind up supporting two or three SAOs rather than a single SAO.

Once you've made a decision about what types of projects that you would like to support, you can then explore SAOs that are working in these areas, become familiar with the mechanisms they have in place to execute, monitor and evaluate these programs and see what they have accomplished in the past. Click here to download a copy of the Directory of Sarcoma Patients Advocacy Organizations and Foundations that was published in 2014. It contains information submitted by over forty SAOs, describing the organization's mission, goals and focus and the services it provides. Although quite large, this directory does not include all sarcoma advocacy organizations and foundations that you might consider supporting, but it provides a reasonable starting place. There are additional sarcoma organizations, foundations and funds whose proceeds are used to support a specific cancer center and, in some instances, give their funds to a specific group within that center, which you can also investigate. Other, regional, national or international general cancer organizations might also provide programs that interest you and might be willing to direct their efforts to the sarcoma community. But you, of course, have to determine if they will actually do so.

Once you've compiled a candidate list of SAOs and other organizations for the areas you'd like to support, it's important to understand how they are organized, how they operate, and how they use your money. I encourage you to obtain as much information as possible about your "candidate organizations." Obtain copies of their current brochures, explore their website and social media sites, and talk with people within the organization about their mission, goals and accomplishments. What are some of the questions you might ask? Let's start with how they use your donation.

**Where does your donation go?**

As a donor, you obviously would like to know how much of the money you donate goes to support the programs you are most concerned about and how is it used.

For example, if you are specifically interested in funding basic science research in pediatric sarcomas, you'd like to know how much of your donation will be used for this purpose when you donate to an SAO that has this as its mission. Some SAOs allow you to target a donation to support a specific program, e.g., their Research Grants Program. If this is the case with the SAO you are donating to, you need to find out how much of a donation to the SAO's
Research Grants Program is used to fund grants and how much is used to help pay the overhead of the SAO itself. Suppose, for example, you donate $100 and the SAO's overhead is 25%. This means that $75 of your donation will go to fund research and $25 to fund the SAO. But, the story does not end there. The institution receiving the grant, the XYZ-Cancer Institute, will have an overhead associated with running its facility and it assesses a fee to each grant as a payment to offset this overhead. SAOs typically limit this depletion of funds by letting the applicants for grants know there is a limit to such overhead that they can include in their proposed budget for their institution's overhead, for example 10%. For a 10% institutional overhead, this means that $75 - $7.50 = $67.50 of your donation will go toward research. Further, I assume that the investigator's proposed budget does not include other non-research related costs, such as funds to pay for publications costs, travel to medical conferences, conference fees, etc. The aggregate effect of these "charges" becomes more meaningful when looking at what happens to each $100,000 of amassed donations that an SAO receives from donors supporting research:

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<tr>
<th>The Impact of Research Donations to an Average Charity</th>
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<tbody>
<tr>
<td><strong>Amount Donated</strong></td>
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<tr>
<td><strong>SAO's Overhead</strong></td>
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<tr>
<td><strong>Amount Granted for Research</strong></td>
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<tr>
<td><strong>Investigator's Institution Administrative Overhead</strong></td>
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<td><strong>Amount Used for Sarcoma Research</strong></td>
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<td>(assuming no non-research items are supported)</td>
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If the SAO does not allow you to direct your donation specifically to their Research Grants Program, then, you'll have to find out from them how much of your "general donation" will go toward their Research Grants Program and how much will go toward their other programs. When you know this, you can modify the above figures appropriately. By asking the program administrator in charge of the SAO's Research Program what their overhead is, what institutional overhead is allowed, and what kind of expenses an investigator is allowed to include in a proposed budget, you'll gain some understanding of how much of your donation will go to help fund sarcoma research.
You can do a similar analysis for other programs that you would like to support. For example, if you want to make a donation to help with the financial expenses of sarcoma families, you'd like to know how much of the donation will go to the needy families and how much will go elsewhere, such as to the SAO's overhead and other program costs. Some SAOs offering financial help use the services of a Third Party to verify the financial data that the sarcoma family has provided them in the application for assistance. The fees that the Third Party charges to do this are considered "program costs". Some SAOs also use a Third Party to process the receipts the sarcoma family must submit to obtain reimbursement for expenses. These fees are also "program costs". For some SAOs, program costs are taken from the donations that are used to support that specific program. By asking the program administrator in charge of the SAO's Family Assistance program what they do and what the costs are, you'll gain some understanding of how much of your donation will go directly to help the needy families.

How is the research program administered?

If you are specifically interested in funding sarcoma research, consider seeking answers to the following questions about SAOs:

How are grant applications solicited?

Some SAOs have a call for grant applications that is widely distributed within the sarcoma community and made available online and at relevant medical conferences and workshops. Calls can be general in nature, not specifying any specific topics or sarcomas, or they can specify specific topics and/or specific sarcomas. Are the researchers encouraged to submit a grant application with no implication that they will be funded? Some SAOs have a grant application form that applicants must use and a set of guidelines and requirements that must be followed. Other SAOs may require only a few pages describing the proposed research and only solicit applications from a few investigators in a few institutions. Some SAOs restrict their applications to be from investigators in specific countries and, in some instances, from specific regions or states within that country. Others fund internationally.

When are grant applications submitted and awarded?

Some SAOs require grant applications to be submitted by a specific date. Some months afterward, they announce which grant applications, if any, will be
funded. Other SAOs allow grant applications to be submitted at any time, allowing a continuous flow of applications without any specific deadlines involved. This means that grants can be awarded at any time throughout the year allowing the research to being as quickly as possible, not holding up an award to a single announcement date.

How are grant applications evaluated?

Some SAOs employ a peer-review process in which grant applications are sent to a number of reviewers who are asked to comment on specific science related issues of the proposed research as well as the budget, facilities, etc. The Research Program Director evaluates the responses and recommendations of the reviewers and sends (anonymized) copies of these comments to the applicant with a letter: (a) accepting the application with specific revisions or without any revision whatsoever; (b) requesting the application be revised and resubmitted for reconsideration; or (c) rejected. If revisions are required, the SAO should request a detailed cover letter from the investigator indicating how each reviewer's comments have been addressed. Potential reviewers recuse themselves if they have any perceived or actual Conflict of Interest.

Other SAOs use either their Medical Advisory Board (or a portion of it) to evaluate grant applications. Board Members should, of course, recuse themselves if they have any perceived or actual Conflict of Interest. In these situations, the decision of the Board is final, i.e., the applicant is either funded or not. Often the applicant does not receive any detailed reviewers' comments and is not encouraged to or cannot revise and resubmit the application. This is unfortunate as such feedback is often useful to help an investigator scientifically improve their proposed study.

Other SAOs have no evaluation mechanism in place. They are simply raising funds to support a given institution or investigator and leave it to that institution or investigator to use the funds as they see fit.

How accountable and transparent is the research program?

One might ask SAOs if the investigators they fund are required to publish on their websites: (a) their experimental plan when the grant is awarded; and, (b) a summary of their findings when the grant period has been completed. If so, this indicates an important level of commitment to disseminating research findings as early as possible in the clinical and research community. Are donors made aware of which grants their funds have been used to support? This demonstrates the level of accountability and transparency of the SAO to its donors.

One might also inquire how many grant applications: (a) they receive annually; and (b) are rejected. Additionally, how many of the grants they funded have
resulted in substantial follow-on funding, e.g., in the US via a National Institute of Health R01 Grant and how many have resulted in journal articles. The answers to these questions are partial indicators of the quality of research they are funding. Finally, you might ask if their Research Grants Program actively encourages collaborative research among investigators in different departments within an institution, among institutions and across national boundaries. Such collaboration has many positive consequences.

**How are additional programs administered?**

After learning the basics about any sarcoma program, it will be helpful to seek answers to a set of questions like those above. For example, how are recipients of assistance chosen? What are the limits of the assistance and how can the funds be used?

**Consider Volunteering Your Time**

The very SAOs that you are willing to support with your funds after using the above vetting process are the obvious ones to consider assisting with your volunteer time. All SAOs need help. Please approach the ones that interest you and volunteer.

**Summary**

I hope that some of the above criteria, questions, observations and insights will help you identify a few SAOs to support. The sarcoma community needs all of the help it can get to provide the wide range of services and programs that are discussed above. Taking the time to choose and support an effective charity with valuable programs is key to assisting sarcoma patients and their families and to advancing research. Finally, since there are so few federal or state funds available for rare cancers such as sarcoma, SAOs play an integral, if not central role, in helping fund sarcoma research.