Ovarian Cancer National Alliance
We work to save women's lives

The Partner Members' Tool Kit

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Partner Member Program

Alone we can do so little; together we can do so much.

– Helen Keller

History of the Alliance

In September 1997, leaders from seven ovarian cancer groups joined forces to form the Ovarian Cancer National Alliance. Their primary goal was to establish a coordinated national effort to place ovarian cancer education, policy and research issues prominently on the agendas of national policy-makers and women's health care leaders.

In the five years before the Alliance formed, the energy and commitment of the founding leaders fueled important efforts around ovarian cancer issues in various parts of the country. Although some of these activists had begun to communicate with each other, few had met until the spring of 1997, when two seminal events occurred. These events, a two-day stakeholders meeting convened by the Department of Defense to launch its Ovarian Cancer Research Program and a town hall meeting convened by the Indianapolis-based Ovar'coming Together, prompted the consumer community to organize a coordinated national effort.

These two opportunities for leaders from the consumer community to meet, share and network opened the door for joint and coordinated activities among the groups they represented. In the ensuing six months, the Ovarian Cancer National Alliance was formed, and the founding members, from consumer groups nationwide, constituted themselves as its board.

The Alliance founders were the "Conversations!" newsletter (Texas); National Ovarian Cancer Coalition (Florida); Ovar'coming Together (Indiana); Ovarian Cancer Coalition of Greater Washington (Washington, D.C.); Ovarian Cancer Survivors Quilt Project (Virginia); Ovarian Plus International (Hawaii); and SHARE: Self-Help for Women with Breast or Ovarian Cancer (New York). Each of these organizations has made a unique contribution to the ovarian cancer movement.

The Ovarian Cancer National Alliance's (OCNA) mission is to conquer ovarian cancer by uniting individuals and organizations in a national movement. Since its inception, the Alliance has been the face and voice of a national network of ovarian cancer survivors and activists dedicated to finding an effective screening test and a cure. OCNA is the only national advocacy organization focused exclusively on legislative issues of importance to the ovarian cancer community. These issues include ensuring adequate and sustained federal funding for ovarian cancer research and education and awareness programs.

Perhaps most importantly, the Alliance is spearheading the National Agenda for Ovarian Cancer, the ovarian cancer community's first national roadmap to advance research and patient care into the next decade. The plan will identify and implement measurable goals to evolve research, improve access to quality care and accelerate advocacy.

Just some of our initiatives include Survivors Teaching Students: Saving Women's Lives℠ in which survivors speak to third-year medical students about ovarian cancer's symptoms and risk factors to help them gain perspective on the real life experiences and emotions of survivors. The Alliance provides an online forum for people dealing with ovarian cancer that includes discussion rooms, blogs, and an opportunity to connect virtually with others facing the same issues. In addition, the Alliance provides a clinical trials matching service, powered by EmergingMed, to help women locate clinical trials being conducted in the United States.

What Is the Partner Member Program?

The Alliance's Partner Member program creates a national movement of grassroots voices across the country, united in purpose and growing in strength. There are now about 50 Partner Member organizations nationwide working in tandem with the Alliance and each other to promote ovarian cancer education, awareness and advocacy. Partner Member groups include a variety of groups that pay dues based on their budgets – national nonprofits, state and local nonprofits and patient support groups.

What It Means to Be a Partner Member

There is a twofold purpose for a Partner Member program: it gives the Partner Members a national identity and affiliation with an organization in Washington, D.C.; and the program gives the Alliance the grassroots advocates who provide the voices and votes.

Together the Alliance and the Partner Members nationwide fulfill the mission to conquer ovarian cancer by uniting individuals and organizations in a national movement.

In addition to belonging to a national organization with a strong policy presence in Washington, D.C., Partner Members have:

- Access to breaking news on Capitol Hill, in research and in federal agencies such as the National Cancer Institute and the Centers for Disease Control and Prevention
- This Tool Kit for new and seasoned members that is downloadable from the Web site
- Organizational exposure along with individual appointments on Capitol Hill
- Regular policy information, briefings and annual training
- Information on opportunities to serve on national review and advisory entities
- Periodic updates and statistics on research and medical topics related to ovarian cancer
- Education on key topics such as clinical trials and access to care
- Regular e-news, newsletters and other materials
- Networking opportunities
- Monitoring and mentoring by the Alliance leadership
- Alliance Web site listing events and contact information
- Online community and discussion groups
- Discounts at the Alliance online store

Partner Member Responsibilities

Partner Members also have responsibilities to the Alliance.

1. Annual dues payment. The dues are based on the organization's budget and are self-selected, but a critical responsibility. Those who cannot pay can apply for temporary status but will not be part of any trainings, meetings or summits.
2. Use of the Alliance logo must be reviewed by the Director of Communications and Marketing.
3. Communications with the national office.
4. Registering as an advocate at the Alliance Web site with the Ovarian Cancer Action Network.
5. Initiating a Survivors Teaching Students: Saving Women's Lives℠ program in a nearby medical school.

Ovarian Cancer National Alliance
We work to save women's lives

Organizing a Partner Member Group

It is not fair to ask of others what you are unwilling to do yourself.

– Eleanor Roosevelt

Organizing a Successful Community Organization

Formally going through this process helps a young organization get off the ground as well as stay focused down the road. Much of this information will prove useful if your group decides to formally incorporate in your state and subsequently file for nonprofit status with the Internal Revenue Service. Examples are provided.

- Identify the problem you want to help with or need you want to fill. Is someone in your community already doing that type of work?
  - *Problem:* *Peer-to-peer patient support is not available for local women battling and/or surviving ovarian cancer. Local women and medical professionals are not aware of the subtle yet detectable symptoms of ovarian cancer. No other groups are locally targeting these problems.*

- Identify your group's shared vision. Hone in on key words. Write a vision statement. Your vision should be a broad statement with lofty goals.
  - *Vision:* *We envision a world in which an effective ovarian cancer screening test is part of every woman's annual gynecological examination.*

- Develop an organizational purpose or mission statement. This is the "who, what, where, when and why" of your organization. Statement should be short and concise, as well as broad enough to encompass your current and future goals and activities. You should regularly revisit your mission statement to help the organization stay focused and on track.
  - *Mission:* *Our mission is to provide peer-to-peer support for local women being treated for and/or surviving ovarian cancer, as well as increase public education and awareness locally about the symptoms for ovarian cancer.*

- Outline mission-related and organizational goals or objectives for your group, both short term and long term. You should regularly revisit your goals as well to help the organization stay focused and on track.
  - *General Mission-Related Goals:* *Hold regularly scheduled support group meetings which are led by a facilitator survivor and gynecological registered nurse; create an informal network of support for members – encouraging regular contact between meetings; reach out to newly diagnosed women through referrals and word of mouth; and work to educate and increase awareness in the local community about ovarian cancer – emphasizing early symptom detection.*
  - *Organizational-Related Goals for the Next Year:* *Elect board officers and establish bylaws; research and make decision on whether to pursue incorporation in your state and pursue nonprofit status or to find fiscal sponsor to piggy back off of for nonprofit status; increase local visibility by designing and implementing a simple Web site and publishing support group meeting information in local newspapers; and create a quarterly newsletter for dissemination to group members and local gynecologic oncologists' offices.*
  - *Organizational-Related Goals for the Second Year:* *Initiate steps for pursuing nonprofit status or identify and establish relationship with fiscal sponsor; create advisory board; and increase organization's public visibility and volunteer base.*

- Outline methods to achieve goals and objectives. HOW you will do things. Methods are processes and activities. Regularly revisit your methods; identify successes and failures and adjust methods as necessary.

- Describe the resources you will need to put your methods into action. Regularly review these needs to ensure adequate funding is available to successfully support your methods.

Models for Starting a Partner Member Group

The Ovarian Cancer National Alliance has received inquiries from women across the country interested in starting advocacy groups in their own communities. There are no hard and fast rules, and the approach that best fits the survivor community in your area will be most successful. Raising awareness about ovarian cancer and advocating for policies and programs that will dramatically improve women's survival from this deadliest of gynecologic cancers requires a clear sense of purpose, tenacity and organization. Described below are several different models used by Alliance leaders.

Georgia Ovarian Cancer Alliance (GOCA): Based in Atlanta, GOCA grew out of a support group. Its primary goal is education. Topping its list of accomplishments in the past two years is winning passage of a $125,000 appropriation from the state health department for GOCA to conduct a statewide ovarian cancer education initiative. GOCA has also held several awareness events, including a candlelight vigil attended by the governor; sponsored a major benefit in conjunction with the Pulitzer-prize winning play "Wit;" enlisted Bristol-Myers Squibb to support an awareness ad in the "Wit" Playbill, similar to OCNA's ad in the Kennedy Center program; and made and exhibited its own quilt. GOCA's board of directors is composed of survivors, friends and family members of women with ovarian cancer, and medical professionals. Staff includes both an executive director and public education director to implement the public education campaign. GOCA is a 501(c)(3) nonprofit organization. Contact: (404) 255-1337 or goca@gaovariancancer.org.

Ovar'coming Together: This Indianapolis-based group serves the state of Indiana and works to increase early detection by raising awareness among women and physicians about ovarian cancer's subtle signs and symptoms. Working closely with the physician community, Ovar'coming Together has produced an awareness brochure endorsed by the leading gynecologic oncologists in the state, and developed an educational slide show on the importance of early detection. Materials and resources for women battling ovarian cancer are arranged through Project Hope. Ovar'coming Together organizes a major fundraising and awareness-raising event each year that enlists support from top leaders in business, government and the community. The organization has a full-time executive director. Funds to support its work are administered through a local community foundation. Contact: Kelly Allen (317) 250-6827 or ovariancancerindy@hotmail.com.

Minnesota Ovarian Cancer Alliance (MOCA): This group has three goals: support, education and advocacy. Its first run/walk raised more than $125,000 with proceeds funding several ovarian cancer research projects in the state. Regular meetings include programs with a speaker. The organization has a medical advisory board of 17 gynecologic oncologists from the Twin Cities and Rochester-Mayo. MOCA has partnered with the Women's Cancer Resource Center to start an ovarian cancer support group, and with the University of Minnesota medical school to promote awareness of early symptoms and surgery by a gynecologic oncologist. Additional plans include an educational initiative on symptoms and early detection targeted to women's groups and the community at large. MOCA has received its own 501(c)(3) nonprofit status. Contact: Kathleen Gavin (952) 890-8775, or kgavin@mnovarian.org or visit its Web site www.mnovarian.org**.**

Whichever model is adopted, there are many common features in bringing people together and getting started. Some well-tested and useful techniques include:

- **Building upon an existing support group**: A group of women who are already in touch with each other through a gynecologic or other cancer support group, or through a group organized by the Wellness Community, provides an excellent base. Some women will and others won't be interested in developing additional activities. Existing groups can easily serve as jumping off points for organized advocacy efforts.

- **Tapping into existing communications vehicles**: Many hospitals and clinics have patient-centered bulletin boards and newsletters, and sometimes even Web sites where notices and information about new groups can be placed.

- **Enlisting the support of health professionals**: Oncology nurses, social workers and physicians are often in a position to identify women and family members who might be interested. They can be alerted through mailings or flyers. Privacy concerns prevent health care professionals from giving out patients' names. This can be overcome if advocacy group organizers provide their contact information, with explicit instructions to give it to patients who can then follow-up if they are interested.

- **Contacting the press**: Local newspapers and television stations are often willing to run advertisements about health group meetings as public service announcements (PSAs) or to list announcements about upcoming community meetings. Sometimes area radio stations are willing to assist nonprofit groups in preparing simple PSAs and even have public service directors who can be helpful. These contacts may also lead to local reporters willing to prepare a story on a new women's health or cancer group.

- **Putting the word out on the grapevine**: "Word of mouth" can be very effective, especially in smaller communities. Asking one person to find a few others can snowball until there is a working group.

- **Using computers**: Many of the people working on ovarian cancer advocacy today came to know each other through the Internet. Getting the word out about the formation of a new group through Internet networks such as the Ovarian Problem Discussion List or the Online Community may reach additional individuals.

- **Exhibiting at area health fairs**: Simple tabletop exhibits with materials about ovarian cancer attract many people who are already curious about health issues and seek new information about unfamiliar conditions and diseases. These exhibits will also draw survivors who may be eager to network with other women with ovarian cancer.

Nonprofit Status Versus Fiscal Sponsor

Nonprofit Status

The process for achieving nonprofit status is lengthy – taking 12 to 18 months; costly – filing fees, attorney and accounting fees; and labor intensive – see the Obtaining 501(c)(3) Federal Tax-Exempt Status section. However, depending on your organization's purpose and financial situation, going "nonprofit" may be appropriate or desirable.

Fiscal Sponsor

As an alternative, small start-up organizations often can secure the benefits of nonprofit status by establishing a relationship with an existing nonprofit organizations or agency willing to serve as an "umbrella organization" or "fiscal sponsor."

- A formal operating agreement, or "contract," would be established between the organization and fiscal sponsor.
- An attorney representing the organization would review the agreement/contract by the fiscal sponsor.
- The organization would develop its own mission statement.
- The general goals and objectives of the two organizations should be compatible or complementary. The beliefs or mission of one should in no way contradict the other.
- The organizations should elect their own officers.
- The organizations could operate as a sub-group, subsidiary or division of the fiscal sponsor. The level of autonomy would be clarified in the formal agreement.

- The fiscal sponsor would impart the benefits of its administrative capabilities and tax-exempt status to the organization.
- The organization can accept donations and donors can claim a tax deduction.
- Funds raised or expended by the organization would be reported to the fiscal sponsor.
- Donations would be made to the fiscal sponsor, but specifically earmarked for the organization's activities.
- The administrative services provided to the organization by the fiscal sponsor would be outlined in the operating agreement. The fiscal sponsor would typically be responsible for the accounting services and the filing of appropriate tax statements.
- The organization typically operates under the insurance coverage of the fiscal sponsor.
- The fiscal sponsor may receive an agreed upon percentage of the total revenues raised by the organization. Or, the fiscal sponsor may require the organization to pay a specific amount in support of administrative services. The formal operating agreement should outline these details.
- An organization can start out with a fiscal sponsor, but then grow over time requiring it to establish its own nonprofit status.

Setting up Your Legal Identity

Once you have decided what the issue, vision, mission and type of organization you want to form, now you will need to consider if you should register with your state or jurisdiction and determine whether you need to set up a legal entity.

Organizations can operate without setting up a legal identity with their state commission IF they are "loose" gatherings, such as book clubs and do not ask for funding from the public. However, if your group intends to act publicly then there is always the possibility that someone might place a judgment against the organization. By incorporating, your exposure loss is limited to the assets of the corporation. Likewise, the organization's assets cannot be touched if the individual has credit problems. For more specific analysis of your situation, you might want to check with the appropriate organization within your state or with an attorney who is knowledgeable in state law for corporations.

Business Registration

All businesses should register with their state or jurisdiction usually with the state Department of Taxation. Through this registration process, the state will assign your organization a business tax account number. Many states allow an on line registration process. During this process, the state may ask for your Principle Business Activity Codes and Description. These codes, the North American Industry Classification System (NAICS), identify the type of business that you are in and allow the U.S. Department of Labor to gather information for comparison with Canada and Mexico. The list is long and evolving. Based upon your mission, search the Department of Labor Web site http://www.census.gov/epcd/naics02/ for the best code. The mission of the OCNA partner member organizations vary so there are a number of possible codes. Your organization will need to determine the correct one but generally the following codes are good starting points: Voluntary Health Organizations (disease awareness fundraising) (813212); Community action advocacy (813319); Civic social organization (813410); Grant-making (813211) etc. Consider trying your search with a variety of single words, i.e., "health," "community," "education." (Note that the word "cancer" appears to relate to governmental organizations not to volunteer organizations.)

Of note: registration as a business is with the Department of Taxation and this is an independent process to incorporation, which is with a different department ("corporation," "commission" or similar name).

Incorporate in Your State

Nonprofit corporation laws are state-specific. State requirements are usually easy to locate on a state's Web site. You should find the actual laws relating to nonprofit corporations, as well as general guidance and/or answers to frequently asked questions. If you need hard copy information or assistance, try calling your state's Department of State or visit your local public library.

When drafting your organization's Certificate of Incorporation, use boilerplate language as a starting point. Boilerplate language is available free on the Web, or by purchase anywhere standard legal forms are sold. Internal Revenue Service Publication 557 (available at www.irs.gov) provides sample language in Chapter 3. If your organization has already established various basic organizational/administrative milestones such as a mission statement and goals, refer back to the narrative in these documents for the articles of incorporation relating to organizational purpose.

Once you have a framework, compare your Articles to any instructions specific to your state. It is important to meet all of you state's requirements, from structure to content, or your incorporation request may be delayed or rejected.

Finally, when you file your Certificate of Incorporation, remember to submit your filing fee using an appropriate method as directed by your state (check, money order, credit card, etc.). The state's nonprofit corporate fee schedule will provide specific instruction.

Articles of incorporation provide your state with a formal registration that your organization exists. There are several common requirements for Articles of Incorporation:

- Name – this must be a unique name for the state or jurisdiction in which you plan to operate
- Initial list of organizer(s)
- Key contact (registered agent) and the address for the organization
- Mission for the organization
- Type of organization: stock/for profit or non stock/nonprofit
- Intended duration of the organization. As a matter of course most organizations declare themselves as permanent but an organization can define a more limited term of operation
- Other language that may be required by your state or jurisdiction

Note that most organizations provide language that allows the Board of Directors to make changes to the Articles of Incorporation. Whenever changes are made, these changes should be sent to your state or jurisdiction.

Bylaws are the organization's operating principles that are the "rules" for operating your organization. These set forth how directors are elected, how meetings of directors (and other operating groups) are conducted, and list the officers the organization along with a description of their duties. Bylaws usually include a provision that the Board of Directors of the Corporation have the ability to change the bylaws.

Bylaws also show outsiders (possible funders, volunteers, and your local community) how your organization operates. Through these they will understand that you are well-organized and serious about your work. Some states require an organization to have established bylaws at the time of incorporation filing. If bylaws exist, they should be included when you file for federal tax-exempt status.

Because bylaws detail how your organization will operate, you might consider drafting your bylaws now rather than down the road. By using generic bylaw language (available free on the Web, or by purchase, or by using the examples included here) as the starting point, your organization can work through some very important details. Regardless of your starting point, you should adjust according to your organizational purpose, needs and priorities. While this discussion and organization preparation will take time, you may see that the advantages of considering HOW your organization will operate will outweigh the time and effort necessary to complete them.

There are a number of Web sites offering some generic (free) forms for both the Articles of incorporation and bylaws. These can provide a good starting point. However, it is always a wise idea to contact your state or jurisdiction to determine its requirements for organization under its authority. An Internet search can yield a number of examples of articles of incorporation and bylaws that other organizations use.

Resources

Articles of Incorporation. Wikipedia http://en.wikipedia.org/wiki/Articles_of_incorporation and http://en.wikipedia.org/wiki/Bylaw

The Foundation Center offers on line information and support services to not-for-profit organizations. http://foundationcenter.org/findfunders/

Request an Employer Identification Number

After your organization has incorporated with the state, you must file Internal Revenue Service Form SS-4 – Application for Employer Identification Number (EIN). An EIN is the organizational equivalent of your Social Security Number. Form SS-4 and its instructions are available free at www.irs.gov or at any IRS office. You may file via the mail, fax, online or telephone.

Obtaining 501(c)(3) Federal Tax-Exempt Status

Although not legally required, it is always prudent to obtain advice/assistance from an attorney and accountant when traversing the process outlined below.

File for Federal Tax-Exempt Status

Once your Employer Identification Number has been received from the Internal Revenue Service, you should prepare and file Internal Revenue Service Form 1023. Both the instructions and form are available free at www.irs.gov or at any IRS office. There is currently a user fee associated with this filing which is based on your organization's annual gross income.

It is necessary to include your Certificate of Incorporation, bylaws, and other organizing documents with this filing.

Although IRS nonprofit literature indicates that the 1023 filing is not required if your organization's gross annual receipts are less than $5,000, it is prudent to file this paperwork regardless of the level of funding you believe your organization will operate with annually. Your organization may grow over time, ultimately exceeding the dollar cap requirement. More importantly, most grantors require an organization to have an EIN and the Form 1023 filed. You could lose out on valuable funding opportunities without this number and status.

File Annual Returns with IRS

Don't forget to file your annual IRS form 990EZ or 990.

Additional Information

- Internal Revenue Service Exemption Requirements
  - http://www.irs.gov/charities/charitable/article/0,,id=96099,00.html
- IRS Publication 557: Tax-Exempt Status for your Organization
  - www.irs.gov (search for Publication 557)
- IRS Publication 4220: Applying for 501(c)(3) Tax-Exempt Status
  - www.irs.gov (search for Publication 4220)
- IRS Publication 4221: Compliance Guide for 501(c)(3) Tax-Exempt Organizations
  - www.irs.gov (search for Publication 4221)

Additional Nonprofit Resources

Idealist.org

Provides nonprofit resources including the uniform registration statement used by many states to allow nonprofit organizations to register to fundraise in their states.
www.idealist.org

Nonprofit Guides
Grant-writing tools for nonprofit organizations.
http://www.npguides.org/links.htm

Nonprofit Good Practice Guide
Provides key information designed to help anyone manage a nonprofit organization efficiently and effectively. Explores articles, tips, resources and glossaries within ten topic areas.
http://www.npgoodpractice.org/

Foundation Center
The Foundation Center helps nonprofit groups learn how to solicit foundation grants and deal with other aspects of financing and managing a new charity.
www.fdncenter.org

Board Source
Formerly the National Center for Nonprofit Boards, Board Source provides many resources related to nonprofit board governance.
www.boardsource.org

Better Business Bureau Wise Giving Alliance
The Web site of the Better Business Bureau's Philanthropic Advisory Service, this Web site includes the operational standards and guidelines developed by the BBB for nonprofit, 501(c)(3) organizations.
www.give.org

Internal Revenue Service
Many forms, instructions and publications of the IRS are available, including Publication 557 Tax-Exempt Status of Your Organization, Form 1023 Application for Recognition of Exemption, and Form SS-4 Application for Employer Identification Number.
www.irs.gov

Minnesota Council of Nonprofits
The Minnesota Council of Nonprofits informs, promotes, connects and strengthens individual nonprofits and the nonprofit sector.
www.mncn.org

Nonprofit Guidance for Organizations in Pennsylvania
www.temple.edu/lawschool/ccno/mechanics.htm
*Each state's Department of State Web site should have state-specific information regarding nonprofit incorporation filings.

National Council of Nonprofit Associations
NCNA advances the vital role and capacity of the nonprofit sector in civil society and supports and gives voice to state and regional associations of nonprofit organizations.
www.ncna.org

Ovarian Cancer National Alliance
We work to save women's lives

Growing Your Organization

We are not born all at once, but by bits.

– Mary Antin

<u>How to Find Volunteers</u>

One of the most important challenges an organization can face is how to secure an adequate volunteer base. Volunteers are the organization's "worker bees" – how the organization amplifies its impact. Equally important, an organization's volunteer force can grow into future organizational leaders – the next generation to effectively develop and fulfill the organization's mission.

For many ovarian cancer organizations, the immediate circle of volunteers includes ovarian cancer survivors, their family members and friends. This is a great strength AND challenge for organizations. When a survivor/volunteer is undergoing treatment, her volunteer capabilities can be severely limited. It can be difficult for a group of advocates to continually watch peers struggle with treatments, recurrences and sometimes loss. This is especially true of support group-based organizations. However, out of such struggle, commitment to the cause is reinforced and volunteer numbers can multiply as more family and friends reach out with the strong desire to spread the word, raise funds for research, etc. Those with direct knowledge of and impact by ovarian cancer will always be an ovarian cancer organization's strongest advocates.

Beyond the initial circle of volunteers, an organization should reach into its own community for additional partners and volunteers. Besides increasing volunteer numbers, this also increases networking and diversifies an organization's strengths and talents. Below are a few suggestions to help move an organization's volunteer base forward.

- Solicit involvement from medical organizations, such as the Society of Oncology Nurses.
- Contact all local media with a call for volunteers. Make sure to reach out to the smaller print magazines since it will be easier to gain coverage and be highlighted for local interest stories.
- Host a volunteer gathering where group members speak about the organization for 15 minutes. Let audience members ask questions for 10 minutes and then socialize for 30 minutes…food, drink and fun!
- Volunteer for speaking engagements at local women's organizations, such as the Network of Women in Business, Red Hat Society and corporate women's groups. Do not overlook men's groups or young mothers groups, etc.
- Seek out breast, colon and gynecologic cancer survivors and their families. Set up volunteer programs where certain events are co-sponsored by women's health organizations, or are staffed by mother/daughter, father/son or father/daughter pairs.
- Set up internships with local schools, teaching hospitals and their nursing or social work students. They volunteer "x" hours a month in return for a letter of recommendation and possibly credit if you can arrange it with the school/hospital. Local universities are a great source of free manpower and talent!
- Go to local health related conferences and trade shows to draw potential interest.
- Offer churches and other community organizations free speaking engagements; ask for volunteers while at the event.
- Conduct volunteer appreciation events and give positive feedback. The current volunteer base will want to maintain their volunteerism as well as spread the word about their positive experiences.

Volunteers want to make a difference. Volunteering is a gift of their time, talent and service. Understanding that volunteers have full time jobs and families outside of the time they give to an organization is extremely important. Do NOT expect volunteers to do everything. DO let them be comfortable in what they can give, and always be thankful for their time and efforts. Give lots of thank you's to your volunteers, send handwritten notes or formal letters of thanks within one week of the event, and always try to ensure that your volunteers are having a positive experience.

Building a Board of Directors

For formal organizations with a 501(c)(3) tax-exempt status, a strong Board of Directors will become the backbone to an organization's long-term sustainability. The following information, published by the National Center for Nonprofit Boards, outlines the basic responsibilities of the nonprofit board, the board building cycle, and how and where to find board members.

Basic Responsibilities of Nonprofit Boards

- Determine the organization's mission and purpose
- Select the chief executive and reach consensus on the position's responsibilities
- Support the chief executive and review his/her performance
- Ensure effective organizational planning
- Ensure adequate resources for the organization to fulfill its mission (fundraising)
- Manage resources effectively by developing an annual budget and ensuring proper financial controls are in place
- Determine, monitor and strengthen the organization's programs and services
- Enhance the organization's public standing (public relations)
- Ensure legal and ethical integrity and maintain accountability (policy development, bylaws, and articles of incorporation)
- Recruit and orient new board members and assess board performance

The Board Building Cycle

1. Identify the needs of the board: the skills, knowledge, perspective, connections, etc., needed to implement the strategic plan. What do you have? What is missing? Identify source of board members with the desired characteristics.

2. Cultivate potential board members. Ask current board members, senior staff and others to suggest potential candidates. Find ways to connect with those candidates, get them interested in your organization, and keep them informed of your progress.

3. Recruit prospects. Describe why a prospective member is wanted and needed. Explain expectations and responsibilities of board members, and do not minimize requirements. Invite questions, elicit their interest and find out if they would be prepared to serve.

4. Orient new board members both to the organization – explaining the history, programs, pressing issues, finances, facilities, bylaws and organizational chart – and to the board – describing committees, board member responsibilities and lists of board members and key staff members.

5. Engage all board members. Discover their interests and availability. Involve them in committees or task forces. Assign them a board "buddy." Solicit feedback. Hold everyone accountable. Express appreciation for work well done.

6. Educate the board. Provide information concerning your mission area. Promote exploration of issues facing the organization. Hold retreats and encourage board development activities by sending board members to seminars and workshops. Do not hide difficulties.

7. Rotate board members. Establish term limits. Do not automatically reelect for an additional term; consider the board's needs and the board member's performance. Explore advisability of resigning with members who are not active. Develop new leadership.

8. Evaluate the board as a whole, as well as individual board members. Examine how the board and chief executive work as a team. Engage the board in assessing its own performance. Identify ways in which to improve. Encourage individual self-assessment.

9. Celebrate! Recognize victories and progress, no matter how small. Appreciate individual contributions to the board, the organization and the community. Make room for humor and a good laugh.

How and Where to Find Board Members

<u>Where to find suggestions of good board members:</u>

- Colleagues
- Board members of other nonprofits
- Articles and reports in the local media
- Chief executive and other senior staff
- Board members
- Volunteer centers

<u>Whom to consider for board membership:</u>

- Current and prospective major donors
- Community leaders
- Executives of local or national corporations, including those not at a senior level
- Owners of small businesses
- Individuals in professions related to the organization's mission
- People who have benefited from the organization's services, or their relatives
- Local leadership programs

<u>Where to look for prospective board members:</u>

- Churches, synagogues, and other religious institutions
- Trade, professional, and fraternal associations
- Organizations representing various racial and ethnic groups
- Local colleges and universities

<u>**Building a Coalition**</u>

One of the best ways advocates can achieve success can be to join forces with other individuals and organizations with shared interest and goals. The Ovarian Cancer National Alliance leverages its resources by collaborating with others in the cancer community to advocate legislative and regulatory issues of mutual interest and priority. As such, the Alliance encourages its advocates and Partner Member organizations to explore opportunities to collaborate with others in the cancer, public health, medical, and research communities to extend their reach, take action on matters of importance and concern, and achieve joint public policy goals.

1. Start small. Identify a relatively easy issue in which you collectively have an interest and on which you can agree.

2. Develop clear, agreed upon goals, objectives and work assignments so everyone is clear on the scope and nature of the "partnership" and who is responsible for what. Deadlines will help the process.

3. Establish processes by which the group will operate, such as having co-chairs and subcommittees. Also have set procedures for review, approval and dissemination of documents to both internal and external parties.

4. Recognize and acknowledge that on other issues you may have to agree to disagree.

5. Scratch each other's backs. Help other organizations on their priorities and they will be likely to help with yours.

6. Think "outside the family." Broaden your view of the types of organizations and individuals who might have an interest or stake in your cause.

7. Express thanks and appreciation; keep your partners up-to-date on your progress and activities.

8. Share credit and responsibility so people have a sense of ownership.

9. Be strategic in terms of what you ask for from whom – recognize that while some organizations may be able to contribute at a high level, others may only be able to give a little to the effort. Having a range of organizations and different levels of participation advances the cause.

10. Occasionally take the "temperature" of the group to ensure that the partnership is still viable and efficacious.

Fundraising

According to the *Handbook for Starting a Successful Nonprofit* published by the Minnesota Council of Nonprofits, individuals in the United States account for nearly 88 percent of all charitable giving in the country. While over 62 percent of household giving in the United States in 1993 was directed towards religious organizations, more than $40 billion went towards health, human services, arts and other types of charitable organizations.

Below are several different types fundraising that can be used to solicit contributions from individuals. Each of these ideas should be considered in the context of an organization's mission and strategic plan, because none of them are appropriate in all circumstances.

- Membership fees or dues
- Direct mail appeals
- Phone appeals
- Planned gifts
- Door-to-door canvassing
- Special events fundraising
- Federated fundraising campaigns

For more information on each of these categories, as well as other fundraising ideas, please visit the Minnesota Council of Nonprofits at www.mncn.org/info_charitable. In addition, many of the Alliance's Partner Member organizations have successfully managed fundraising events and campaigns, and are very willing to share their ideas and lessons learned.

Grant-Seeking and Writing

Grant research and writing can be an overwhelming process. However, once the process and techniques are learned, grants can provide funding for programs or initiatives that other wise may never be undertaken due to resource shortages.

Steps

1. Determine and understand your organization's area of greatest need for funding. Develop a budget, and compile research and reference material, which supports the need for this program or initiative.

2. Use the Foundation Directory found in most libraries to research funding prospects. Look in your state's local Foundation Data Book, which lists virtually all granting organizations in your state, or call your local community foundation. Research potential grants with relevant government agencies at the local, state and federal levels.

3. Conduct an Internet search for granting organizations. Focus your search on grants related to your organization's needs: e.g. "grants for women's health initiatives."

4. Compile all your research data on a spreadsheet. Include contact information, the grant's mission and what the grant supports, application guidelines, average funding gift, and deadlines.

5. Write the proposal per the grant's individual instructions, or in a report format with section headings and bullet points. Include all the information the granting organization requires. Be sure your narrative justifies the program and expense, and outlines how your proposal will measure success.

6. Include a cover letter briefly stating the amount of funding you are requesting. Give a concise summary of your project.

7. Submit your cover letter and proposal. Always save a copy for your organization's files.

Tips

- Check with www.guidestar.com to find a granting organization's IRS 990 form and discover their funding patterns and history
- If a granting organization does not have a specific application format, provide a summary. Include program goals, how funds will be used, the history or your organization and any other relevant information.
- Be careful to adhere to all the funder's guidelines or your proposal will most likely be disregarded
- Consider finding a book on grant writing, or taking a local grant-writing course

Warnings

- Do not send out mass, blind proposals to granting organizations. It is important to tailor each proposal to the grant funder's guidelines.
- Remember that grant money is not "free" money. A grant establishes a contract between your organization and the funder. Your organization is legally bound by the grant's intended funding
- Be prepared to provide the funding organization with status reports

Ovarian Cancer National Alliance
We work to save women's lives

Legislative Advocacy

We don't accomplish anything in this world alone…and whatever happens is the result of the whole tapestry of one's life and all the weaving of individual threads from one to another that creates something.
– Sandra Day O'Connor

Finding Information

The advocacy section of the Ovarian Cancer National Alliance Web site has a wealth of information about current policy issues. The site is updated to reflect current legislation, as well as information on federal appropriations.

On the advocacy site, you can join the Ovarian Cancer Action Network, through which you will receive e-mail updates and e-mail action alerts. These alerts will often ask you to contact your member of Congress, and provide a sample e-mail.

The "Action Alert" section of the site will show you past and current legislation in addition to current action alerts. You can see how your representatives voted by viewing the "Issues & Legislation" section of the site.

Calling Congress

Calling the offices of members of Congress can be one of the easiest and most effective ways for ovarian cancer survivors and supporters to communicate with policy-makers on issues of interest and priority. Such a phone call, if done correctly, may result in garnering support for the Alliance's public policy priorities.

When calling policy-makers, be sure to do so on your own time and with your own phone, as your employer might not share your views on the topic. While calling the local offices of your members of Congress does not require a long-distance call, it would be best to contact their Washington, D.C. offices which are better equipped to handle a greater volume of constituent calls and most policy staff work in the Capitol Hill office, not in the district.

To reach the offices of your two senators as well as your representative in the House, just call the U.S. Capitol Switchboard at (202) 224-3121 and ask to be transferred to their offices. For those unsure of who represents you, simply visit www.senate.gov and www.house.gov to learn the policy-makers' names.

Be sure to keep a record of the date and time of your call(s), and the person with whom you spoke or for whom you left a message. Sometimes the staff loses phone logs so you may need to follow-up with the office to ensure a response.

Identify yourself as a constituent. Clearly state your first and last name, your hometown and why you are calling. If you know the health legislative assistant (Health LA), be sure to ask for that staffer by name. If not, ask for the staffer's name and request to be transferred. Sometimes, the receptionist will indicate the need to leave your comments with him/her. If so, request the name of the Health LA so that you have it for future reference.

"My name is Jessie Johnson. I am an ovarian cancer survivor from San Francisco, and I would like to speak with the health legislative assistant about an ovarian cancer research issue."

Immediately identify the topic you are calling to discuss.

Briefly state your concern and what you want Congress to do. Limit this part to one or two sentences, so that the staff understands why you are calling.

"I am a constituent who is concerned about ovarian cancer. I would like Congress to…"

Make a few brief points as to why the issue concerns you, your community and the nation and why the member should take action. Some may choose to write notes in advance to help stay on topic and remain clear in the discussion while articulating your case.

Be clear as to what you are asking the member to do (e.g., cosponsor a particular bill, vote for or against a specific measure, sign a "Dear Colleague" letter).

Be polite in tone and language. Oftentimes staffers can be overworked, overwhelmed, underpaid, and receives dozens – if not hundreds – of calls a day. In fact, in some offices, you may be speaking with a junior staffer or a college intern, so be sure to be patient and forgiving. Also, be sure not to use any "lingo" or "slang" (e.g. do not use acronyms like "DoD" when you mean Department of Defense). Try not to assume that the person on the other end of the phone is familiar with the issue in question so be as clear and concise as possible.

Keep it brief. Limit your call to no more than five minutes unless the staffer asks you questions and seems engaged in the discussion. Offer to send additional or follow-up information to the staffer and request their preferred mode of communication (e.g. e-mail, fax).

Specifically request a written response from the office on the member's position or action on the issue you addressed.

"I would like a letter from your office spelling out the senator's views on this issue and what she is doing specifically to address ovarian cancer."

Provide your full name, mailing address, e-mail address and phone number.

"My name is Jessie Johnson. 123 Main Street, San Francisco, CA 94123. My phone number is (415) 555-1234. I look forward to hearing back from your office."

Thank the staffer for his/her time and indicate that you appreciate his/her willingness to listen and record your comments. Be sure to get the name of the staffer so you can have it for future reference, and be sure to record the day and time the conversation took place if you need to follow up.

"May I have your first and last name for my records? Thank you very much for your time and for recording my views and seeing that I receive a response from the senator. Goodbye."

If you do not receive a response within a reasonable timeframe (approximately a month), either call or write to follow-up and request a response. Reference your phone call and mention with whom you spoke and about what topic to help facilitate a meaningful reply.

Other Tips
If you receive the voicemail of a staffer instead of speaking to someone who can record your request and contact information, be sure to leave a brief, clear message for the staffer (noting his/her name for future reference). Providing your full name, contact information, and the reason for the call and specific request (e.g. sign the Snowe-Reed Dear Colleague). Be clear to state that you would like a return call and/or a letter from the member about the topic in question.

Keep in touch with the offices of your members of Congress to establish a relationship and make yourself available as a local resource on ovarian cancer issues. Many times will exist where you and an elected official will "agree to disagree," but over time, you also may find that the policymaker may be supportive and helpful on other matters.

Writing Congress

Writing to members of Congress should only be used for matters that are not time-sensitive. Mail takes approximately six weeks to get to the office, due to increased security. Also, enclosing items such as photographs, originals of articles, or other documents is not recommended; it is best to save these items for hand delivery or drop off for any possible meetings in their office. However, if you choose to write to Congress, please follow the same tips for e-mail (below).

E-mailing Congress

Each Congressional office maintains a different policy about how they handle e-mail from constituents. The majority of members do not accept e-mail, but require you to use the forms on their Web sites. To access these forms, visit each member's Web site, which you can find at either www.house.gov or www.senate.gov, or locate them through www.ovariancancer.org/advocacy. Responses to Action Alerts are submitted to Congressional offices in the manner they have requested. Many Congressional offices provide a generic, automatic acknowledgement of receiving e-mails but then will follow-up with either a specific e-mail response or a letter via regular U.S. Postal Service. A handful of offices still do not respond individually to e-mails but count the input and inform the policymaker how many people have written in on the particular topic. It is best to contact your members' offices to learn about their individual policies about constituent correspondence.

When writing to policy-makers, be sure to use your personal e-mail account, as your employer might not share your views on the topic. For all forms of communication, be sure to include your full name, return mailing address, e-mail address and phone number.

Always be polite. When addressing correspondence to any government official, be sure to use the proper forms of address (at the end of this document). Even if you are angry, frustrated or disappointed, be sure to use a polite tone and appropriate language; be sure not to be threatening, confrontational or rude. Communicate with your members of Congress in the same manner you would with your colleagues, neighbors, family and friends – clearly, concisely and with respect and honesty.

Be clear to identify yourself and your reason for writing. In the opening sentence, be clear up front and identify yourself as a registered voter, constituent and someone who has been touched by ovarian cancer. For example: *"As someone who has been affected by ovarian cancer and who lives, votes, and works in your district, I am writing to request…."* If you know the member or staff aide, say so at the beginning of the message; this fact may alert the aide reading your correspondence to give it special attention. Those who hold a leadership position and have clearance to write in that capacity (e.g. chapter president, board member, etc.) be sure to use your title and indicate how many people that you represent vis-à-vis your state or local organization.

Be concise and informed. If possible, try to keep the letter to a single page. Do not feel the need to be an expert on the issue, but try to be familiar with the basic facts and points (e.g., name of the legislation and the associated bill number and why it should be supported or opposed). If you are requesting that the policymaker cosponsor a particular measure or are writing to express disappointment at a particular vote the policymaker cast, check the list of cosponsors and the vote record first at http://thomas.loc.gov/ to ensure that you have the most up-to-date information and that all of your facts are straight.

Personalize your message. Remember, your expertise lies in what it is like to be affected by ovarian cancer – living with it, watching a loved one battle it, or surviving it – and as such, you can share many experiences. Tell a personal story and explain the relevance to the issue at hand. Although form letters and postcards are "counted," they often do not elicit a response from a Congressional office. Personal stories and illustrations of local significance will have a lasting impact on policy-makers and their staff more than statistics and generic examples. Moreover, personal stories often spur policy-makers to action – not numbers. In reality, our policy-makers often legislate by anecdote. Your own words offer the most power and can influence the legislator's response or vote. If you wish to use a template letter (like those provided at www.ovariancancer.org), please take a few moments to personalize it. Try to include relevant state or local information to explain how the issue affects your community.

Be honest and accurate. If you are including statistics or other scientific information, be sure to verify your sources and have them handy if the Congressional office follows-up and wants additional information. Also, be sure not to exaggerate the situation or issue; do not oversell the policy solution you are advocating or overstate the consequences if the policymaker does not agree to your request.

Be modest in your request. Although you may wish to address multiple issues it is often more effective to focus on only one or two issues of priority. Your communication will be clearer and policy-makers or staffers will be more receptive because you have not overwhelmed them with too many requests.

Be of assistance and serve as a resource. Policy-makers and their staffers can be overworked and overwhelmed, so offer them some assistance; they will appreciate any input and help. Those who have an article of interest or relevance should be sure to include it with the correspondence, or mention it and indicate that you would be happy to provide it should they be interested.

Express appreciation. Too many times we just “spank” and forget to “thank.” If in response to earlier correspondence, you receive a letter informing you that the member shares your views or took the action you requested, write back expressing your thanks for the response and support. Or, if you learn through the newspaper, or the Alliance’s Web site or Ovarian Cancer Action Network E-newsletter, or other means that the policymaker recently cosponsored a bill you support or voted the way you hoped, send a letter expressing your pleasure at his/her action. At the close of this correspondence, be sure to acknowledge and thank the member for his or her attention to your concerns.

Ask for a response. Because policy-makers and their staffers work for you, you have every right to (politely) ask for a response and hold them accountable if your communication goes unanswered. In fact, entire systems, processes and staff exist in Congressional offices to respond to constituent input. It is important to note, however, that because of the volume of constituent input, receiving a response could take weeks or month. Make clear at the close of your correspondence to request a written response regarding the policymaker’s views on the issue or legislation in question.

Be sure to follow-up. If you do not receive a response in a timely fashion (in excess of a month for most offices, a little bit longer for Senators from large states like California and Texas), be sure to follow up with the office by phone or with another letter (by fax is best) with your original attached (make sure to keep or print a copy for your records before sending it) and indicating the lack of a response and this second request for one. Those who receive an unsatisfactory response to your correspondence should write or call again to express appreciation for the response. Be polite, yet firm, in communicating that the response lacked what you anticipated or requested. Reiterate your points and address any concerns or points the policymaker has made concerning the issue in the correspondence.

Other Tips

Keep in touch with the offices of your members of Congress so as to establish a relationship and make yourself available as a local resource on ovarian cancer issues. Many times exist where you and an elected official will “agree to disagree” but over time, you also may find that the policymaker may be supportive and helpful on other matters.

Proper Forms of Address for Members of Congress

Members of the United States House of Representatives
The Honorable [First Name Last Name of Member of Congress] United States House of Representatives Washington, D.C. 20515

Dear Mr./Mrs. [Last Name of Member]:

United States Senators
The Honorable [First Name Last Name of Member of Congress] United States Senate Washington, D.C. 20510 Dear Senator [Last Name of Member]:

<u>Congressional Meetings</u>

Meetings with members of Congress and/or their staff represent terrific ways for ovarian cancer survivors and supporters to communicate with policy-makers on issues of interest and priority. Visiting with them enables you to educate them about your concerns, avail yourselves to them as a resource and establish a relationship that can prove mutually beneficial over time. It is best to build a relationship before you need it. Such meetings can be conducted at Congressional offices in Washington, D.C. or "at home" in district offices, and if done correctly, can garner support for the Alliance's public policy priorities.

Prior to arriving in Washington, D.C. or at the district office, be sure to schedule a meeting with the staffer or through the appointment secretary/scheduler for a visit with the member of Congress. Be clear who will be attending and what issue(s) will be discussed. The day before, confirm the appointment as the Congressional schedule changes often – and such changes often occur beyond their control.

Prepare and be on time. Members of Congress and their staffs have busy schedules and often have several commitments during the day. Be respectful of their time by allowing plenty of time to go through security, find your way to the office, and announce yourself to the receptionist. If you attend in a group, discuss with your colleagues in advance what will be covering in the meeting. Be sure to select a primary spokesperson and determine who in the group will raise which points and requests. Open by thanking the member or staffer for his or her time. Be sure that everyone in the group identifies herself – first and last name and connection to ovarian cancer – and remember to mention that you are a voting constituent and provide some context about where you live/work in the district/state. If the policymaker or staffer has been helpful in the past or taken action that you appreciate, be sure to say thank you and acknowledge that up front. Prior to your meeting with the member/staffer, it is best to get a sense of what matters are currently pending before Congress, and the committee(s) on which the member sits. For recommended resources for this type of information visit thomas.loc.gov or check out the Advocacy Toolkit Resources at www.ovariancancer.org/advocacytoolkit/.

Be brief and clear, as meetings typically last only 10 to 25 minutes in their entirety. Cover only a few (one to three) topics. Consider preparing talking points beforehand to ensure that you and your colleagues "stay on message." Anticipate the kinds of questions that may be asked from both supporters and opponents. Attempt to be prepared to answer such questions in the meeting; if asked a question to which you do not know the answer, acknowledge the validity of the question and indicate your uncertainty of the answer. Mention that you will need to follow-up with them later (and remember to do so). Do not assume that the member or staffer is so knowledgeable about the pertinent issue – be sure to provide them with some background. If you are not discussing a specific piece of legislation, explain that you want to provide background information or provide your perspective on an issue of importance to you and your community.

Be sure to provide a personal story or real-life illustration of the problem, as personal stories resonate more than statistics. As necessary, briefly cite evidence or facts to support your position, particularly any local, regional or state data. However, be sure not to overwhelm the policymaker or staffer with too many statistics and references to studies (this kind of information can be in the materials you leave behind or can be sent with your thank you note). Discuss how the policy change (e.g. increased funding for ovarian cancer research, enactment of Johanna's Law, etc.) will have an impact on your community. Be concise and honest about the issue(s) and the solution(s) and make clear the relevance of the issue(s) to their constituents.

Be polite and listen carefully to the policy-makers' or staffers' views and comments. Even if you disagree, it is important to be courteous. Be flexible and consider the opposing view. Be sure not to be argumentative or threatening. You may agree to disagree on an issue today and find that you can agree and work together on another matter tomorrow. Much of ovarian cancer advocacy is about building and maintaining relationships over time. Some of the best friends of the cancer community were not always allies but due to a combination of advocates' tenacity, a history of being respectful, providing reliable information, and making a compelling case – we have won over some terrific champions.

Be sure to get a response – in a nice way. Ask directly, and politely, for the policymaker's views and position on the issue and what s/he plans to do about it. Do not let the policymaker or staffer distract you with other issues (gently steer the conversation back to your issue), avoid responding, or dismiss your specific concerns with a broad statement such as, "I am working against cancer by supporting more funding for biomedical research." Be sure to stay on message and the topic as politely as possible. It is your constitutional right to "petition Congress for redress of grievances" – so take this opportunity to do what you can to get a commitment from the member to take action on your request(s). However, if the member truly remains undecided or the staffer is not familiar with the member's position, do not force the issue – reiterate your interest in knowing, offer to answer any additional questions/provide additional information, and request a written follow-up letter from the member once they have reached a decision regarding your request.

Bring a short set of materials to leave behind. However, do not give the materials until the close of the meeting, or the member or staffer may choose to start reading the material and only listen to the meeting with one ear. Early in the meeting, indicate that you have materials to leave on the topic(s). Be sure to follow-up and follow through on any promises of additional information.

Leave your contact information. Those who leave a business card should clarify that you are visiting on your own time and not representing your employer unless you have received such clearance. Be sure to get a business card from the member/staffer so that you know how/where to reach them. Be sure to ask the member/staffer their preferred mode of communication (e.g. e-mail, fax, voicemail/phone).

Summarize your requests of the member/office and any responses the member/staffer have given to ensure clarity about where they stand on the issues. Make a summery of the member's/staffer's requests and indicate how you plan to respond. Express thanks and appreciation for their time, interest and courtesy.

Report back to the Alliance and any other advocacy partners involved in the issue or effort so that others can follow-up with the office with any additional information and reinforce the message you delivered.

Follow-up with a thank you note to the member/staffer referencing the date of the meeting, who attended, and the issues you discussed. Your follow-up letter should express appreciation for the time and consideration extended to you during your meeting, reiterate your request(s) and ask for a written response from the office. Be sure to call/e-mail/write with answers or information the member/staffer requested. Be sure to keep in touch with the member/staffer to maintain and strengthen the relationship. Great ways to keep in touch include sending an article of interest from the local paper, e-mailing a copy of the latest Alliance e-newsletter or inviting the member/staffer to attend a support group meeting at home during their next visit. *If your initial meeting is in Washington, D.C., be sure to schedule a similar meeting with the staff in the district or state office and check in with your policymaker when she or he comes home to reinforce the relationship and follow up on your issues of priority.*

Other Tips
When visiting Capitol Hill, you could encounter long lines to get through security (bags and all contents from your pockets must be put through the X-ray machines and almost everyone must step through a metal detector). Be sure to allow plenty of time to get through security.

The Congressional schedule can be fluid and members and staffers often are pulled away for various events and activities that cannot be predicted in advance (e.g. last minute press conference, meeting with the chairman of a committee the member sits on, etc.) and, as such, your meeting could be delayed or bumped (the member may not be available and you may instead meet with staff). In addition, space on Capitol Hill comes at a premium so your meeting could occur in the reception area in the office, in the hallway, or downstairs in the coffee shop. Do not take any last minute meeting changes personally and make sure to be gracious and flexible.

Ovarian Cancer National Alliance
We work to save women's lives

Education/Awareness/Media

Let us not look back in anger or forward in fear, but around in awareness.

– James Thurber

Importance of Current Information

Starting a community organization carries with it the responsibility of ensuring the information you provide to others is up-to-date and from reliable sources. Most ovarian cancer groups rely on OCNA or other organizations, such as the Gynecologic Cancer Foundation, for current statistics and symptom information. Many groups include disclaimers on their Web sites stating that their organizations do not provide medical advice, and that individuals should always defer to information and advice from their personal physicians.

Whether your organization chooses to focus on fundraising, symptom/disease education and awareness, survivor support, or legislative advocacy, you should make every effort to stay current with the latest information. It is also a good idea to compile a list of your chosen resources. This list can be posted as links on your Web site, or printed in hard copy for dissemination to interested persons.

Suggested Resources

- **Centers for Disease Control and Prevention:**
  - www.cdc.gov
  - 800-CDC-INFO

- ***CONVERSATIONS!*: The International Newsletter for Those Fighting Ovarian Cancer:**
  - www.ovarian-news.org
  - 806-355-2565
  - A monthly newsletter with reports on treatment options, coping skills, clinical trials, etc. It is upbeat and contains humor with input from survivors.

- **Department of Defense: Congressionally Directed Medical Research Program:**
  - http://cdmrp.army.mil
  - 301-619-7071
  - Call for questions relating to the CDMRP

- **Eyes on the Prize:**
  - www.EyesOnThePrize.org
  - This Web site offers support and information for women living with gynecologic cancer.

- **Gilda Radner Familial Ovarian Cancer Registry:**
  - www.ovariancancer.com
  - 800-OVARIAN
  - This is a registry to track families with a history of ovarian cancer. They have a help-line, education, information, and peer support for women with high risk (family history) of ovarian cancer.

- **Gynecologic Cancer Foundation:**
  - www.thegcf.org
  - 312-578-1439
  - The GCF is a nonprofit organization established by the Society of Gynecologic Oncologists to support ovarian cancer research, training of cancer specialists in laboratory research, and programs for patient education and public awareness of gynecologic cancers. The GCF sponsors the Women's Cancer Network (www.wcn.org) for information on gynecologic cancers.

- **Facing Our Risk of Cancer Empowered (FORCE):**
  - http://www.facingourrisk.org
  - 866-824-7475
  - To improve the lives of individuals and families affected by hereditary breast and ovarian cancer.

- **National Ovarian Cancer Coalition:**
  - www.ovarian.org
  - 888-OVARIAN
  - Its mission is to raise awareness about ovarian cancer to promote early detection and education about the disease. NOCC offers a toll-free helpline.

- **Ovarian Cancer Online Community:**
  - http://ovariancancer.clinicahealth.com/
  - The Ovarian Cancer National Alliance provides a way for the entire ovarian cancer community to stay connected through an online health and wellness community. The Ovarian Cancer Online Community provides registered members with moderated discussion groups, access to up-to-date information and space to post personal blogs, enabling them to support one another through their individual journeys and experiences.
  - The online community is also a critical tool for Partner Members to search for and reach out to potential members!
  - The Ovarian Cancer Online Community includes various features to encourage communication and network-building between members, including personal profiles (that can include photos), moderated discussion groups and a community help desk. The discussion groups will include newly diagnosed issues, clinical trials, treatment, side effects, caregivers, fundraising, events and other items.

- **Ovarian Cancer National Alliance:**
  - www.ovariancancer.org
  - 202-331-1332
  - The Ovarian Cancer National Alliance is the nation's voice for ovarian cancer issues. The Alliance, a 501(c)(3) nonprofit organization, leads the national movement to conquer ovarian cancer by uniting local, state and national organizations in a movement to increase public and professional understanding of ovarian cancer and to advocate for more effective diagnostics, treatments and a cure.

- **Ovarian Problem Discussion List:**
  - www.acor.org
  - ACOR offers an e-mail support group for ovarian cancer survivors to exchange information and give/receive support. The easiest way to subscribe is to go to www.acor.org and browse through cancer lists until you get to Ovarian. Then you can subscribe online. There are 1,200 ovarian cancer survivor subscribers.

- **SHARE: Self-help for Women with Breast or Ovarian Cancer:**
  - www.sharecancersupport.org
  - 212-719-1204

- SHARE provides information hotlines for breast and ovarian cancer in English and Spanish.

- **Society of Gynecologic Nurse Oncologists:**
  - www.sgno.org
  - 800-446-3180
  - The SGNO is dedicated to the advancement of patient care, education and research.

- **Society of Gynecologic Oncologists:**
  - www.sgo.org
  - 312-644-6610
  - The SGO's purpose is to improve the care of women with gynecologic cancers and to raise the standards of practice in the treatment and prevention of gynecologic malignancies.

- **The Ovarian Cancer Research Fund, Inc.:**
  - www.ocrf.org
  - 800-873-9569
  - This is an organization dedicated to the formulation of early diagnostic treatment programs and research. OCRF seeks to help patients understand the disease and its treatment.

Working with the Media

The greatest achievement of the human spirit is to live up to one's opportunities and make the most of one's resources.

– Vauvenargues

I. Introduction

- **Purpose of the Media Guide**
  - Increase awareness of ovarian cancer, your organization and the Alliance
  - Help save lives
  - Help Partner Member organizations approach the media with confidence

II. Getting Ready: the Nuts and Bolts

- **Creating a media contact list**
  - **Who to include:**
    - Newspapers
    - Local magazines
    - Radio
    - Television – broadcast and cable, public television
    - Internet – news outlets, key bloggers, etc.
  - **Creating core contacts:**
    - Local phone book for listings of television and radio stations, local daily and weekly newspapers and magazines
    - Check out the U.S. Newspaper list: www.usnpl.com
    - Bacon's Media Yellow Book or the News Media Yellow Book – might be able to borrow a copy from a major business or association, as these are costly
    - Be sure to ferret out health reporters, and those who write on family issues
      - Social reporters needed for special events
      - For walks, etc. consider adding sports media
    - Radio: names and information for news and/or assignment editors, hosts of local talk shows
    - Television: key on-air reporters and anchors, assignment editors, producers of news broadcasts, producers of community shows, etc.
    - Develop details on reporters as you learn them – deadlines, cell phone contacts, e-mail and fax, mailing address – and ask them how they prefer to be contacted – i.e., e-mail, phone, etc.
      - Avoid sending out a media release to a mass e-mail list rather than to individual reporters!
    - Include "calendar" listings for media outlets
    - Adhere to general rules about media deadlines unless you receive information differently:
      - Television: Call assignment or news editors after 10 a.m. and before 3 p.m., but not in the 11 a.m. to noon window if the station does a noon newscast
      - Radio: Varies, but generally the early morning – 8 a.m. or so – is reliable. Call again after 10 a.m. if you cannot reach anyone.
      - Print: Generally use the 10 a.m.-2 p.m. window

- **Targeting your audience(s)**
  - Who are you trying to reach with your news? The more targeted, generally the better
  - Just who in the media you contact depends on your target audience. Link the most appropriate media contacts for your particular story. Don't send everything to everyone!
- **Developing a fact sheet**
  - Document with key information about the organization, key spokespeople/leaders, brief (one paragraph) history, and key facts about ovarian cancer – especially local information – i.e., how many women in the community have the disease, how many die each year, etc. Add national data from credible sources including the Ovarian Cancer National Alliance, the National Cancer Institute, the American Cancer Society or the Centers for Disease Control and Prevention.
  - Brief biographies (a paragraph or so, no more) of key leaders can be included, usually on a separate sheet
  - An "FAQ" – "Frequently Asked Questions" Sheet – might be useful. This should focus on ovarian cancer, available resources and help, etc.
- **Choosing a Spokesperson**
  - Survivors are the strongest voices – the personal story is most compelling
  - Spokesperson does not have to be the president or chair of the Partner Member organization if there is a reason for using someone else
  - It is OK to have multiple people speaking for you if some are experts in a particular aspect of either ovarian cancer or the event you are planning
- **Preparing a media kit**
  - Contents include
    - News Release – 1 to 2 page document on letterhead with factual information and quotes about your news. Use this ONLY for time-sensitive events and activities
    - Media Advisory – A short (usually one-page) document that contains enough information to interest the media in what you are doing/planning. These are sent to the media BEFORE an event or major announcement.
    - Fact Sheet about your organization – see above
    - Bios – see above
    - FAQ – see above
    - Include an organizational brochure if you have one
    - Include a listing of your medical advisory committee, if you have one
  - Kit should be in a glossy folder, with an identifying label on the cover
- **Pitching your story**
  - A "pitch" is simply a news story idea or proposed article given to a reporter or editor.
  - This can be done by phone or e-mail or even in writing; generally a phone call works best
  - Plan your pitch before calling or e-mailing. It should answer these basic questions:
    - Who?
    - What?
    - Where
    - When?
    - Why?
    - How?
  - Do not quit on one try. If a given reporter is not interested in a particular story or event, come back to him or her later with something different.
  - Be suitable…meaning make sure you are not pitching a national news writer with a local health story. Simply knowing a reporter's name isn't good enough – it is essential to know the "beats" each reporter covers (print and broadcast) so you can make appropriate contacts.
  - Follow up on conversations, and "add value" with a good e-mail, for example, offering more information about the topic
  - Say thank you! After the event or a good story, it is entirely appropriate to thank reporters who helped. Frame this thank-you in terms of the good it has done for your community.

III. What's News?

- **Key components**:

- A key point is to understand <u>why</u> you are doing outreach – and closely define the outcome you want before setting forth to achieve it. If you don't know why you are doing what you are doing, it will be hard to make a compelling news story about it.
- <u>Timeliness</u>: its happening NOW, its new – but think about when you are releasing your news. It's not usually wise to release news on weekends, during holidays or on Fridays.
- <u>Importance</u>: numbers matter – how many people are affected or potentially affected? Impact on the community?
- <u>Local angle</u>: keep it local to attract local attention; national information is secondary
- <u>Human interest</u>: stories that appeal to emotion
- <u>Personality</u>: are locally well-known people involved? Big names? Not essential but it helps

- **Samples:**
  - Launching an outreach campaign
  - Holding an event – i.e., fundraiser, walk, race, special symposium, etc.
  - New information about something important – i.e., the findings about intraperitoneal chemotherapy for ovarian cancer would have a good local news hook if the research announcement was paired in your community with an interview with a patient and an area gyn-oncologist

<u>IV. Becoming Known and Advancing the Cause</u>

- **In general**
  - Deliver on your promises. If you say you'll have data by a given time or date, be sure to do so.
  - To make your case for a story, generally a phone call is more effective than an e-mail approach. Human-to-human conversation is always more compelling.
- **Interview tips**
  - Review your key messages before talking with a reporter or doing a news conference
  - If possible, working with a few colleagues, anticipate questions you think the media might ask, and think through answers to give
  - Do not be afraid to be assertive and make sure to get your key points across in interviews. Take the lead!
  - Dress simply and professionally. Solid colors work best on television – avoid busy patterns of dots, checks or plaids. Avoid tight or short skirts: bad things happen when one sits in these. Tailored slacks are fine.
  - Don't take a wad of papers on camera with you. A sheet or two that may have data is fine, but do not read from it.
  - Don't look at the camera. Talk with your interviewer.
  - If you don't know, say so. Never fudge. Simply say, "I don't know. Let me get back to you on that." And do so, later.
  - Avoid talking in jargon. Survivors and others working in ovarian cancer work pick up a lot of technical terms that may puzzle the public. Speak in simple language as much as you can.
  - If you are calling a reporter for initial contact, be sure to introduce yourself clearly at the beginning of the conversation; on subsequent calls, gently remind them who you are using more than just your name: "Hi, this is Sally Johnson, with the Ovarian Cancer Coalition of Minneapolis. We talked a few weeks ago…" Reporters talk with dozens of people each week, and anything to help jog memory will be appreciated.
- **Promoting Your Events**
  - Advance planning is an essential component to success. Ideally, follow this timeline for alerting the targeted media of your event:
    - Three weeks out: call or e-mail pitch to core reporters you want to reach
    - Two weeks out: do a reminder call or e-mail
    - One week out: send a full media advisory to local media
      - Call your core reporters once the Advisory is out
      - Talk with television assignment editors to get it on their "daybook" – listing of events they plan to cover
    - Day before: reminder calls, e-mails with media advisory attached
      - If any reporters have requested special interviews, lock down details now

        - Press the TV stations and see who will cover/urge coverage
    - The big day:
        - Ask media to sign in
        - Be readily available to answer questions, etc.
        - Monitor media coverage

V. Evaluating Your Efforts

- Keep a clipping file of newspaper and magazine stories, in the order in which they appear.
- Monitor radio and television coverage (ask members of the organization to help).
- A record of your coverage can help serve as compelling reasons for donors and potential donors and funders to contribute to your efforts.
- Share your good coverage with OCNA and the other Partner Members – we love good news and can all learn from each other.
- Keep track of all the media outlets you contacted and what, if anything, each of them did regarding coverage. This shows a pattern of responsiveness that will guide your future work.
- If no coverage is forthcoming, or very little, it's time to analyze what went wrong and, if necessary, get help in assessing and planning for next steps.