

SECTION TWO:
*G***UIDE FOR COMMUNITY
ORGANIZATIONS**

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THE GROWING NEED FOR BILINGUAL CANCER SUPPORT

*W*e are in an age when non-profit organizations are increasingly used as the safety net for the poor. Sweeping changes in the health care industry, welfare reform, and enormously strained resources for social services and public health agencies can make starting another new service program a daunting undertaking. Yet for those of us who continue to work in the non-profit sector, the need to shore up an eroding social contract with the poor and to make those who write our healthcare, economic development and social service policies more accountable to the communities they serve is a most important mission.

California is home to over 6 million immigrants, a number that does not reflect those who are undocumented. For a state that is increasingly economically dependent on immigrant labor, particularly in the service industry and agriculture, we have yet to answer the educational, employment and healthcare issues that plague immigrant communities. The widening income gap and lack of affordable healthcare continue to be two of California's most pressing problems. According to Children Now, California ranks 45th among states and the District of Columbia in poverty among children and youth¹. California also has the third highest uninsured rate

in the United States. A recent report from UCLA and UC Berkeley shows that there are 7.3 million people in California who are currently uninsured and an average of 50,000 more are added to these numbers each month².

Hispanics are singularly the largest uninsured population in the state. In 1995, 3.3 million Latinos were uninsured³. Equally alarming is the reality that the uninsured rates among Latinas increased from 39% in 1995 to 45% in 1998. At the same time, Medi-Cal coverage declined from 18% to 13%⁴.

The worst possible news for anyone without insurance is a diagnosis of a life threatening illness. Cancer can undermine even the most financially secure individuals and families. But for an immigrant who does not have insurance, does not speak the language, perhaps has limited education, is afraid of deportation, and may be living far away from extended family support systems, a diagnosis of cancer takes on a whole new dimension. Even for those who have family support, navigating our present day managed care medical delivery system without insurance or a "green card" is difficult.

A diagnosis of cancer is a frightening and lonely experience for anyone, regardless of culture, race or socioeconomic background. The role of psychosocial support groups* in the past decade has been proven to be particularly effective for many people, helping them cope better with the diagnosis and *providing a crucial support system for reclaiming a healthy and productive life*. A research study at Stanford University in 1989⁵ showed that people with cancer who attend support groups become more active participants in their own treatment. They understand their diagnosis better and find understanding and support that can only come from others living with the disease.

The proliferation of breast cancer support groups in the last decade has been the result of women advocating for themselves and taking control of a frightening situation when no one else was listening. But, for the most part, these groups serve white women. Women from other cultures that respond to illness differently, and who do not speak English, would not find an English speaking group useful or

supportive. The Spanish language support group model that we have helped to develop, provides empowerment, safety, warmth and companionship without judgment to women who do not speak English. The absence of support programs seems unthinkable, especially in regions where there is a significant Spanish speaking population. If your agency is in such a region, there is no better reason to start a cancer support group for Latinas.

*See pages 10 & 11 for an explanation of the differences between psychosocial support and psychotherapy.



STARTING A CANCER SUPPORT PROGRAM

The key to starting a cancer support program is having a combination of a strong mission, time, passion and resources. It also requires a solid connection to the Latino community where there is a clear need for this type of service. This chapter provides an overview of who, what and how to start this program.

Who Should Sponsor a Spanish Language Support Group?

This program can be started by an individual agency or by a consortium of organizations. In San Jose, a program that is now called Las Isabelas was originally started by a group of passionate women working with Latinas who had cancer. They initially used a fiscal agent as a sponsor for the group, then went on to form their own non-profit entity.

Having a strong connection to the Latino community or a demonstrated capacity to build such a connection (through previous outreach projects) is also an important element in sponsoring a successful Spanish language cancer support group.

Agencies that understand cancer from diagnosis through treatment, recovery and/or death are somewhat better suited to starting this kind of program than those with no relationship to cancer or health-related issues. However, it is not necessary that the agency be in the field of healthcare. Again, *any institution that works closely with the Latino population and has the ability to sustain a new program over time can start a cancer support group.*

But those with limited experience with cancer or health will need to fill in the experiential gaps with a **community-based cancer advisory committee** and **qualified group facilitators** who have an understanding of cancer either through work or personal experience.

We strongly advise that all sponsoring agencies develop an advisory committee regardless of having experience with cancer because it builds community support, helps define issues specific to Latino cancer patients in their community, increases resources, and establishes relationships with key members of the medical community. The advisory committee is discussed in greater detail on page 60.

Financial Base

An individual non-profit agency must be on firm financial footing to develop a new program. A consortium must also be able to bring to the project consistency in its participation and a balance of shared financial and human resources. A consortium requires a non-profit fiscal agent to be the conduit for charitable donations to the program. The fiscal agent might be one of the organizations within the consortium or a separate agency altogether. Most fiscal agents charge fees averaging from 5 to 15% of all funds raised. These fees go towards financially administering the support group.

Developing a secure financial base is important since the most important responsibility of the sponsoring agency is to raise sufficient funds to cover the program expenses on an annual basis. To build a strong foundation for the program, the organization will want to enlist the help and financial support of a diverse community base and create community partnerships. Laying this foundation from the very beginning creates community ownership of the program and increases the opportunities for sustainable financial support. Advanced planning, outreach and fundraising will ensure a successful start-up and will help develop an infrastructure that can sustain continued operation of the group. With adequate pre-planning and qualified group facilitator(s), the actual running of the support group will require minimal supervision by the sponsoring agency.

Costs of the Program

The primary expenses of the program include the group facilitators' fees or salaries, outreach and overhead. Depending on the prevailing wage for this kind of work in your region *and* if administrative overhead and basic program costs such as printing, postage and meeting space rent can largely be absorbed by the agency, the group can operate on an annual budget of anywhere from \$30,000 to \$40,000 a year. With overhead, the program can average \$50,000 or more annually. Most agencies will find that approximately 70% of the budget covers the fees or salaries of the facilitators and 30% covers operating and outreach expenses. The budget is discussed in greater detail on page 56. Sample budgets can be found in **Appendix B**.

Using A Co-Facilitator Model

The sponsoring agency must recruit, hire, supervise and evaluate the facilitators as well as support their outreach efforts. Finding one experienced facilitator, let alone two, is not always easy. However, we propose using a co-facilitator model for a number of reasons. As discussed later in this guide, co-facilitators can essentially split the facilitation, outreach and case management responsibilities, making the work easier to handle. They can cover for each other when one is on vacation or ill, preventing the need to cancel a group meeting. Equally important is the role the facilitators can play in supporting each other. Facilitating a cancer support group is hard work. It essentially forces one to confront one's own mortality. A facilitator must also cope with the death of a group member while helping the other members face their own feelings of loss and fear. Co-facilitators can help provide support to each other when they must take a leadership role during difficult periods.

How the Group Operates

Although the sponsoring agency, group facilitators and members ultimately should determine what works best for all parties, we have found that holding a biweekly support group (two times a month) for two hours each session is a good working model. Most groups operate best in the early evening to accommodate working women's schedules. We have found from experience that the hour of the meeting can make a difference in attendance, so women in the group should be asked what works best for them. Having a space (page 87) that is close to public transportation is also important, but the agency and group facilitators may also need to help arrange transportation.

Summary

Again the primary requirement of the sponsoring agency is a commitment to:

- Raise the necessary funds to operate the group.
- Provide the infrastructure needed to maintain the support groups including patient recruitment, outreach, telephone, and meeting space.
- Hire and supervise the group facilitators.
- Periodically evaluate the program.
- Help facilitate linkages between the agency and the medical community, social service agencies, cancer service programs, key religious institutions, and the Latino community.
- Integrate the support group program with the agency's other programs, whenever appropriate.
- Provide minimal administrative support.
- Protect the confidentiality of the support group members.

THE PITFALLS OF PROVIDING CANCER SUPPORT

Starting a cancer support group, like any program, requires a commitment of time and resources. Too many cancer support programs have failed over time for a number of reasons, including:

- Inconsistent and/or a permanent drop in attendance at support group meetings.
- Inadequate outreach, home and hospital visits to newly diagnosed women.
- Lack of relationships with medical and other professionals that serve cancer patients.
- Insufficient funding base.
- Inadequate training of the group facilitator(s).
- Facilitator burn-out.

To avoid these pitfalls, the support group facilitators must be adequately supported by the sponsoring agency, and they must have the time for case management and one-to-one outreach with patients. The group has to have a sufficient operating budget and sustainable, renewable sources of income. *This is not a job that can be done indefinitely on a volunteer basis.* Facilitators must be paid professional salaries or fees for their time, or they burn out having to juggle other work. They also need time off. They should be provided with clear job descriptions that delineate their case management, outreach and other responsibilities. Finally, inexperienced facilitators require training.

UNDERSTANDING YOUR AGENCY'S CONCERNS



If the requisites for starting a Spanish language support group outlined in the previous chapter will create an undue strain on the organization's staff and resources, your agency is probably not ready to start a group. The agency's staff and Board of Directors, as well as the community the program will serve (which includes both patients and the medical community) must buy into the program from the beginning. This 'buy-in' requires a belief that the resources can be raised.

However, there are ways to explore financial and staffing issues that may ease some of the anxieties about starting a new program. The organization first needs to take a hard look at its internal resources. Assuming there is a need for a Spanish language cancer support group in your community, some of the questions that must be addressed before moving forward include:

1. Does the program fit into your agency's mission?
2. Are your staff and board excited about the program?
3. Is staff available to develop the program in its pre-planning phase?
4. Will offering a cancer support group pull resources away from your agency's already existing programs? If the answer is yes, can the agency manage this until the program has built its own funding base?
5. Is there community support (or can community support be organized) for the program?
6. Does your agency have the capacity to raise the necessary funds?

An agency may see that the program fits into their mission but has inadequate internal support either from the board or key staff. Clearly the most significant issues are where the funds will come from and whether already over-burdened staff members can take on more responsibility. Such support can be developed over time if certain conditions or circumstances change. For instance, an agency may find internal support if they can partner with another agency to share staff and resources. A few examples of partnership scenarios are:

- A Latino social service agency that has strong contacts with local businesses for financial support teams with a clinic that serves the Latino community and can reach out to Latino cancer patients.
- A hospital partners with a local cancer support organization by offering the services of its bilingual staff oncology social worker as a group co-facilitator, covering her hours in the support group as part of her salary.
- A group of strongly committed leaders in the cancer community form an advisory committee to start a Spanish language cancer support group. They help underwrite close to 50% of the group's operating costs by convincing three local hospitals to provide renewable support for the group and organize an annual fundraiser.

Partnerships, whether within a community-based advisory committee or between agencies, can be very creative and can hold the key to securing sufficient program resources. But, they can also be difficult if issues such as turf, recognition, division of labor and competition for resources are not addressed when exploring a collaborative relationship. *Good collaborations are based on shared self-interest, mutual respect, and ability to compromise.*

Researching Community Response

Another way of securing staff and board 'buy-in' to the support group is to set aside a short period of time (one to two months) to collect information and to research available community resources and program feasibility. This can be done in numerous ways as a needs assessment or in focus groups.

But face-to-face, one-to-one meetings of no more than 30 to 45 minutes in duration, often produces greater depth of conversation and the possibility of a continuing relationship. What follows are some suggestions about conducting these kinds of meetings, including who to approach and what kinds of information to solicit.

DISCUSS THE ISSUES WITH PEOPLE SERVING LATINO CANCER PATIENTS.

Hearing what obstacles health care and social service professionals face when trying to serve Latinas who have cancer helps define the issues from their side. Ask these professionals the following questions:

- What are some of the issues and frustrations that you see arise for monolingual Latino cancer patients (e.g., lack of hospital translation services, inadequate case management, etc.).

- Would you be willing to sit on an advisory committee for a Spanish language cancer support group?
- Who can you suggest to approach for funding this service (and can I use your name for a referral)?
- Who else should I be talking with for information, perspective, and funding ideas?
- Who do you know that might be a good candidate for the advisory committee?
- Do you know any Latino cancer patients who would be willing to share their personal experiences of cancer with me?

MEET WITH LATINO CANCER PATIENTS.

Their stories help put a human face on the cultural and language barriers faced by Latino cancer patients, especially by those who are monolingual. Also, having cancer survivors on the advisory committee is important to the process of developing a cancer support program since they intimately understand the need for and bring a special sense of urgency to the program.

Eliciting stories about personal experience must be done with sensitivity and with full permission. Assuring confidentiality is critical, as is sharing some of your own experiences with cancer to help develop trust and model what kind of stories you are looking for. For example, telling a story about someone you have encountered who waited a long time to check out the lump in her breast because she didn't have insurance or a green card opens up the door for someone else who has experienced something similar.

TALK WITH LOCAL BUSINESS OWNERS WHO SERVE THE LATINO COMMUNITY.

These can be Hispanic business owners, bank branch managers, restaurant owners, etc. The idea here is to *assess how willing the community might be to support this kind of program*. Talking to a businessperson without asking for anything other than advice can develop the beginnings of a very productive and ongoing relationship. If you know that the person has had some family experience with cancer, you will likely garner immediate interest in the program. In addition to explaining the need for the program (substantiated by your discussions with medical and other professionals and cancer patients), you should solicit some feedback on the following:

- Do you think there would be sufficient support in our community for a program that will cost about \$40,000 (or whatever amount you have determined is necessary) a year?
- What businesses do you think might be willing to invest in this program? Would you be willing to help me set up a few meetings?
- Who else should I be talking with for information and perspective, funding ideas, prospective advisory committee members, etc.?
- Would you be willing to sit on an advisory committee?

DISCUSS THE PROJECT WITH ONE OR MORE OF YOUR KEY FOUNDATION PROGRAM OFFICERS.

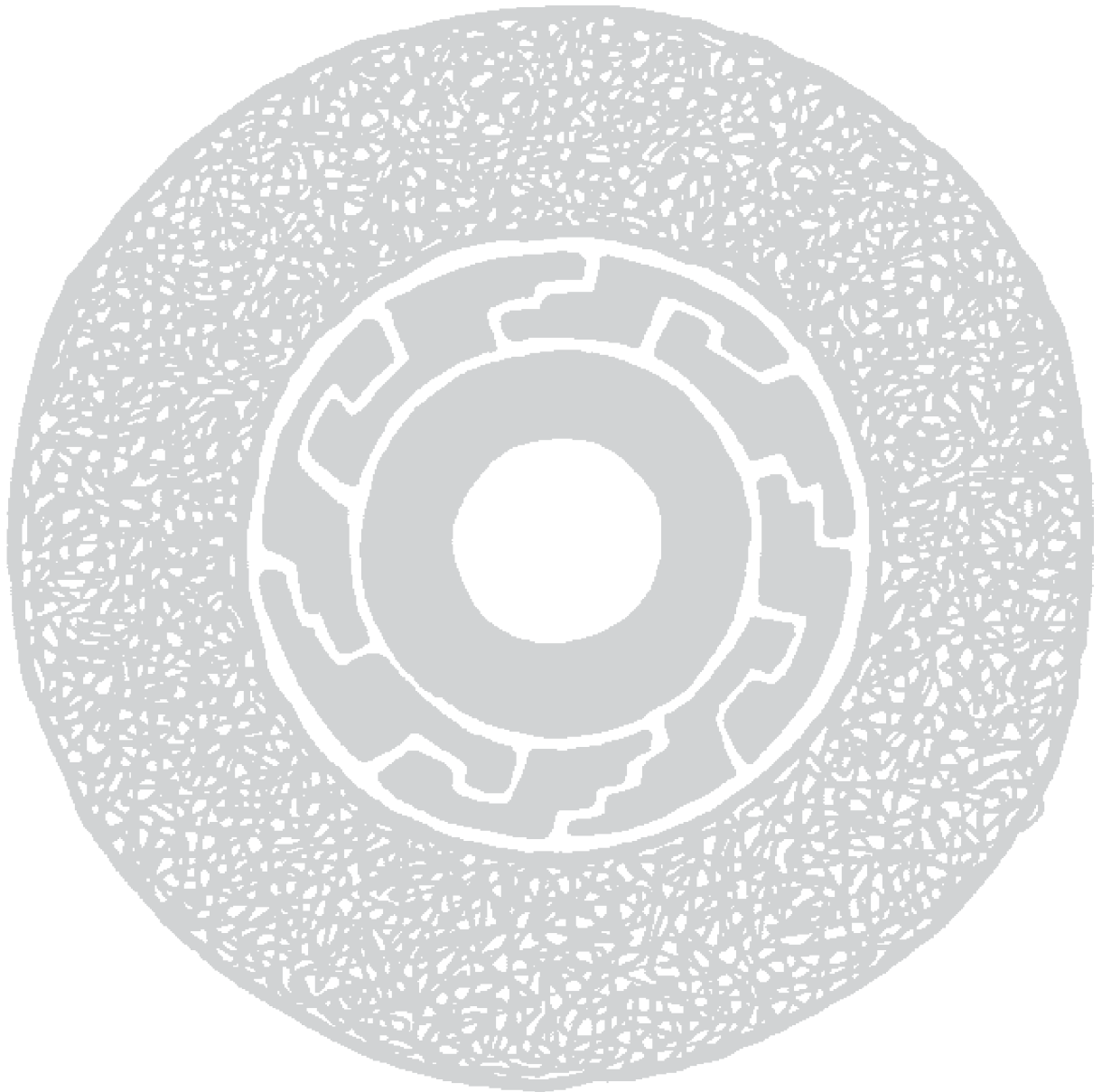
If you are concerned about competing for funding with your already existing programs, you can have a frank discussion with a program officer and share

your apprehension about taking support away from the agency's other programs. Take this step *after* you've conducted other meetings with members of the community. The information you gather from the earlier meetings not only documents the *need* for a support group, but can also assure a foundation that you are seeking a broad range of community support. You can also leave the program officer with a brief written summary of the findings from your conversations.

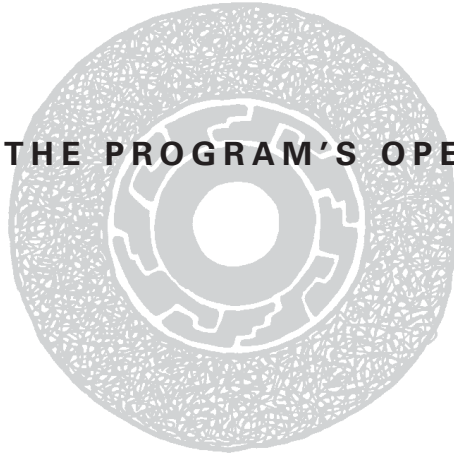
Philanthropic foundations reasonably want their grantees to have a plan for developing more sustainable sources of income in order to prevent long-term dependency on a single foundation. By being honest and straightforward about your concerns, you may even open doors to additional funding and/or pilot funding. If a program officer is available, ask this individual for suggestions of other people in the community (including the funding community) whom you could talk with.

Taking the time to meet with about ten people in the community as outlined above will help the agency determine the overall feasibility of the project, garner support and ideas, and develop an initial list of people who would be willing to serve on an advisory committee. This groundwork can allay any concerns board and staff members have about starting a program. On the other hand, if the agency does not find support and energy for the program during this feasibility phase, they should not proceed. However, these meetings can generate energy and excitement in the community and an initial group of passionate individuals may emerge as the leaders for this new program.

BUILDING THE FOUNDATION



ESTABLISHING THE PROGRAM'S OPERATIONAL BASE



Taking the time to develop a strong infrastructure for the support group program has many rewards. Too many support groups have been started with a nominal seed grant and volunteer staff and then failed because no one was responsible for securing ongoing funding. The best intentions alone cannot sustain a support group over time. But a program that is carefully developed with diverse community and financial support will have a stronger foundation and a far greater long-term success rate.

Part 2 of this Guide looks at building this foundation. This chapter is an overview of the core decisions that must be made during the pre-planning phase about *how the program will operate*—from how much the program costs to what kinds of operational procedures must be developed. The other chapters in Part 2 examine how to create a community-based advisory committee, develop a plan that will move the program from conception to implementation, and establish a diversified funding base.

The Budget

One of the first steps in building the program's infrastructure is developing the program budget and procuring approval from the agency's Board of Directors. In general, the budget should include the following:

- Professional fees or salaries for the facilitators.
- Related payroll expense if the staff is salaried.
- Rent for a meeting space if donated space is unavailable.
- Group refreshments.
- Phone.
- Printing and duplication.
- Postage.
- Office supplies.
- Insurance (liability, workers' compensation, etc.).
- Administrative overhead.

The agency must be realistic about how much of its own overhead can go into the program budget. Too many agencies make the mistake of seeing start-up programs as a way to secure a significant part of its own administrative costs and/or staff salary support. Often agencies over-inflate their overhead, making an on-going program of this nature too costly to maintain. On the other hand, agencies incur real expenses in developing a new program, so realistically these expenses must be covered.

On average, overhead for the support group should not equal more than 15% of the program's annual budget (as opposed to the agency's budget). Since a considerable amount of the agency's time will go into the initial creation of the program, it may be necessary to build more overhead into the program's first year or to establish a separate budget for a pre-planning period while the program is in development. (A sample pre-planning budget is included in **Appendix B**.) Some agencies, especially smaller ones, may need to first raise funds for this preplanning period to cover staff time. Once the program is up and running, the agency's overhead can be scaled back to 15% in subsequent years. Also, depending on the size of the agency and its internal capacity for fundraising, there may be a need to add a line item to the budget for a grantwriter or for other fundraising costs.

We strongly advise that sponsoring agencies determine how much of their staff time and resources they can *donate* to this program—at least during the first year—without putting an undue strain on the agency. Exactly how much time will depend on each individual agency and their internal staff and financial resources.

Since it is offered free of charge, a cancer support group is not a moneymaking operation. Start-up funds may be easier to secure than ongoing operational expenses in subsequent years of the program. This is an important consideration when developing a budget that can be financially supported over several years. It also speaks to the need to develop a diversified fundraising plan with renewable sources of income.

The facilitators should clearly understand any specific budget limitations. For example, if the agency can pay mileage expenses for outreach, home and hospital visits, any limits on how much can be spent on a monthly basis must be spelled out in the facilitators' contracts and/or job descriptions. Similarly, the number of hours the facilitators work should be determined at the onset. A sample one-year budget in **Appendix B**, uses the assumption that a *minimum of 20 hours* a week is needed for this program. This can be divided between two co-facilitators at 10 hours each.

Finally, the agency must create a realistic fee or salary structure for the facilitators and consider paying minimal expenses such as mileage, parking, books and publications. Facilitating cancer support groups is emotionally and psychologically difficult work. Burnout is common among group facilitators. Providing adequate pay, a policy for vacations, and systems for facilitators to process the work and the grief they feel when a group member dies, helps build commitment and stability to the program.

Determining on What Basis to Employ the Group Facilitators

When budgeting for the program, the agency must decide whether it will contract the services of the group facilitators, hire them as staff or use a combination of both. Obviously, professional fees can cost less than salaries, since the agency must pay for related payroll taxes and expenses on all exempt and non-exempt staff positions. Worker's compensation is another related expense that the agency must include in the budget.

The IRS and the State of California have strict rules about what constitutes contracted professional services and the overall standard of how a contractor's work is performed. If the agency chooses to engage the services of the group facilitators as independent contractors, they will need to develop a written agreement that clearly outlines the facilitator's hourly fee, scope of work, reporting procedures, etc. As contracted personnel, the agency cannot control *how* the facilitator does her work as long as it falls within the agreed upon scope of work and time-frame as written in the contract. Contracted personnel are responsible for their own taxes, but the agency must provide them with the IRS form 1099 at the end of the year, which details the total fees paid out during the year.

Determining whether the facilitators shall be contracted personnel or staff depends on the agency's scope of service and the extent to which the program is an integral part of this work. Licensed therapists often work as independent contractors, so a licensed clinical therapist may better fit into a contracted position than a lay facilitator.

Additional information on recruiting and hiring facilitators can be found on page 78.

Supervision, Reporting, Evaluation and Other Procedures

Building a strong infrastructure also includes developing clear policies that ensure group members' confidentiality, as well as documentation and evaluation procedures. Reporting on group progress and evaluation of participants' satisfaction of the group will be discussed on page 93. Creating these procedures prior to the start-up of the group sets the standard for how the group will run. Procedures can be refined and altered once the group has been meeting for a period of time.

Other internal procedures include how often facilitators meet with their agency supervisor or other staff to report on outreach and group process and to share the experience so the agency staff is adequately informed. This is important for many reasons. It helps integrate the support group with other agency programs. It helps the group facilitators process their own experience in the group. It also provides an avenue for problem solving. For example, if a group participant is having problems with transportation to and from the group, the agency may be able to assist with volunteer support or taxi vouchers.

Outreach

Outreach is a major component of starting and maintaining a cancer support group. It provides the venue for recruiting group members and builds visibility and credibility within the cancer, medical and Latino communities. Although outreach is especially important in starting up the group, it must be viewed as a continuous process. Support groups have their own natural ebbs and flows. Members who feel more complete in their recovery may drop out. Some members become too sick to attend a group or will leave when they are in end-stage cancer. Outreach helps recruit new members at a time when the group may need them the most. *Maintaining a stable number of group participants (an average of six to ten) is important to building and sustaining group cohesion.*

Outreach is also essential for building relationships within the medical community and social service agencies. Group referrals can come from doctors, nurses, social workers, patients, and agencies that serve cancer patients. Keeping the community at-large informed requires ongoing attention. Additionally, outreach helps build the kind of visibility that attracts donors. Outreach is discussed in greater detail on page 88.

CREATING AN ADVISORY COMMITTEE



Forming a community-based cancer advisory committee can help the agency get the program up and running and ensure that the support group will meet the needs of the community. A good advisory committee is one that is active, especially during the founding of the program, and represents a real commitment from the community for the support group. This kind of community involvement is also impressive to donors and can assist with securing pilot funding.

The advisory committee can help you develop your program by:

1. Identifying donor prospects.
2. Recruiting candidates for the positions of support group facilitator or lay co-facilitator, as well as other advisory committee members.
3. Conducting outreach to their individual constituencies and the community at large.
4. Providing entrée to key oncologists, radiologists, oncology social workers, nurses, etc., all of whom will be important sources of patient referrals to the support group.
5. Serving as 'ambassadors' who will credential the need for this program in your community and get the word out about the program.
6. Assisting the facilitators with locating a venue for the support group and securing other donations such as food, furniture, books, etc.
7. Ensuring that the program is culturally appropriate and sensitive, and accessible.

Recruiting Committee Members

The advisory committee should be comprised of a mix of individuals that not only represent the local Latino community and cancer population, but also your organization. This mix can include (but is not limited to) the following:

- Oncologists and/or radiologists, especially those who treat Latinos with cancer and who are concerned about the lack of resources for monolingual cancer patients.
- Bilingual health care professionals including nurses and nurse practitioners, etc. from local hospitals and neighborhoods clinics.
- Oncology social workers (bilingual if possible) and other social workers.
- Representatives from the county Department of Public Health and neighborhood health clinics.
- Social service providers from agencies like the Department of Social Services, Catholic Charities and other organizations that serve immigrant communities.
- Local religious leaders serving the Latino community.
- Other community leaders from the business community, especially from local banks, Hispanic owned businesses, educational institutions, etc. Those leaders with a personal connection to cancer are especially sensitive to the issues.
- Breast cancer survivors, especially bilingual survivors.

- In California, a representative from your county's Breast Cancer Early Detection Program (BCEDP) and in other states, representatives from any public or private early cancer detection programs.
- Bilingual and other representatives from the local philanthropic community or one of your major donors.
- A representative from your Board of Directors.
- A media or public relations person.

Size and Meeting Schedule

The advisory committee should be comprised of at least ten people in order to represent the broadest community base possible, although not everyone will attend every meeting. Ideally the committee should meet once a month for the first six to eight months—or until the group opens. After the group opens, the committee can meet every two months or so to help resolve any issues that arise from the running of the group. The advisory committee can also continue to be very useful making important connections in your community for the support group facilitators, as well as contacts with potential major donors, which include local banks, hospitals, Hispanic-owned businesses, foundations, corporations and individuals.

Preparing for the First Meeting

If you have conducted some interviews with members of the community, as suggested on page 53, you will likely have a growing list of individuals interested in becoming involved in this new program. The following steps will guide you through the process of formalizing the committee and conducting its first meeting.

1. Put together an initial list of prospective candidates for your Advisory Committee, including names, titles and addresses.
2. If you are unfamiliar with bilingual healthcare or social service providers or other community leaders, call people you know for suggestions of advisory committee members.
3. Set a date and time for the first meeting within the first six to eight weeks of starting the pre-planning phase of the program.
4. Develop the copy for a brief letter inviting people on your list to the first meeting of the Advisory Committee. Include a paragraph about the program and why it's important to the community and set a date for an R.S.V.P.
5. Mail the letter three to four weeks prior to the meeting date. Make follow-up calls to the people who did not meet the R.S.V.P. deadline and either call or send an email reminder a few days in advance of the meeting to remind people of the date, time and location of the meeting.

Meeting Agendas and Time

The sponsoring agency's executive director can chair the first few meetings until a chair of the Advisory Committee is selected. These meetings should not be longer than 1-1/2 hours. They should start and end on time in order to be respectful of committee members' time. The initial agenda introduces the community to the program, including why the sponsoring agency is starting a Spanish-language cancer support group. An agenda for the first meeting might look something like this:

- Welcome and Introductions.
- History of (or rationale for) the Program (*if possible, tell a story about a Latina cancer patient that will underscore the need for the program. If you developed a handout with the results of your research in the community, be sure to have it available.*).
- The Program Budget (include a handout).
- Initial Timeline for:
 - Raising funds.
 - Recruiting, hiring and training facilitators.
 - Outreach.
- Start date for the support group.
- Role of the Advisory Committee (include a handout of the role of the Advisory Committee). See **Appendix C**.
- Recruiting additional Committee members (Determine what kind of 'experts' or community representatives are missing from the mix and ask members to suggest names such as local business owners, representatives from area hospitals, media people, etc.).

- Recruiting facilitators (Job descriptions or announcements can be handed out. Discussion on this item can be limited for the first meeting and picked up again in more detail in the second meeting.).
- Next Steps (This should include the most immediate needs such as places to approach for funding).
- Next meeting date and time.

In general, the first meeting is a time to get people excited about the program, committed to helping the committee grow and be broadly representative of the local Latino community, and to begin to identify individual member's strengths. The meeting should not be overwhelming. In the first or second meetings, nominate a chair or co-chairs to help run the Advisory Committee. This develops a leadership base within the committee.

Subsequent meetings can focus on key action items from developing a press release announcing the formation of the support group to fundraising to recruiting facilitators and patients. A committee member may volunteer to get more representatives from area hospitals. Other members may volunteer to develop brochures: one in English (for the medical community and for funders) and another in Spanish (for cancer patients). Someone may be willing to approach a local bank branch manager or the owner of a local business for funding. Each meeting should culminate in asking for some kind of help on tasks needed to get the program up and running. Reporting on the tasks that committee members volunteer for should also be worked into the agenda, but these reports should be brief.

Early Media Exposure

Early media exposure that highlights the need for the program and the lack of services for Latino cancer patients can jump start the program's fundraising efforts. Someone on the advisory committee may have experience writing press releases, so they can develop some media advisories about the program. The cost of the program—what has to be raised and by when—must be prominently placed in all press releases. It is not unusual for a number of individual donors to approach the sponsoring agency with a gift if they read about it in their local newspaper or hear about the group on television or radio. The media is also interested when there is broad community support for new programs. Of course if there is a prominent member of the community on the advisory committee, this can bring more media attention to the program. The Spanish language print and electronic media should be factored into any media campaign announcing the program.

Media exposure used to recruit women into the support group is discussed on page 88. A sample press release is included in the **Appendix D**.



Once the budget has been developed, the agency can put together a simple strategic plan for the cancer support group program. This plan is a realistic and highly focused set of objectives that outline a one-year strategy to get the program up and running. It lists the action steps needed to meet the fundraising goals, find a venue, hire the facilitators, etc. It can stand as a discrete document on its own, or be part of the agency's long-term plan. The plan does not have to be a long or complicated document—*its goal is to develop a realistic process that will enable the agency to start the group on time and with adequate resources.*

A strategic plan also can serve as a tool for volunteers and Board members to commit to implementing the part of the plan that best suits their interests and level of expertise. The action steps assist staff in organizing, delegating and prioritizing work. The plan helps manage deadlines, provides the basis for evaluating progress and delineates who is accountable for specific tasks. A good plan will provide ways for using volunteers effectively on time-limited projects that have measurable accomplishments. Volunteers who can see the tangible results of their work achieved in a limited timeframe are more likely to volunteer for additional projects than are those whose work drags on indefinitely. For example, a volunteer may take on the responsibility of designing a flyer to notify professionals in the field about the upcoming availability of the support group. Others may write, mail or fax, and follow-up on press releases.

Just like an organization's strategic plan, the elements of the program's plan should include the following:

- **Vision:** Describes the program and its potential impact on cancer patients.
- **Mission Statement:** The sponsoring agency's mission statement may already sufficiently support the program's mission. In general, this is a philosophical statement of the organization's values and reason for being; it identifies the need and why this need must be addressed.
- **Goals:** Summarize the principal accomplishments the program hopes to achieve, such as opening a support group that will serve 12 or more women, increase understanding of cultural attitudes towards illness in the medical community, etc.
- **Objectives:** Delineate specific, measurable and results-oriented details on how these goals will be met: who, how and by when.
- **Action steps:** Provide the details on tasks, timelines and people responsible for specific tasks.

Initial Timeline

The agency should project a start-up date for opening the group and work backward from that date. **TABLE 1** on Page 66 illustrates how working backwards from the start date for the group helps provide a simple planning overview of primary tasks and key deadlines, such as drop dates for when funds have to be raised.

Action Steps

Once an agency has developed this overview, a more detailed timeline with an action plan can be developed for each segment of the strategic plan: developing the Advisory Committee, implementing outreach, marketing, fundraising, hiring, training, etc. **TABLE 2** on page 68 demonstrates initial fundraising action steps and determines who is responsible for specific tasks.

Relationship of the Group to the Agency's Other Programs

The strategic plan should also include how the program is linked to the agency's other programming. For agencies that already work in the field of health (healthcare, health education or promotion) within the Latino community, starting a support group may be a logical progression of services. In these cases the support group then must be developed with a clear relationship to the agency's other programs. Are there staff members from other programs that may be appropriate for one of the facilitator positions? How can outreach be shared?

For example, if the agency is involved in health education, the support group can be linked to health fairs and community presentations on breast and other cancers. Are there patients from other programs that may need a cancer support group? How to integrate the support group into the agency's other services should be addressed in the plan. By coordinating outreach and staffing whenever possible, the agency may save on expenses and prevent duplication of effort.

TABLE 1: SAMPLE PROGRAM TIMELINE

This sample program timeline is a *pre-planning tool* to devise realistic goals and deadlines, as well as the actual start-up date for the support group. It assumes there has already been a preplanning phase for the program. Fund-raising goals are highlighted to keep goals on track.

PROJECTED SUPPORT GROUP START-UP DATE: _____

Jan.	<ul style="list-style-type: none"> • Foundations/Corporations/Businesses are researched and targeted as potential funders. • Facilitator job descriptions are distributed. • Boilerplate grant proposal is written, adapted for different funders, and submitted (continuous). • Major donors (including banks) are researched.
Feb.	<ul style="list-style-type: none"> • A team of Board, staff and volunteers is put together for major donor campaign. • Major donor team is trained. • Prospects for a community cancer Advisory Committee are identified. • Date set for 1st Advisory Committee meeting; Letters to potential AC members are sent out. • Facilitator recruitment begins.
March	<ul style="list-style-type: none"> • Major donor campaign begins (individuals, hospitals, banks, Hispanic-owned businesses), grantwriting continues. • First press release is sent out announcing the development of the support group; articles are solicited. • Follow-up calls are made to advisory committee members prior to first meeting. • First Advisory Committee meeting is held. • 1st Quarter Fundraising goal: The first \$5,000-\$7,500 is raised.
April	<ul style="list-style-type: none"> • Facilitator interviews begin. • Training Contracts for Facilitators are developed. • Second Advisory Committee meeting is held. • Major Donor campaign and grantwriting continues.
May	<ul style="list-style-type: none"> • Facilitators selected and training contracts are signed. • Facilitator training begins. • Third Advisory Committee meeting is held. • Major Donor campaign & grantwriting continues. Possibility of planning a fundraising event for September is discussed and initial planning started.
June	<ul style="list-style-type: none"> • Facilitator training begins. • Fourth Advisory Committee meeting is held. • Major Donor campaign, grantwriting, event planning continues. • 2nd Quarter Fundraising goal: \$15,000 is raised (A total of \$22,500 raised to date).
July	<ul style="list-style-type: none"> • Facilitators formally hired; new contracts signed. • Outreach begins with one-to-one patient contact, hospital and clinic visits, etc. • First mailing of group flyer to community. • Fifth Advisory Committee meeting is held.

Aug.	<ul style="list-style-type: none"> • Venue secured. • Major Donor campaign, grantwriting, event planning continues. • Media advisories out. • Distribute Patient flyer.
Sept.	<ul style="list-style-type: none"> • 2nd distribution of patient flyer. • Outreach continues. • Special Event? • 3rd Quarter Fundraising goal: \$15,000 is raised. (A total of \$37,500 raised to date).
Oct.	<ul style="list-style-type: none"> • First Support Group meeting is held. • Advisory Committee meets. • Fundraising continues. • Outreach continues
Nov.	<ul style="list-style-type: none"> • Group meets biweekly. • Fundraising continues. • Outreach continues. • Advisory Committee meets: begins new schedule of meeting bimonthly.
Dec.	<p>\$10,000 is raised. \$45,000 IS RAISED FOR YEAR ONE (JULY-JUNE).</p>

TABLE 2: SAMPLE FUNDRAISING ACTION PLAN (FIRST 3 MONTHS)

DATE	TASK	WHO	ACTION STEPS
Jan. 4-10	To research Foundations/Corporations/Businesses and target those with the most likely "fit."	Executive Director (or Development Director, Program Director, or volunteers)	<ul style="list-style-type: none"> • Review foundations currently funding agency. • Research foundations online and at the foundation center. • Ask Board, volunteers, etc. about connections to local businesses, foundations and corporations. • Create calendar of grant deadlines.
Jan. 10-30	<p>To write a boilerplate grant proposal and to adapt it for different funders.</p> <p>To begin to submit proposals.</p>	Executive Director (or Development Director or Program Director)	<ul style="list-style-type: none"> • Research data on county cancer statistics to document need. • Develop problem statement and program budget. • Collect anecdotal stories about Latinas with cancer.
Feb. 1-28	<p>To research major donors, including individuals, bank, Hispanic-owned businesses, area hospitals that will refer patients to the program, etc.</p> <p>To begin contact with foundation & other funders.</p>	Executive Director (or Development Director or Program Director) and Board or Advisory Committee Members (after Advisory Committee has begun to meet)	<ul style="list-style-type: none"> • Set up initial prospecting process for everyone involved with the program and agency to list potential donors, including local banks. • Research (Internet, Who's Who, etc.) prospects' backgrounds to determine connection, funding capacity and interest. • Make calls to program officers at X, Y & Z Foundations to set up appointments. • Have Board President contact colleague at ABC Corporation.

DATE	TASK	WHO	ACTION STEPS
March 1-7	To convene a team of Board, staff and volunteers to spearhead a simple major donor campaign.	Executive Director (or Development Director) Board President and/or Advisory Committee Members, etc.	<ul style="list-style-type: none"> • Determine who is most excited about the program and can speak authoritatively about the work (can include volunteers, staff, board members, etc.). • Set minimum commitment level of time and amount of funds to raise (e.g. each team member commits to raising \$2K.). • Set and hold first meeting to discuss the program & set campaign goals. • Develop a 1-page case statement for team members to use.
March 11 10am-3pm	To train Major donor campaign team members.	Consultant, Executive Director or Development Director	<ul style="list-style-type: none"> • Conduct role-plays in making the “ask” and presenting the case statement. • Set procedures for communication with development office about progress and record keeping.
March 15-28	To continue the prospecting process and begin to approach donors.	Team Board and/or Advisory Committee	<ul style="list-style-type: none"> • Prioritize initial donor list based on donor’s connection to agency or issue, capacity to give and interest.



The Agency's most immediate task is securing approximately \$50,000 in seed funding for the first year of the support group's operations with an eye towards building a base of support for subsequent years. Pilot funding can help leverage new support once the program has completed its pilot year if the agency works to develop and sustain relationships with its donors. Since most foundations give time-limited grants (one to three years), the *support group cannot become dependent on any one source of funding*. As is often the case, the uncontrollable can happen when it is least expected and dependency on one source of income can be disastrous. A foundation can change its guidelines and program priorities. A donor can become interested in another charity. A corporation can move its headquarters and stop funding in your region.

Therefore, a **diverse fundraising plan** is the best strategy. A healthy mix of grants from foundations and corporations, small business donations and major donor and small dollar contributions provides the most stable funding base. It also offers many different opportunities for anyone interested in participating in fundraising for the program.

A diverse fundraising plan requires the agency to creatively look at the work in order to 'market' it in a variety of different ways, thus appealing to many different interests. For example, a hospital or HMO may wish to donate to a Spanish language support group because of their own lack of resources for monolingual Spanish speaking cancer patients. In this case, the support group fills a critical gap by

providing an important service for their monolingual patients. On the other hand, a church that recognizes how a support group enriches the quality of life of its members may have the ability to offer free space (or at a greatly reduced rate) for the group as part of their mission to serve their congregation and the poor. An individual may wish to donate in memory of a loved one who died of cancer. In each of these cases, the interest of the donor is very different.

Every project, large or small, needs many more prospects than one might initially think necessary. Many professional fundraisers work with a "60% rule". This means that to project actual income, an agency should not count on raising more than 60% of its total requests in any category of giving: foundations, corporations, small businesses, major donors, small donors, etc. Thus, if your goal is to raise \$30,000 in foundation grants, you would need to submit a number of requests that total at least \$50,000.

For major and individual donor campaigns, this percentage can be even lower. Most donor campaigns are built on the **4:1 premise**: for every one donation at any particular giving level, there must be four prospects.

Outlined below are the most basic steps required for creating and implementing the program's fundraising plan.

Identifying Foundation, Corporate and Local Business Prospects

Foundations

Initially, the agency should review its lists of current or past individual, foundation and corporate funders. New foundation guidelines may open up additional opportunities without detracting from the agency's other fundraising campaigns or programs. Many foundations will fund more than one agency program at a time, if the programs serve different needs or communities. Additionally, there may be foundations or corporations that have funded the agency in past years, but not recently. A new program requiring seed funding can often provide another entree into a foundation with which the agency has had a past relationship. (Individual donors may also be interested in providing an additional gift to help start a new program.)

If the sponsoring agency is not in the health or cancer field, or has limited experience writing grant proposals, research must be conducted to determine what foundations fund cancer or health-related programs in your region. Research should focus first on local foundations, then on regional and community foundations (like the Peninsula Community Foundation or San Francisco Foundation that fund in a number of local counties), and finally, state foundations. Additionally, many community foundations offer technical assistance grants which can be useful when an agency needs help with fundraising, teaching Board members to be more effective at approaching major donors, or covering the cost of training facilitators.

Foundations that fund statewide are often looking for programs that have the potential for statewide impact and/or address a problem with a seriously

underserved community. Large statewide foundations tend to fund well-established organizations. Therefore, smaller grassroots organizations may consider partnering with a larger organization in their region to give the program credibility and financial stability.

Research

Most states have a guide to foundations. In California, the Northern California Grantmakers Association publishes *The Guide to California Foundations* about every two years or so. This Guide lists foundations in the state, what and where they fund, sample grant awards, grant range, grantmaking process, contact person, deadlines, etc., and is an essential resource for those who are unfamiliar with the foundation world.

Another important resource for research on foundations and corporations is the Foundation Center. There are branches in various metropolitan areas, including San Francisco. The Center can also be accessed via the Internet at <http://fdncenter.org>. The Internet is a valuable resource for all kinds of donor research, including foundations, corporations and individual donor prospects. Numerous foundations have their own web sites. The Foundation Center in New York also provides a wealth of information, including links to foundation web sites. Some local libraries also carry basic information on foundations, corporate giving programs and grantwriting. *Each targeted foundation must be contacted for current guidelines, grant deadlines, and, if available, an annual report.* Again, many foundations have this information on their website.

Corporations

The agency's relationships with businesses in their own community (see the next section for more on this) such as vendors, hospitals, HMO's, financial institutions, as well as large corporations with local headquarters, can provide a wealth of prospective donors. Major newspapers often publish a list of a region's top 100 companies, which can serve as a starting place when researching corporations. Larger corporations may have their own company foundation with published guidelines. Other corporations donate to community programs through either a special corporate giving program, employee matching program, or public relations department.

The geographic location is often an important criterion for funders. Many businesses regularly support local charitable work. While corporate foundations may require a grant proposal similar to those required by charitable foundations, smaller businesses usually prefer a one to two page letter making the process easier.

Locally-Owned Businesses

Local businesses such as banks, Hispanic-owned businesses and other companies that were either started in your community or have a local plant, store or facility should be among the program's earliest prospects. Local companies tend to be most rooted in the community and the most dedicated to its social and economic health. Local companies are often more approachable than larger corporations. It is likely that members of the advisory committee or the agency's Board of Directors know bank branch managers by name. If the person you are approaching has had a personal experience with cancer, there can be an automatic connection to and interest in this cancer support program. A number of local businesses give reduced rates or in-kind services such as printing for community-based programs.

Area Hospitals

Finally, the sponsoring agency should also approach local hospitals utilizing any direct contacts it has within the system. These may be contacts that the advisory committee members, personal friends, staff, or Board members have with the local medical community. Because this program would directly benefit any Latino patients of area hospitals, there is a natural link that should be explored. Larger HMO's have charitable giving programs as well.

Developing a Grant Proposal

A foundation's guidelines usually outline what elements must be addressed in the proposal narrative, program budget, and attachments. Some foundations restrict the number of pages that can be submitted. Some utilize a common grant application form shared by many foundations, which has an application cover page, clearly lays out what the proposal must address in the narrative and how long the narrative can be (usually 5 pages), and provides a format for the budget. Other foundations require a letter of intent (2 pages in length), which briefly describes the program, including measurable outcomes, the organization's background (history, mission and accomplishments), the amount of the request and how it will be used. *This general format for a letter of intent can also be used to request a donation from a local business.*

If the foundation is interested in the program and it fits within its guidelines, it will then request a formal proposal. In general, most proposals include the following:

- The applicant organization's history, mission statement, and accomplishments.
- A statement of need: why the program is important.
- A description of the program, including who it will serve.
- An analysis of the benefits, outcomes and risks of the program.
- How the program will be evaluated and by whom.
- A specific grant request and a description of how the funds will be used if awarded.

- How the organization supports itself (its sources of revenue) and where other funds for the proposed program will come from (e.g., grants pending, awarded, etc.).

Grant proposal attachments generally include:

- A cover letter.
- A program budget.
- The organization's annual budget, including expenses and income.
- The most recent year's financial statement (audited for large organizations).
- A list of the organization's Board of Directors and their affiliations.
- The IRS 501(c)(3) letter.
- Press (news coverage, press releases), program flyers, letters of support, etc. (no more than 2-3, if available).

Identifying Prospects for Major and Individual Donor Campaigns

Major or individual donor campaigns (\$100 to \$5,000 gifts) take time to build momentum. For this reason, the Agency should develop a plan with the help of its Advisory Committee *and* Board to begin even the smallest campaign during the program's pilot year. Over time, with adequate stewardship, individual donors can become the most stable source of unrestricted funds. Establishing an annual campaign at the very beginning of this program will also build community ownership of the program.

Again, the agency and its Advisory Committee should first start with identifying people and small businesses with which they already have a relationship. There may be members of the agency's Board, key donors, local banks, family-owned businesses, Latino-owned businesses, personal and professional friends and colleagues, etc. The program's Advisory Committee should be involved in this prospecting process beginning with its first meeting. *The basic rule is to leave no stone unturned.* Garnering community support takes time, but the collaborative efforts of the agency's Executive Director, Board of Directors, and the program's Advisory Committee increases the success rate of any donor campaign.

As mentioned earlier, the base for any donor campaign should be in the setting of realistic goals using the 4:1 premise. For example, if a small agency with limited experience in soliciting individual gifts, wishes to raise \$7,500, they will need to identify enough prospects with the capacity to give a total of \$30,000 in gifts. This is necessary to secure \$7,500, since not everyone who is approached will donate. Another key principal involves the determination of the quality and quantity of gifts. In most large campaigns, 10% of the gifts produce 60% of the campaign's goal. For smaller campaigns, the breakdown is usually closer to 70% of the gifts coming from the larger gift range, with about 30% coming from smaller gifts. Table 3 illustrates the 4:1 premise, as well as how in a smaller campaign, close to 70% of the gifts come from the two highest gift ranges: \$1,000 and \$500.

TABLE 3: GIFT-RANGE CHART FOR AN INDIVIDUAL DONOR CAMPAIGN

GIFT RANGE	NUMBER OF GIFTS	NUMBER OF PROSPECTS	TOTALS BY GIFT CATEGORY
\$1,000	3	12	\$3,000
\$500	4	16	\$2,000
\$250	6	24	\$1,500
\$100	5	20	\$500
\$50	10	40	\$500
	28	112	\$7,500

This chart also points to the fact that the higher the gift range, the fewer number of prospects needed. This is an important consideration to make when developing an individual donor campaign because it actually takes less effort to go after the larger gifts. Other key factors that will help shape a campaign include the following:

- The number of volunteers the agency has to work on raising individual donor gifts.
- Advisory Committee and Board members' and other volunteers' fundraising experience.
- Training in the cultivation of donors and making 'the ask'.
- The agency's past successes or difficulties raising individual donor gifts.
- The ability to prospect from the agency's donor list, mailing lists, personal and professional lists.

Special Events

Some agencies and/or advisory committees may want to do a kick-off and/or annual special event to raise funds and get media exposure. Special events can take an incredible amount of staff and volunteer time and energy, but they can also be almost entirely driven by a committed group of volunteers. In one instance, a Spanish language support group in San Jose, California decided to apply for its own non-profit status rather than be part of a sponsoring agency. They needed seed funding for the group. A local Latina news reporter who had agreed to serve as President of the Board worked with other members of the newly formed Board of Directors to host a highly successful gala celebration and silent auction, netting over \$20,000. The media as well as local and state Hispanic politicians came out in support of the event. This same group raised \$10,000 by working with a local Hispanic-owned cheese company that donated a percentage of sales during a special promotion held in select markets in San Jose.

Similarly, a restaurant in Union City, California hosted a breakfast to increase community awareness about the Spanish language support group that was scheduled to open in the community. The sponsoring agency was also able to raise close to \$20,000 in major gifts when the local newspaper wrote an article about the project and noted the agency was trying to raise \$25,000 to start the group. The press coverage also peaked the interest of another major donor who offered to organize a family golf tournament to benefit this group. In San Francisco, the Advisory Committee for the local Spanish language support group organized an art sale as a fundraiser for their program.

Special events create a great deal of good will and awareness for new programs. They also can create the beginnings of an individual donor base. But to raise a significant amount of money, the agency must:

- Solicit corporate sponsorships and underwriting for the event.
- Ensure adequate marketing and media exposure.
- Have solid volunteer support with committee chairs willing to take charge of every aspect of the event including managing ticket sales, securing a venue and caterer, soliciting donations, entertainment, invitations, set-up and clean-up, program, acknowledgements, and follow-up.
- Set realistic goals and develop a realistic budget.
- Get as much donated as possible (wine, auction items, paper goods, decorations, flowers, etc.).
- Have as many people sell tickets as possible, including Board and Advisory Committee members, staff and volunteers.
- Do adequate follow-up after the event: writing thank you letters to sponsors and donors; developing a database of everyone who attended; and setting up meetings with event attendees who express interest in more involvement.

Special events are hard work. Without sufficient volunteer support, they can burn out everyone involved. But when done well, they have the potential of producing a sizeable part of the program's income and provide invaluable public relations. For agencies that have never attempted an annual individual donor campaign, this is a great way to build a database of people who can be approached every year for donations and to volunteer for future events.

STARTING THE PROGRAM



HIRING AND SUPERVISING THE GROUP FACILITATORS



This program has been designed using a **co-facilitator model** for the support groups. Co-facilitators help ensure that the group meeting will not be canceled if one of the facilitators is ill or on vacation. They also allow for the work to be divided according to skill, experience, and available time.

If the agency does not already have appropriate people in mind for the positions of facilitators, hiring staff for the program will be one of the most crucial decisions that the sponsoring agency will make. The hiring of the clinical facilitator should be done as early as possible.

Recruitment

Finding bilingual, bicultural facilitators, especially licensed clinicians, can be difficult if the agency does not have people in mind. Like outreach in general, recruitment is most successful if the sponsoring agency enlists as many resources as possible during the search process. This should include:

- Using the Advisory Committee, staff, Board members, etc. for referrals and outreach.
- Advertising, especially in trade and non-profit job bulletins like *OpportunityNOCS* (see www.opportunitynoc.org for more information on this publication).
- Extensive mailings of the job announcement to hospitals (oncology, radiology, social service and health education departments), neighborhood clinics, cancer organizations, breast cancer early detection programs, local colleges and universities

with programs in psychology and social work, mental health agencies, Latino social service organizations, etc.

- Internet advertisements such as Craigs List www.craigslist.com.

Required Experience

One of the group leaders must be either a licensed clinician with experience facilitating groups or have demonstrable clinical experience in order to conduct a thorough assessment of each potential group member. Extreme depression, suicidal ideations, and other psychological and traumatic issues unrelated to the cancer diagnosis (such as rape or molestation) are signs that the individual might be better served by psychotherapy.

The second facilitator can be a lay person who might not have direct clinical experience, but can be trained to co-facilitate the support group. Ideally, this facilitator should be a local person with experience conducting outreach in the Latino community.

We encourage the sponsoring agency to identify at least one facilitator who has had first hand experience with cancer. This can be someone who has had cancer herself or has had a loved one with cancer. When recruiting for these positions, the agency should look for a clinician with a license such as an MFC (marriage and family counselor), PhD in psychology or some related field, PsyD. (Doctorate in clinical psychology), LCSW (licensed clinical social worker), or MSW (master of social work). However,

it is not always possible to find experienced, licensed facilitators. Candidates with clinical experience but no license, as well as experienced facilitators from Spanish speaking countries who were licensed in their country of origin but not in the United States, should also be considered for these positions.

Obviously, language skills will be essential for this job and the facilitators should be bilingual and bicultural. If possible, part of the interview process should be conducted in Spanish. The facilitator must have excellent listening skills, understand key cancer issues and be willing to learn more about the disease.

Scope of Work

The facilitators are responsible for the following:

- Outreach to the community (page 88 covers how to conduct targeted outreach).
- Recruiting group members and running the support groups.
- Simple case management for each group member which might entail making referrals to social service agencies, home and hospital visits when a member is too ill to attend the group, and follow-up calls between meetings.

Since we propose that the group meet twice a month, basic case management is a necessary part of the scope of work. Phone calls between meetings serve to remind women about the next meeting and allow the facilitators to follow-up on members who have missed a meeting or are in crisis. Some patients may need referrals to other agencies such as the American Cancer Society or social services. The facilitators must be knowledgeable about community resources for low-income families.

As mentioned earlier in this Guide, the minimum hours (depending on how the job descriptions are broken down) is *a total of 20 hours per week*, averaging 10 hours per facilitator. The group cannot operate effectively on less time without losing continuity and group members.

A full scope of work is provided in the job descriptions found in **Appendix E**.

Division of Responsibilities

The two positions can be broken down in many different ways, depending on the availability of clinical and/or lay facilitators in your community. In general, the program will require a minimum of 20 hours per week, divided between the two facilitators. Although not preferable, in some cases it may not be feasible to use co-facilitators. If it is necessary to have one person performing all aspects of outreach, case management and group facilitation, the agency must provide sufficient support to the facilitator.

On the whole, *both* facilitators will be responsible for the development and facilitation of the Spanish-language cancer support group. Both will perform some level of community outreach functions related to providing psychosocial support for this population, including home and hospital visits as necessary. Working as co-equal partners helps avoid hierarchical issues and provides a supportive environment, but some agencies may require a licensed person for supervision. *Regardless, the division of labor between the facilitators must be clear from the onset.* For example, the Clinical Facilitator and Lay Co-Facilitator may initially share in outreach functions prior to starting the group. The Clinical Facilitator might serve as the principle contact with prospective participants for the group, but depending on the two facilitators' experience and available time, this responsibility might be shared after the group becomes fully operational. At that time, each facilitator can follow-up with half the current group members, as well as make home and hospital visits if a member is in treatment or too ill to attend the group meetings.

Once the group meetings have begun, the Clinical Facilitator's time outside group meetings might be devoted to one-to-one contact with prospective new participants. The lay Co-Facilitator might be responsible for other outreach responsibilities, such as making periodic educational presentations about breast cancer to community centers, senior centers, church groups, as well as attending health fairs. There are innumerable ways to divide responsibilities and the division of labor may require periodic adjustment.

Some other ways to break down the two positions include the following:

1. **Clinical Facilitator**–10 hours/week
Lay Facilitator–10 hours/week

In this scenario, the two facilitators share equally in the number of hours, and work responsibilities are divided evenly. Each conducts some kind of outreach and is responsible for regular follow-up with approximately half of the group members. Recruiting new members, making home and hospital visits, providing community presentations, and other responsibilities are shared.

2. **Clinical Facilitator/Program Coordinator**–16 hours/week
Lay Facilitator–4 hours/week, mostly for the group meetings.

In this scenario, the clinical facilitator serves as program coordinator and conducts most of the one-to-one outreach with cancer patients who may be prospective group members. She serves as the primary contact for support group members. The lay facilitator is trained to co-facilitate the support group and can take over when the clinical facilitator is unable to make a meeting. The lay facilitator in this case, may also be responsible for contact with certain group members.

3. Clinical Facilitator –5 hours per week

Lay Facilitator –15 hours per week

Some licensed therapists might be interested in facilitating a Spanish-language support group but are unable to devote 10 hours a week to the program. This situation will require a different method of breaking down job responsibilities, and program supervision may have to be conducted by an agency staff member.

Careful planning and communication between the facilitators is critical to this scenario and each will need to build ongoing contact with support group members into their weekly work plan. The clinical facilitator may devote an hour a week to working with the lay facilitator and the other hours to case management, intake and assessment of new patients, and the group meetings. The lay facilitator would then be responsible for all the outreach, most home and hospital visits and some case management.

Other Facilitator Responsibilities

This Guide assumes that the agency will be responsible for fundraising, grant writing and reporting. However, the facilitators can be helpful in assessing the real needs of the group. They can share critical issues facing their clients and, without compromising confidentiality, basic stories that can focus and/or enhance grant proposals. They might also have a role in developing some aspects of the program budget.

Progress regarding the group facilitators' work is also essential information for grant reports. The agency should establish a procedure whereby the facilitators submit periodic written reports that can be used when reporting to funders. These responsibilities must be included in the scope of work at the time of contracting/hiring the facilitator(s) and/or in the written job descriptions.

Reports should document all patient contact, even if a patient does not eventually join the support group. Some women will want only information or referrals. *Therefore, a program of this nature is not defined solely by the number of women in the support group at any given time. The actual numbers of women served will be considerably higher and it is important to be able to accurately track these numbers.*

Supervision

*To maintain the co-facilitator relationship, we do **not** recommend that one of the facilitators be designated as the supervisor.* Once the facilitators have been hired, the agency must designate another staff person as program supervisor. Supervision can be minimal. During the pre-planning period (prior to opening the group), supervision may involve brief weekly meetings to report on outreach progress. Once the group is in progress, monthly check-ins, as well as a review of the facilitators' monthly report will likely suffice.

Basic Requisites for the Facilitator Positions

- One of the facilitators is preferably a licensed psychotherapist or social worker. If the candidate is not licensed, she must have sufficient clinical experience to conduct patient assessments, recognize suicidal ideations and other emergency situations, and determine whether the person is appropriate for the support group.
- One of the facilitators is a "lay person" from the local community with experience conducting outreach to the Latino population.
- One of the facilitators preferably is a cancer survivor or has had a loved one with cancer.
- Both facilitators are bicultural and bilingual.



While the previous chapter discusses recruiting and hiring facilitators, this chapter looks at how to keep them. Too many businesses fail to adequately invest in their primary asset: *their employees*. Non-profit organizations, for budgetary reasons, too often do not make the connection between staff development and program development. But there are many misconceptions about the expense of staff development and training.

Program sustainability is actually helped by a staff that is informed, has options for continuing education and training, is evaluated regularly, and given time to reflect on their work. *For those working in the field of cancer, time for reflection and processing loss is essential for the prevention of burnout.* This chapter reviews some simple—and inexpensive—ways to build staff development into the breast cancer support group program.

Reading

Facilitators should be encouraged to keep informed about new articles, books and other reading materials on issues related to cancer. They should research issues that will help them better support women in their group. Because there is a serious lack of materials about cancer published in Spanish, group members may raise questions on a wide variety of subjects ranging from the specificity of their diagnosis to up-to-date cancer treatments; from complementary therapies such as acupuncture and massage to nutrition and meditation. The more informed the group facilitators are, the better prepared they will be to answer their group members' basic questions.

Although it can be considered an optional expense, the sponsoring agency may want to add a line item of approximately \$250 a year for books, publications and subscriptions. Funding for some or all of this line item may be raised as an in-kind donation or there may be an individual donor who would like to support this kind of continuing education. A local bookstore may also offer a discount if asked.

Additionally, the facilitators can establish an advisory relationship with a qualified medical professional who is associated with the program (or on the advisory committee, etc.) to answer basic questions that may arise from a group meeting. Research can be done on the Internet, at local libraries, as well as at specialized medical libraries such as the Planetree Libraries in San Francisco and San Jose.

Workshops and Conferences

It is important that the facilitators know of any pertinent workshops or conferences relating to cancer and/or psychosocial support. The agency should allot some funding for conference fees. Many local agencies that conduct conferences offer scholarships, therefore reducing fees. *Again, facilitators should be encouraged to attend workshops that will increase their knowledge, understanding and practice in the field.* Appropriate workshops and conferences may include:

- Nutrition for cancer patients.
- New treatments for cancer.
- Breast cancer and sexuality.
- Alternative and complementary therapies.
- Guided imagery and other meditation classes.
- Mindfulness-based approach to stress and pain reduction.
- Yoga.
- Processing the work.

Group facilitators need time to process the outcomes of the issues that arise in their support group. Just as group members must find ways to deal with grief and loss, especially when one of the group members dies, so must the group leaders. Holding a monthly meeting with agency and program staff provides group leaders with an opportunity to talk about their feelings and work; it also keeps the agency's other staff tuned into the support group process. Group leaders and/or the agency may also wish to host a meeting several times a year with other breast cancer support group leaders in the region, especially

those conducting groups in Spanish. This is a useful process to share information and concerns, as well as to assist each other with issues related to death and dying.

Spiritual Retreats

A cancer diagnosis raises many spiritual and existential questions for patients. These same questions are raised for support group leaders. The best support group leaders have reflected on their own death in order to be comfortable working with the terminally ill. But this kind of work on a daily basis can be emotionally and psychologically draining. Burnout is a frequent result and can be avoided with some focused attention. *Spiritual and/or meditation retreats are one option that has been proven to be very useful for group facilitators to release grief, affirm life and avoid burnout.*

Retreats can run for a weekend, a week or even longer. While this is an optional program cost, the agency can either include all or part of the expense of a retreat into the budget or offer to give the facilitator equivalent time off with pay. Again, there are creative ways to help underwrite this cost. The overall sustainability of the group and the long-term commitment of the support group leaders are greatly enhanced by these minimal costs and staff development efforts.

BUILDING RELATIONSHIPS IN THE COMMUNITY



The sponsoring agency will want to work with the facilitators to identify other agencies serving the target population to help develop key relationships within the community. The Advisory Committee can also assist the facilitators by sharing contacts with the medical community, social service agencies, religious institutions, and the Latino community. These relationships will:

- Increase community support.
- Help avoid duplication of effort.
- Provide opportunities to share and/or increase resources.
- Build a base of referrals to the support group.

There are three primary fields in which the cancer support group program should begin to develop linkages and relationships:

1. The Medical Community

Outreach to the medical community is essential for the success of this program. The facilitators need to develop relationships within area hospitals. Physicians, nurses, and oncology and other social workers who are diagnosing and treating the target population are important to know. Finding allies in the medical community who understand the unique problems Latinas face when diagnosed with cancer will not only help build the base of referrals, but will also lend credibility and visibility to the Program.

2. Social Services

A diagnosis of cancer can bring about a number of personal and family crises including transportation to and from doctor's appointments; housing; emergency assistance for rent or medications; food and/or meal preparation, etc. Knowing what services are available in the community is essential since many cancer patients cannot focus on their own recovery if their—or their family's—basic needs are not being met.

3. Cancer Organizations

Other cancer organizations should be made aware of the opening of a new support group in Spanish. By creating linkages with organizations such as the Northern California Cancer Center (NCCC), Cancer Information Service (CIS), American Cancer Society (ACS), Breast Cancer Early Detection Program (BCEDP), local hospitals and clinics, among others, the program can share information and referrals, and help like-minded agencies to better understand the need for culturally specific and appropriate cancer education and services. These linkages can sometimes lead to partnerships on special projects, helping fill in the many gaps in culturally sensitive support services. For example, a San Francisco-based support group and the American Cancer Society became partners on a Spanish Language *Look Good, Feel Better* program for Latinas, offering free makeovers, prostheses and wigs.

Sharing literature tables and booths at health fairs also increases community awareness about breast cancer and the availability of psychosocial support and other services for women of color and monolingual women who have been diagnosed with the disease.

The group facilitators should have available (for their use and for patients) lists of local resources. The Better Health Foundation, located in Oakland, produces the Bay Area Breast Cancer Guide both in Spanish and English. Other agencies such as the Cancer Information Service (1.800.4.CANCER) and the American Cancer Society may also suggest resources. However, lists can become out-of-date fairly quickly. The facilitators may wish to compile their own list of basic services that are able to respond to Spanish speaking women and families in their own community.



SECURING A PLACE TO MEET

*F*inding a meeting place may be designated as one of the responsibilities of the group facilitator(s). The sponsoring agency, depending on its resources, may already have an available room or a lead on a space for the group. *The most successful cancer support groups are held away from a hospital or medical setting.* Cancer patients spend enough time in hospitals and often find that such a setting produces anxiety as opposed to a sense of safety. However, many hospitals and clinics are able to donate space and this may be an important budgetary consideration. Prior to making this decision, other venues such as churches, neighborhood centers, social service agencies, senior and other community centers should be researched and solicited. Many agencies will be willing to donate space as a service to the target population.

Wherever the space, creating a safe and home like environment is a priority. Comfortable sofas and chairs can transform an institutional room into a living room. Folding metal chairs are not adequate, particularly for cancer patients suffering from bone metastases. Adequate lighting and a comfortable temperature are also important.

Sharing food creates a communal feeling. Ideally the group should have access to a kitchen area or, at the very least, a water cooler/ heater for tea, beverages and snacks. These small amenities make an enormous difference in building a sympathetic and warm atmosphere. The budget should include a modest line item for refreshments such as tea, water, fruit juice, fruit and cookies. Group members will often bring food to share, making this only a minimal expense.

TARGETED OUTREACH FOR SPANISH LANGUAGE BREAST CANCER SUPPORT GROUPS



W

hile the medical community has embraced the usefulness of psychosocial support in cancer treatment, groups for non-English speaking cancer patients are difficult to find. Many support groups designed for women of color have failed to attract patients because of lack of attention to, and inadequate resources for, marketing and outreach. Outreach to specific groups ultimately must address unique cultural differences, including language barriers, educational level, general understanding of cancer and the function of support groups, cultural experience with physicians in an immigrant patient's country of origin, and other factors that can influence whether a woman will join a group or not.

Outreach, therefore, is critical to the success of developing a program of psychosocial support for Latina cancer patients. *The purpose of any well-designed outreach plan is to establish contact with cancer patients, build on-going relationships with professionals in the field of cancer, create a community base for patient referrals and to increase public awareness about the Spanish language cancer support group.* Outreach and marketing are also essential components of successful fundraising plans. **This chapter should be given directly to the group facilitators to help them develop an outreach plan for their group.**

Approaches to Outreach

The first steps for producing a strategic outreach plan involve determining **who** needs to know about the program, **why** they need to know about it, and

the *best way of delivering the information* to the target population. Necessarily, outreach must include four distinctly different approaches:

- Individual meetings with cancer patients
- Targeted outreach in the form of one-on-one meetings with social workers and health care providers serving the population
- Exposure in the Spanish-language media
- Coordinated efforts with agencies that provide health education and cancer screening to the targeted community.

Developing a Case Statement for Outreach

Developing a one to two page case statement, focused on the need and plan for the program, is a useful tool (which can eventually be supplemented with a program brochure) that can be left with professionals in the field after initiating a meeting. The statement should include:

- Why the community needs the program.
- The role of psychosocial support in cancer treatment.
- A description of the sponsoring agency, its mission and connection to the Latino community.
- Details about the support group: likely meeting time and place, biographies of the facilitators, contact person and phone number, etc.

Building a List of Professionals in the Field

Outreach starts where Latino cancer patients are served: the hospitals and clinics where they are screened, diagnosed and treated. The facilitators should plan on one to two months for these early outreach efforts. An initial list of social workers, oncologists, radiologists, nurse practitioners and other medical professionals in county hospitals and neighborhood clinics should be developed through research and personal visits. Social workers - particularly if they are bilingual - are often the most helpful in identifying key professionals in their agency, as well as cancer patients who may be interested in a support group.

Once an initial list of key contacts is developed, individual meetings should be scheduled with the healthcare professionals. The purpose of these early meetings is to:

- Inform the provider about the formation of the support group.
- Encourage patient referrals.
- Solicit suggestions about other professionals in the community who should know about the group.
- Establish the facilitators' credentials.
- Discuss the unique issues facing Latinas with breast cancer.
- Discuss the need for one-on-one outreach with Latina cancer patients to develop rapport and trust, especially for patients who are newly diagnosed.

The facilitator should leave the case statement and, if available, bilingual brochures about the group, at each individual meeting during this initial phase of outreach. *She should also request permission to visit clinics where Latinas are screened, diagnosed and/or treated.*

The Referral Base

In addition to building a base for referrals from professionals in the field, the group facilitator(s) need to establish a creative plan that makes use of other agencies and institutions serving the population. These can include social service agencies such as the Department of Social Services and Catholic Charities, churches, senior centers, ESL* classes, non-profit organizations that provide food and transportation programs, etc.

Cancer agencies and information services should also be notified of the program on a regular basis. Such agencies include the American Cancer Society (ACS), Northern California Cancer Center (NCCC), Cancer Information Service (CIS), Breast Cancer Early Detection Program (BCEDP), and Breast and Cervical Cancer Control Program. However, some cancer agencies rely heavily on volunteer support and facilitators should check periodically that they have accurate and up-to-date information on the support group program.

Other organizations and hospitals that provide support groups should also be notified of any new groups opening for Latinas with breast cancer. Facilitators of other groups often receive phone calls requesting information about Spanish language support groups and they can refer these patients to your group. Similarly, hospitals in your area and in nearby counties also need to know about the support group. In these cases, contact the social work, oncology, radiology and health education departments and periodically send them notices, press releases and program brochures (or flyers) in both Spanish and English.

* English as a Second Language

Finally, creating a cancer Advisory Committee comprised of key professionals in the medical field and local Latino community who are bilingual and especially sensitive to the issues Latinas with breast cancer face, can help get the word out, and make referrals. The Advisory Committee should be of help in creating the list of professionals in the field and in the community for the facilitator(s) to meet.

Contact with Patients and Assessing Patient Needs

More than anything, it is the one-on-one meeting, home and hospital visits and personal phone calls, particularly when a patient is newly diagnosed or has just had surgery, that make the biggest difference in recruiting women to the group. *Establishing rapport and trust should be the initial goal with no immediate expectation of getting a woman to a group meeting.*

Regular visits to outpatient clinics where women are treated for breast cancer is an excellent way to begin to develop a presence, identify patients, and build trust. When meeting or speaking on the phone with a patient for the first time, the facilitator must assess the patient's situation:

- Does she fully understand the diagnosis and treatment protocol?
- Was she given adequate information to make a decision about treatment?
- Was an interpreter available for her when she was told of her diagnosis?
- Does she have a support system of family members and/or friends?
- What are her immediate concerns and fears?

- Would she like a home or hospital visit before or after surgery or treatment?
- Does she need referrals for special needs such as transportation to treatment appointments, wigs, prosthesis, mental health services, etc.?

The availability of the support group should be introduced as an option if and when the patient is ready to connect with others going through the same experience. Newly diagnosed patients may not be emotionally, psychologically or physically ready for this step. Personal contact with the facilitator helps the patient experience the value of psychosocial support first hand in a safe, one-to-one environment.

Marketing: Increasing Public Awareness

Marketing is a less personal way to reach patients, but is another vital tool in increasing public awareness about the group and the role of psychosocial support in cancer treatment. It is also helpful in reaching women whose initial diagnosis was made one or more years ago and who are no longer in treatment. Women who are out of treatment may still suffer from isolation and must deal with a myriad of "re-entry" issues, such as returning to work, body image and sexuality, fear of recurrence, etc.

First and foremost, the Spanish language media should be notified of the support group. Press releases and public service announcements should be written in Spanish and English. Follow-up is an essential component for any media campaign to make sure that the media received the information and to solicit feature articles. It is also important to thank media contacts for any coverage of the support group. Establishing relationships with local media adds to the sense of community ownership and is important to both outreach and fundraising.

Joint Ventures

Also of importance is creating cooperative partnerships and joint ventures with other agencies providing health promotion, cancer education, screening and services to the Latino community. Cooperative ventures might involve sharing a table with a like-minded organization at health fairs, having the support group flyers available in (mobile) mammography units, making educational presentations on breast cancer in Spanish and/or English at senior centers and churches, hosting joint fundraisers, etc. While these endeavors may be sporadic during the year, they do help increase awareness about the support group and help establish relationships for future referrals.

Distribution of the Group Informational Flyer or Brochure

Periodic mailings and delivery of a simple flyer or brochure with a short cover letter is an ongoing part of an effective outreach plan. The program should build a database of local doctors, nurses, pharma-

cists, social workers, therapists, nutritionists, acupuncturists and agencies serving the Latina cancer population in general, and the breast cancer population in particular, to use for these mailings. Making support program flyers or brochures available in doctors' and hospital waiting rooms increases visibility to the general public.

Outreach is Ongoing

More than anything, outreach should be considered an ongoing process of running a Spanish language support group for Latinas with breast cancer. Once the relationships with professionals in the field have been instituted, there is a solid foundation for patient referrals. When the group has a steady number of participants, outreach may slow down while individual contact with current group members may increase. However, other Latinas will be diagnosed and need information about available support services. Ongoing outreach is essential to keeping the group visible in the community. Coordinating key efforts with other agencies serving the population, conducting periodic presentations on breast cancer and the role of psychosocial support introduces new women to the importance of early detection and ways of coping with cancer.

Visibility is also essential to the development of continued financial resources for the support group. **Outreach and fundraising should be a coordinated effort to ensure adequate funds to keep the group open and ongoing.** This coordination is especially important when there is a need to open additional group(s) or a desire to expand services.



PROGRAM EVALUATION

The sponsoring agency is responsible to the support group members, the community and the program's funders for regularly evaluating the effectiveness and accountability of its programs. Instituting an evaluation procedure and conducting periodic reviews helps the agency and facilitators process the work and devise solutions to any problems that may arise. Making these reports part of advisory committee meetings also increases resources for problem solving and gives committee members a continued connection to the work.

Evaluation will necessarily include:

- Monthly reporting on *group* progress.
- Evaluation of group and *facilitators'* work.
- Evaluation of the *Agency's* role in securing funding and maintaining the program's infrastructure.
- Evaluation of *participant* satisfaction.
- Evaluation of the effectiveness of *outreach* and *marketing*.

Monthly Reporting on Group Progress

The facilitators should record group attendance and any important issues that arise from the group discussion. These can be individual issues, such as an illness in the member's family or an upcoming medical appointment, or issues such as a group member's response to the loss of a fellow member. The report should be submitted monthly to the agency director or program supervisor. (See **Appendix F** for a sample Monthly Group Report Form.) *These reports are confidential.* They should only be reviewed by a supervising staff member and must always be kept in a locked file cabinet.

Evaluation of the Group Facilitators

The facilitators should debrief after every group. During the debriefing, they can evaluate their facilitation skills, listening and interpretation skills. This time can also be useful in processing a difficult session, issues that were raised, etc. If the facilitators have been hired as employees (as opposed to independent contractors), they should receive an annual performance evaluation. Once the support group is up and running, the clinical facilitator can feel isolated, especially if the venue for the group is not located at the sponsoring agency's facility. An evaluation can be part of the process to keep the facilitators connected to the agency, and provides a process for problem solving and feedback.

If the facilitator is on staff, then the job description should be used as the starting point for the evaluation. If the clinical facilitator is a contracted position, then the scope of work outlined in the contract becomes the foundation for an annual review.

Evaluation is especially important while the groundwork for the program is being laid. Are timelines being followed and deadlines being met? It is very discouraging for new participants who cannot meet because a space has not been secured or because there are not enough participants by the target start-up date. Requiring a *brief* (1-2 pages) biweekly or monthly written work report helps quantify actions, determine and resolve problem areas, and revise action plans. Such reports can shorten, and sometimes eliminate the necessity for, staff meetings and even lessen the amount of bureaucracy for all parties. This is especially important when maintaining a tight budget. Work reports can also be used as the basis for foundation grant reports.

Internal Evaluation

The sponsoring agency must also evaluate its own progress on meeting goals and deadlines. Clearly, raising the necessary funds for the program is the most important goal to meet. Having a timeline with dates by which funds have to be raised helps keep fundraising on track. Other internal questions can include:

- Is the agency providing the necessary contacts for outreach and the development of an advisory committee?
- Is the agency responding in a timely manner to questions or concerns the facilitators may raise?
- Is communication between the agency and facilitators consistent and effective?
- Do the facilitators feel supported by the agency? Is the program supervisor accessible?
- Is the program on budget?
- Are the agency's internal procedures bogging down the program down or helping it?
- Is the space comfortable and conducive to the support group process?
- Does the space provide adequate privacy in the event the facilitator needs to see a group member on an individual basis?

Assessing Group Participants' Satisfaction

Once the group has begun to meet, more criteria must be added to the evaluation process to determine how participants are responding to the group and facilitators. The facilitators should determine the reasons for low or inconsistent attendance. In a cancer support group, attendance is not always a factor of something inherently wrong with the group. Illness, hospitalization, work, family obligations, transportation difficulties, or the death of a fellow group member are a few of the reasons attendance can be irregular. Conducting consistent follow-up when a group member misses a meeting will not only help the facilitators discover the cause of an absence, but also shows the participant the concern the whole group feels when she misses a session.

The agency supervisor should step in if, after a period of time, it appears that there is a significant drop in attendance. In this situation, a discussion with the group facilitators should be held to determine what some of the issues may be and how they can be resolved. A steady drop in attendance may indicate a problem with outreach or with follow-up for new and current participants. *Many support groups have ended prematurely because too few hours were allotted for follow-up and outreach.* This is why it is absolutely essential to budget adequate hours for the facilitators to conduct ongoing and thorough outreach and case management.

Annually, a confidential questionnaire can be given to group members to assess their satisfaction with the group. Such a questionnaire must be in *Spanish* and must be brief and to the point. There should also be an option for anonymity. A self-addressed stamped envelope can be given to participants to return the questionnaire to the agency. Results should be compiled and shared with the facilitators.

Some questions that may be asked include:

- Do you attend this group regularly? If not, why?
- Do you have any problems getting to the group? If so what are they?
- Do you feel free to discuss issues arising from your cancer diagnosis or treatment?
- Do the group leaders create a safe and comfortable environment?
- Do you receive adequate follow-up between group meetings or when you are unable to attend the group?
- Is the group useful to you? If so, how? If not, why?
- Do you have any suggestions for the group?
- Has the group helped you learn more about your diagnosis and/or treatment?



Some Do's and Don'ts for the Agency and Group Facilitators

Starting a Spanish language cancer support group program is a challenge. But going back to the beginning, it is important to remember the impetus for providing this service. Working with women facing life-threatening illness is richly rewarding work. It is a lesson in courage, hope and faith. And it makes a real and tangible difference to the cancer patient and her family and friends.

Because there are very few support services for monolingual Spanish speaking cancer patients, this program also provides a real model for the community. It helps level the playing field by providing social services in a language other than English. The medical community needs concrete evidence that cancer support in Spanish is urgently needed and can be cost effective. This project can provide the evidence and hopefully generate the necessary financial support.

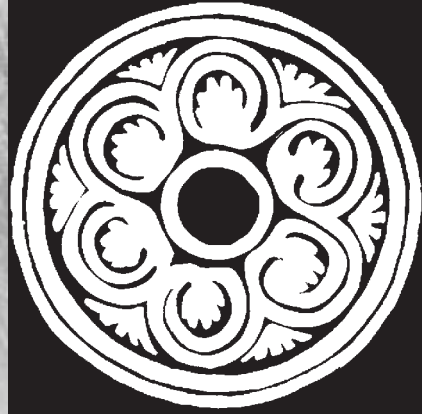
Over the years, we discovered a few universals that apply to operating a Spanish language support group. They include the following:

- DO make frequent patient visits and calls. One-on-one contact is an essential component of building trust and confidence.
- DON'T expect cancer patients or their families to call you.
- DO have a separate, dedicated telephone line for support group members and prospective members.
- DO set specific hours for participants to call, and be there to answer the phone during those times.
- DON'T expect Latinas to leave a message. At the same time, DO record a bilingual Spanish/English voice mail message that lists the hours someone is available to answer the phone in person and/or return calls.
- DON'T post a notice about the support group and expect Latinas to respond. Ongoing outreach must be part of the program's work plan.
- DO use both the Spanish and English print and electronic media, your advisory committee members, other local agencies, community leaders and funders to inform the community about the program.

FOOTNOTES

- 1) "Report Card 2000," CHILDREN NOW, www.childrennow.org/california/rc-2000/report-card-2k.htm.
- 2) *San Francisco Chronicle*, January 12, 1999.
- 3) ER Brown, et. al., "38% of California's Non-elderly Latinos Are Uninsured," *Policy Brief*, UCLA Center for Health Policy Research, August 1997.
- 4) HH Schaffler and ER Brown, *The State of Health Coverage in California*, 1999, Berkeley, CA: Regents of the University of California, January, 2000, p. 21-23.
- 5) Spiegel, D.S.; Bloom, J. R.; Kraemer, H.C.; Gottheil, E. *Effect of Psychosocial Treatment on Survival of Patients with Metastatic Breast Cancer. Lancet* 1989, 888-891.

SECTION THREE:
*R***ESOURCES AND MATERIALS**





The following pages include a variety of materials and resources that may be helpful to cancer support group facilitators as well as to agencies who are sponsoring support groups. The list is intended to help you get started with your search for more information. It is not all-inclusive and does not represent an endorsement by the Northern California Cancer Center.

For a more complete list of Bay Area resources contact the Better Health Foundation (see San Francisco Bay Area Organizations). The Bay Area Breast Cancer Guide, developed by the Better Health Foundation, is available in English and Spanish. It includes information for medical services, prostheses, wigs, medical equipment, and other resources.

Spanish Speaking Cancer Support Groups

Circulo de Vida

Cancer Support and Resource Center
2929 Mission Street
San Francisco, CA 94110
415.648.9423

Las Isabelas

93 Devine Street, Suite 100
San Jose, CA 95110
408.287.4890
Email: LasIsabelas@sbcglobal.net
www.lasisabelas.org

Latina Cancer Support Group

Pittsburg Community Council
1760 Chestnut Drive
Pittsburg, CA 94565-3920
925.439.2061
www.ppscc.org
Offers bi-weekly meetings in Spanish for Latinas who need counseling and emotional support.

Entre Nosotras

Salud Para La Gente, Inc. ("Salud")
406 Main Street, Room 309
Watsonville, CA 95076
831.457.2273-English
831.761.3973 Spanish
www.womencaresantacruz.org
Latina support groups are co-sponsored by WomenCare and Salud Para La Gente, Inc

Women's Cancer Resource Center

5741 Telegraph Avenue
Oakland, CA 94609
510.420.7900
www.wcrc.org
Spanish and English-speaking support groups.

Vida con Esperanza Support Group

Centro de Servicios
525 H Street
Union City, CA 94587
510.489.4100
www.ci.union-city.ca.us/centro/centrodeservicios.html
Spanish speaking support groups are offered.

San Francisco Bay Area Organizations

Bay Area Breast Cancer Network (Y-Me/San Jose Affiliate)

4320 Stevens Creek Blvd., Suite 185
San Jose, CA 95129
408.261.1425
www.babcn.org

An organization committed to finding the cause, prevention and cure for breast cancer through education, support, and advocacy. Programs and services include the BABCN hotline, support groups, newsletters, open door educational forums, and a speaker program. BABCN is an affiliate of the Y-Me National Organization, the California Breast Cancer Organizations (CABCO) and the National Breast Cancer Coalition (NBCC).

The Better Health Foundation

414 Thirteenth Street, Suite 450
Oakland, CA 94612
510.444.5096
www.betterhealthfoundation.org

A non-profit organization dedicated to providing individuals with the knowledge and support services needed to make informed health decisions. Publishes Bay Area Breast Cancer Resource Guide(s) in English and Spanish.

CIRCLE Resource Center

Marin Medical Library
Marin General Hospital
2nd Floor, East Wing
250 Bon Air Road
Greenbrae, CA, 94904
415.925.7000

www.marigeneral.sutterhealth.org/services/
Offers medical resources, free booklets, video programs, and audiotapes. For a small fee, they will research and gather information on a medical topic and prepare a packet for you.

Community Health Library of Los Gatos

815 Pollard Road
Los Gatos, CA 95030
408.866.4044
www.healthlib.org

A consumer health/medical library providing resources that enable the public to become more informed about health care issues. Most services are free.

FamiliesCAN

650.941.6852
www.familiescan.org

Provides financial assistance for services the family can no longer afford as a result of cancer treatment. Contact FamiliesCAN for eligibility and geographical limitations.

Grail Community Resource Center

2003 E. San Antonio Street
 San Jose, California 95116
 408.347.7892
www.sjdc.org

A family resource center that includes a health library, English classes for adults, computer classes for adults & children. Spanish speaking.

The Health Library

2-B Stanford Shopping Center
 Palo Alto, CA 94304
 (Near Bloomingdales)
 650.725.8400

www-med.stanford.edu/healthlibrary/

A community health library with a wide variety of resource materials for the public and for health professionals. Offers e-book lending library.

Kaiser Permanente Medical Centers

Many Kaiser Permanente Medical Centers incorporate a library within their facilities. Contact the Kaiser Permanente Medical Center in your area for more information or call Regional Health Education at 510.987.3155.

John A Graziano Memorial Library

Merritt-Peralta Health Education Center
 400 Hawthorne Avenue
 Oakland, CA 94609
 510.869.8900

www.samuelmerritt.edu/library/index.cfm

Health library for public and health professionals. Includes periodicals, books, videos, computers and software.

Older Adult Resource Center

El Camino Hospital
 2400 Hospital Drive
 (behind El Camino Hospital)
 Mountain View, CA 94040
 650.988.7622

A consumer health and gerontology library that also specializes in caregiver education, health insurance counseling, and assistance with advance directives. There is also information on support groups and wellness classes, as well as a speakers bureau and a newsletter.

Planetree Health Library

2040 Webster Street
 San Francisco, CA 94115
 415.600.3681
www.ihr.com/planetree.html

Planetree is a health and medical library open free to the general public. The library contains a wide range of health information from conventional to alternative therapies, medical textbooks, lay health information books, medical journals, consumer health newsletters, clipping files, and audiovisuals on a variety of topics.

Planetree Health Resource Center

at San Jose Medical Center
 98 North 17th
 San Jose, CA 95112
 408.977.4549
www.planetreesanjose.org

Consumer health and medical libraries with textbooks, general health books, journals, audio and videotapes, files on health and medical topics, including complementary therapies. Features a health bookstore and information about local and national support groups. Materials available in Spanish.

Susan G. Komen Breast Cancer Foundation

San Francisco Bay Area Affiliate

P.O. Box 29316

San Francisco, CA 94129-0316

415.561.3377

An affiliate of the National Susan G. Komen Foundation (see next entry). Supports bay area breast cancer programs.

Susan G. Komen Breast Cancer Foundation

National Office

5005 LBJ Freeway, Suite 370

Dallas, TX 75265

1.800.IM.AWARE

www.komen.org

A national fundraising organization for advances in breast cancer research, education, screening and treatment. Sponsors Race for the Cure. Information in both English and Spanish.

Valley Care Health Library

5698 Stoneridge Drive, Suite 120

Pleasanton, CA 94588

925.734.3315

www.valleycare.com/library.

A consumer health library with a collection that includes medical textbooks, consumer health books, professional journals and health magazines, computerized periodical indexes, audiotapes, and videotapes.

WomenCARE

617B Water Street

PO Box 944

Santa Cruz, CA 95061-0944

831.457.2273-English

831.761.3973 Spanish

www.womencaresantacruz.com

Provides advocacy and free resources, education and support to all women who are living with cancer (plus families, friends and health practitioners) throughout diagnosis, healing, surviving, or dying. WomenCARE provides a lending library, internet access, a lecture series, individual consultation, special classes, and support groups in English and Spanish. The Spanish group meets in Watsonville at Salud Para La Gente, Inc.

Women's Cancer Resource Center

5741 Telegraph Avenue

Oakland, CA 94609

510.420.7900

www.wcrc.org

An organization that provides education forums and workshops, resource library, support groups in English and Spanish, information referral hotline, and in-home support service.

National and Regional Organizations

Many of these organizations have staff that speak Spanish.

Cancer Information Service

1.800.4.CANCER (1.800.422.6237)

www.cancer.gov

The Cancer Information Service is the National Cancer Institute's link to the public. Information provided in both English and Spanish. Trained information specialists assist callers. Available information includes cancer types, symptoms, screening, treatment, treatment side-effect management, and clinical trials. The CIS interprets and explains research findings in a clear and understandable manner. Free publications. Callers are not solicited for donations. Names, addresses, and telephone numbers are not kept in a data bank.

American Cancer Society

1.800.ACS.2345

www.cancer.org

A nationwide health organization that provides information about cancer prevention, detection, treatment, chemotherapeutic drugs, and resources; headquartered in Atlanta, Georgia, with state divisions and units. Also provides information/assistance with transportation for doctor visits, equipment loans (e.g., wheelchairs), wigs, and prostheses.

American Society of Plastic Surgeons

Plastic Surgery Educational Foundation

44 E. Algonquin Road

Arlington Heights, IL 60005

1.888.4.PLASTIC

www.plasticsurgery.org

Provides information on a variety of reconstructive plastic surgery procedures and has a Plastic Surgeon Referral Service.

Cancer Care, Inc.

212.712.8080

www.cancercare.org

A national non-profit organization providing free professional information to people with cancer. Counseling, education, information, and referrals are provided. Financial assistance available, depending upon patient's city of residence.

Cancerstop.net

El sitio oficial contra el cancer en Mexico para Lationamerica. En Espanol. Includes a list of hospitals specializing in cancer care in Mexico and United States, a reading list, and website links.

www.cancerstop.net

Intercultural Cancer Council (ICC)

6655 Travis, Suite 322

Houston, TX 77030

713.798.4617

www.icc.bcm.tmc.edu

Promotes policies, programs, and partnerships as well as research to assist racial and ethnic minorities.

Minority Health Project

(University of North Carolina)

www.minority.unc.edu

The purpose of the Minority Health Project (MHP) is to improve the quality of available data on racial and ethnic populations, to expand the capacity of minority-health researchers to conduct statistical research and develop research proposals, and to foster a network of researchers in minority health.

National Alliance of Breast Cancer Organizations

9 East 37th Street, 10th Floor

New York, NY 10016

1.800.80.NABCO

www.nabco.org

NABCO offers information and education resources on breast cancer to the public. They also give referrals to patients, survivors and their families, along with medical professionals and their organizations. All services are free of charge.

National Alliance for Hispanic Health

1501 Sixteenth St., NW.

Washington DC 20036

202.387.5000

www.hispanichealth.org

The organizations mission is to improve the health and well-being of Hispanics in the United States by informing, educating and advocating for Hispanic consumers, and working to strengthen communities and their health and social infrastructures.

National Cancer Institute

NCI Public Inquiries Office

Suite 3036A

6116 Executive Boulevard, MSC8322

Bethesda, MD 20892-8322

1.800.4.CANCER (1.800.422.6237)

www.cancer.gov

The National Cancer Institute is an institute within the National Institutes of Health. NCI was established in 1937 and is the Federal Government's principal agency for cancer research and training. The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients

and the families. NCI supports and coordinates research projects conducted by universities, hospitals, research foundations, and businesses throughout this country and abroad.

National Center For Complementary and Alternative Medicine

NCCAM Clearinghouse

P.O. Box 7923

Gaithersburg, MD 20898

1.888.644.6226

info@nccam.nih.gov

www.nccam.nih.gov

NCCAM is one of 27 institutes and centers of the National Institutes of Health. NCCAM supports research on complementary and alternative medicine, trains researchers, and provides information to the public and health professionals about how complementary and alternative medicine work, which medicines do not work, and why.

National Coalition for Cancer Survivorship

1010 Wayne Avenue, Suite 770

Silver Spring, Maryland 20910

877.622.7937 or 301.650.9127

www.canceradvocacy.org

A national network of independent organizations and individuals; provides information, educational programs, publications, and a newsletter.

National Institutes of Health (NIH)

Building 1

1 Center Drive

Bethesda, Maryland 20892

301.496.4000

www.nih.gov

The National Institutes of Health (NIH) is comprised of 27 institutes and centers. Their mission is to uncover new knowledge that will lead to better health for everyone. Its programs conduct and support research, train research investigators, and foster communication of medical information. NIH is one of the agencies of the Public Health Service.

National Library of Medicine

8600 Rockville Pike

Bethesda, MD 20894

1.888.346.3656

www.nlm.nih.gov/libserv.html

This is the world's largest medical library and includes books, journals, technical reports, manuscripts, microfilms, photographs, and images. NLM publishes Index Medicus, MEDLINE, and other databases. Also the Library publishes a monthly subject/author guide to articles in 3400 journals that are accessible via the World Wide Web.

PDQ-Physicians Data Querywww.nci.nih.gov/cancer_information

A database that summarizes the current cancer therapy literature into specific treatment recommendations. Information is available in both patient-oriented and technical levels. PDQ also contains comprehensive lists of standard and experimental treatments for cancer plus a directory of physicians and organizations involved in cancer treatment and research. PDQ can be accessed through medical school libraries, large public libraries, community health libraries, and the Cancer Information Service (1.800.4.CANCER).

National Lymphedema Network

1611 Telegraph Ave. Suite 1111

Oakland, CA 94612

1.800.541.3259

www.lymphnet.org

A non-profit program providing education, support, information and resource guides, equipment, etc. to assist individuals who have lymphedema.

The Office of Minority Health Resource Center

PO Box 37337

Washington, DC 20013-7337

1.800.444.6472

www.omhrc.gov

The mission of OMH is to improve the health of racial and ethnic populations through the development of effective health policies and programs that help to eliminate disparities in health. OMH has a role in the development and coordination of Federal health policy by addressing minority health concerns and works to improve collection and analyses of data about the health of racial and ethnic populations.

Patient Advocate Foundation

753 Thimble Shoals Boulevard, Suite B
Newport News, VA 23606
1.800.532.5274
www.patientadvocate.org

A non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys. Publishes "The Managed Care Answer Guide".

Redes en Acción

Baylor College of Medicine
8207 Callaghan R., Suite 110
San Antonio, Texas 78230
210.348.0255
www.redesenaccion.org

A National Cancer Institute-funded initiative to combat cancer among Latinos, involves cancer research, training and awareness. Redes En Acción is building a nationwide network of community-based organizations, research institutions, government health agencies and the public. Core activities include promoting training and research opportunities for Latino students and researchers, generating research projects on key Latino cancer issues, and supporting cancer awareness activities within the Latino community. Any individual or organization in the U.S. engaged in research, training or public education activities related to cancer in Latinos is encouraged to join the Redes En Acción network.

Y-Me

24-hour hotlines
800.986.9505—Spanish
800.221.2141—English
www.y-me.org

A national organization for breast cancer information, education, and support. Operates a 24 hour hotline in both English and Spanish. Newsletter available.

Pamphlets/Booklets**Bay Area Breast Cancer Resource Guide**

Comprehensive directory of Bay Area breast cancer services, including screening, diagnosis, treatment, emotional support, prostheses and other information. First copy free; additional copies \$3 each. Also available on-line. Information is updated regularly. Contact: Better Health Foundation, Oakland, CA. 510.444.5096
www.betterhealthfoundation.org

The National Cancer Institute-Educational Literature

The literature titles listed below are available through the Cancer Information Service 1.800.4.CANCER, www.cancer.gov, and the Office of Cancer Communications, National Cancer Institute, Building 31, Room 10A24, Bethesda, MD 20892. Some titles are in Spanish. Small quantities are free.

Below is an *abbreviated* list of materials. Titles and availability change. (Ask also for information on different kinds of cancer and cancer treatments, as well as literacy levels.)

- Answers to Your Questions About Metastatic Cancer
- Chemotherapy and You: A Guide to Self-help During Treatment
- Eating Hints: Recipes and Tips for Better Nutrition During Cancer Treatment
- Facing Forward: A Guide for Cancer Survivors
- Lymphedema Treatment
- Medicine for the Layman: Cancer Treatment
- Questions and Answers about Pain Control
- Questions to Ask Your Doctor About Breast Cancer (English and Spanish)

- Radiation Therapy and You: A Guide to Self-help During Treatment
- Taking Time: Support for People with Cancer and the People Who Care for Them
- What are Clinical Trials All About?
- What You Need to Know About (specify which cancer when you make request)
- Preguntas y respuestas acerca del Estudio del Tamoxifeno y el Raloxifeno
- Cancer del Seno (mama): Tratamiento (Health Professional)
- Cancer del Seno masculino: Tratamiento (Health Professional)
- Cancer del Seno: Que Es? Cancer del Seno: Tratamiento

Cancer de Mama

American Academy of Family Physicians
P.O. Box 11210
Shawnee Mission, KS 66207-1210
www.familydoctor.org/
1.800.274.2237

Cancer de seno: (Guias de tratamiento para los pacientes) Version III, June 2000.

National Comprehensive Cancer Network
1.888.909.NCCN
www.nccn.org
OR
American Cancer Society
1.800.ACS.2345
www.cancer.org

Informacion del Seno

American Cancer Society
www.cancer.org
1.800.ACS.2345

Autoexamen del Seno

www.med.utah.edu/healthinfo/spanish/breast
University of Utah

Indice de La Medicina Complementaria y Alternativa [//uuhsc.utah.edu.health/info/spanish/altmed](http://uuhsc.utah.edu.health/info/spanish/altmed)

Sin costa alguno mamogramas y pruebas pap

Columbia, MO, 1999. 1 page handout from the Missouri Department of Health, Breast and Cervical Cancer Control Project.
www.health.state.mo.us/warehouse/
DHSS Warehouse, Department of Health & Senior Services
573.751.6400

Sus derechos laborales como sobreviviente de cancer, pautas y opciones para considerar

(Working It Out: Your Employment Rights as a Cancer Survivor)
Elizabeth J. Clark, PhD with assistance from Elmer Huerta, MD. 1999. \$2.00.
Available from National Coalition for Cancer Survivorship
www.canceradvocacy.org
1.877.NCCS.YES or 1.877.622.7937

Trabajo en Equipo: Guia del Paciente de Cancer Para Hablar con Su Medico

(Teamwork: The Cancer Patient's Guide to Talking with Your Doctor)
Elizabeth J. Clark, PhD with assistance from Elmer Huerta, MD. 1998. First copy is free. \$2.00 shipping fee.
Available from: National Coalition for Cancer Survivorship.
www.canceradvocacy.org
1.877.NCCS.YES or 1.877.622.7937

La Esperanza Es Lo Ultimo Que Se Pierde

(You Have the Right to be Hopeful)

Elizabeth J. Clark, PhD with assistance from
Elmer Huerta, MD. 1998. \$5.00

Available from National Coalition for Cancer
Survivorship

www.canceradvocacy.org

1.877.NCCS.YES or 1.877.622.7937

***Lo que los sobrevivientes de cancer deben saber acerca
de los seguros de salud***

(What Cancer Survivors Need to Know About
Health Insurance)

Kimberly J. Calder, MPS and Karen Pollitz, MPP
1999. \$3.00

Available from: National Coalition for Cancer
Survivorship.

www.canceradvocacy.org

1.877.NCCS.YES or 1.877.622.7937

***Hispanics/Latinas: Developing Effective Cancer
Education Print Materials***

The Susan G. Komen Breast Cancer Foundation
5005 LBJ Freeway, Suite 370
Dallas, Texas 75244

www.komen.org

1.800.I'M AWARE or 1.800.462.9273

Pocket Guide to Minority Health Resources

US Dept. of Health and Human Services, 1999.
PO Box 37337

Washington, DC 20013-7377

Email: info@omhrc.gov

www.omhrc.gov

1.800.444.6472

Books

A Cancer Survivor's Almanac: Charting your Journey
by Barbara Hoffman, (Editor), 1998.

Strategies and support for living with and beyond
cancer; includes personal experiences and profes-
sional insights.

The Alternative Medicine Handbook

by Barrie R. Cassileth, Ph.D., W. W. Norton & Co.,
1998.

A review of more than 50 different types of alterna-
tive and complementary medicine and techniques,
the scientific research available for each, usage, etc.,
as well as practical advice for decision making.

Assess Your True Risk of Breast Cancer

by Patricia T. Kelly Ph.D., Owl Books, 2000.

Discusses hereditary and non-hereditary breast
cancer risks, different kinds of breast cancer, genetic
testing, prophylactic mastectomy and informed
decision-making.

Atlas de cirugía de la mama (Atlas of breast surgery)

by Samuel A. Wells, Leroy V. Young and Dorothy A.
Andriole. Madrid: Mosby/Doyma Libros, 1995.

Breast Cancer: A Psychological Treatment Manual

by Sandra Haber (Editor), Heather Goodare, New
York University Press, 1997.

Written to educate and involve therapists and coun-
selors in the psychological treatment of patients and
their families. Also available in Spanish.

***Cancer de mama: mitos y realidades: lo que usted
necesita saber*** (Breast cancer myths & facts: what
you need to know).

by S. Singletary, Eva and Alice F. Judkins,
Huntington, NY: PRR, 1997.

Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer

by Michael Lerner, MIT Press, 1994.

A comprehensive review of different choices of treatments and living with cancer.

Confie en el mañana: guía para el tratamiento del cáncer de seno

by Vladimir Lange, Lange Productions, 2000.

Available in both English and Spanish.

Directory of Pharmaceutical Indigent Programs

Offered by the Pharmaceutical Research and Manufacturers Association. Includes the name of the program, the company providing it, information on how to make a request for assistance, the prescription medicines covered, and eligibility criteria. Free. Contact: Pharmaceutical Manufacturers of America 1100 15th Street NW, Washington, D.C. 20005. 202.835.3400

www.phrma.org/searchcures/dpdpap

Dr. Susan Love's Breast Book

by Susan M. Love, MD with Karen Lindsey, Addison Wesley Publishers, 2000.

A practical, straightforward discussion of the types of breast cancer, diagnostic tests, treatments, reconstructive surgery, breast pain, and more.

Dr. Susan Love's Hormone Book

by Susan M. Love, MD with Karen Lindsey, Random House, 1998.

Discusses various hormones and drugs used in relation to menopause; also addresses homeopathic, dietary, herbal and other non-traditional remedies for specific conditions and complaints associated with menopause.

Entre mujeres: su recuperación física y emocional después de la mastectomía

by Rosalind D Benedet, Benedet Publishing, 1999. 415.281.3380

Topics include breast surgery, mastectomy and rehabilitation.

Handbook for Mortals: Guidance for People Facing Serious Illness

by Joanne Lynn, Oxford University Press, 1999.

Practical information to help face end-of-life choices.

Healing: A Women's Guide to Lumpectomy & Radiation Therapy

by Rosalind Benedet and Mark C. Rounsaville, Benedet Publishing, 1996.

415.281.3380

Healing: A Guide to Recovery after Mastectomy

by Rosalind Benedet, Benedet Publishing, 1993.

415.281.3380

A practical guide with easy to understand information including questions for your doctor, getting back to normal routines, emotional recovery, lymphedema, and more. (also available in Spanish)

Healing Words: The Power of Prayer and the Practice of Medicine

by Larry Dossey, MD, Harper Mass Market Paperbacks, 1997.

Discussion of the complementary role of prayer and medicine.

How to Help Children Through a Parent's Serious Illness

by Kathleen McCue & Ron Bonn, St. Martin's Press, 1996.

Assists parents addressing children's fears relating to disease, loss of parental daily support and death.

Lenguaje de niños: los niños hablan claro sobre el cáncer del seno

by Laura Numeroff, Wendy S. Harpham, and David McPhail, Samsung Telecommunications American and Sprint PCS, 1999.

A short question & answer booklet for children.

Liberese del Cancer

by Sidney J. Winawer & Moche Shike, & Phillip Bashe (Contributor), Simon & Schuster/Libros en Espanol, 1995.

Explains how to evaluate genetic and personal history to determine risk of cancer.

Living Beyond Breast Cancer

by Marisa Weiss, MD, and Ellen Weiss. Times Books/Random House, 1998.

Provides practical and timely information, sound guidance, comfort and a few laughs to help one live as well as possible beyond breast cancer. Addresses issues such as an intimacy and sexuality, fatigue, treatment and side effects, weight control, nutrition, health insurance, fear of recurrence, menopause, talking with doctors, and more.

Living with Breast Cancer: A Guide for Facilitating Self Help Groups

by Pat Kelly and PISCES Partners in Self-Help Community Education and Support. Susan G. Komen Foundation and Y-Me National Breast Cancer Organization. Publisher: BC Decker, 2000. 905.522.7017

Email: info@bcdecker.com

Mamografía: intervencion e imagen

by Luz A. Venta, Lippincott Williams & Wilkins Publishers, 2000.

Managing the Side Effects of Chemotherapy and Radiation

by Marilyn J. Dodd. Englewood Cliffs, NJ: Prentice-Hall, revised 2000.

An easy-to-use resource for cancer patients and their families. Gives a review of chemotherapy drugs and radiation therapy, potential side effects, and specific suggestions about how to minimize or alleviate the side effects.

Peaceful Dying: The Step-By-Step Guide to Preserving Your Dignity, Your Choice, and Your Inner Peace at the End of Life

by Daniel R. Tobin MD., Karen Lindsey (Contributor), Perseus Publishing, 1998. Addresses issues and concerns of dying.

Recovering from Breast Surgery

by Diana Stumm, Hunter House, 1995.

Information about postsurgical needs and physical restrictions, exercises to alleviate pain and increase mobility, self care measures, and support resources.

Sexuality and Fertility after Cancer

by Leslie R. Shover, John Wiley & Sons, 1997.

Issues and options relating to sexuality, intimacy and fertility after cancer, the kinds of sexual problems that may be encountered after treatment, infertility treatments, how to assess risks of pregnancy, information on body image, low sex drive, performance anxieties, medications, menopause, and more. For men and women.

Supportive Cancer Care: The Complete Guide for Patients and Their Families

by Ernest H. Rosenbaum MD., Isadora R. Rosenbaum, Alan Glassberg, Sourcebooks Trade, 2001.

Answers questions concerning treatment, the will to live, stress, depression, spirituality, nutrition, therapeutic massage, and sexuality. It also covers medical, social support services, and financial aspects of cancer.

Todo Sobre Sus Senos: Guia Facil Para Que la Mujer Cuide Sus Senos y Evite el Cancer Mamario

by Adrienne Lang, Editorial Concepts, 2001.
Discusses prevention, care and hygiene.

E-books

The Health Library
2-B Stanford Shopping Center
Palo Alto, CA 94304
(Near Bloomingdales)
650.725.8400
www-med.stanford.edu/healthlibrary

Breast Cancer Video Tapes***Breast Self-Examination***

Kaiser Permanente (Spanish and English versions)
See Organization Section and your local Kaiser hospital or call Regional Health Education.
510.987.3155

Breast self-exam. Available in Spanish and English.
American Cancer Society
650.578.9902

El Examen de los pechos y su salud

(Breast self-exam and breast health)
Publication: Milner-Fenwick Video, Timonium, Md., 1993.
410.560.1212

Shows step-by-step demonstrations of breast self-examination techniques and discusses the overlapping roles of self-exams, clinical exams, and mammography in the prevention and early detection of breast cancer. A 13-minute videocassette.

MammaCare

Mammatech Corporation
930 NW 8th Avenue
Gainesville, FL 32601
www.mammacare.com
1.800 MAMCARE (626.2273)

Specially constructed breast models, videotape, and booklets available for self-instruction in Breast Self Exam. Available in Spanish and English.



APPENDIX A: Topics for Support Groups

Several years ago the Northern California Cancer Center developed a Guide to help trained group facilitators lead support groups for young women with breast cancer. The following is excerpted from that Guide. Perhaps some of this information will be helpful to you:

TOPIC	OBJECTIVES	METHODS
Impact of Cancer	<ul style="list-style-type: none"> • Develop group cohesion • Share personal feelings 	<ul style="list-style-type: none"> • Story-telling. Ask each member of the group to share their individual experience with breast cancer. • Invite a breast cancer survivor who has survived cancer for more than five years.
Locating Resources	<ul style="list-style-type: none"> • Identify personal needs of each member in the group • Identify resources to meet those needs 	<ul style="list-style-type: none"> • Discussion of personal needs. • Review with group information that you as a group leader have about local resources.
Taking Care of My Needs	<ul style="list-style-type: none"> • Identify personal needs • Share experience in finding and using resources discussed in last meeting • Help to identify additional resources 	<ul style="list-style-type: none"> • Story-telling and discussion. • Guest Speaker. Have the speaker (long term breast cancer survivor) discuss what they identified as their personal needs after a diagnosis of cancer.
Assertive Communication	<ul style="list-style-type: none"> • Develop assertive communication skills 	<ul style="list-style-type: none"> • Story-telling and discussion. • Role Playing.
My Body and Body Image	<ul style="list-style-type: none"> • Provide answers to questions about the effects of breast cancer and its treatment on the body. • Learn how to do breast self-examination and why this is important. • Express feelings about changes in the body caused by breast cancer and its treatment. 	<ul style="list-style-type: none"> • Invite breast cancer survivor.

TOPIC	OBJECTIVES	METHODS
Healing My Inner Self	<ul style="list-style-type: none"> • Recognize that thoughts, feelings, actions, and body image are related. • Acquire information and skills to improve self-esteem. 	<ul style="list-style-type: none"> • ACS “Look Good-Feel Better” session. • Story-telling and discussion.
Nutrition	<ul style="list-style-type: none"> • Recognize that eating involves choices. • State basic principles of good nutrition. • Identify techniques for assessing nutrition information. • Develop a realistic individual “eating plan.” • Obtain answers to questions about eating difficulties and the efficacy of vitamins, vitamin supplements and herbs. 	<ul style="list-style-type: none"> • Invite Guest Speaker(s) who can discuss nutrition, vitamins, and herbs.
Improving Relationships	<ul style="list-style-type: none"> • Discuss how breast cancer has changed their relationships. • Identify specific problems in relationships. • Develop problem-solving strategies for improving relationships. 	<ul style="list-style-type: none"> • Story-telling and discussion. • Invite a marriage and family therapist.
Pleasant Activities	<ul style="list-style-type: none"> • Share in a pleasant activity of the group’s choosing. • Expand awareness of activities that bring pleasure. • Make a commitment to explore new activities that may bring pleasure. 	<ul style="list-style-type: none"> • Visualize Exercise. • Discussion and story-telling.
Constructive thinking and problem-solving	<ul style="list-style-type: none"> • Develop a personal plan. 	<ul style="list-style-type: none"> • Discussion and story-telling. • Personal planning. • Invite breast cancer survivor to discuss how she has developed her skills in this arena (optional).
Planning for the Future	<ul style="list-style-type: none"> • Review coping strategies. • Develop a personal plan for coping. 	<ul style="list-style-type: none"> • Discussion and story-telling. • Personal planning. • Invite breast cancer survivor to discuss how she has developed her skills in this arena (optional).
<p>*NIH Grant No. R01 CA 64730, Breast Cancer in Young Women: A Population Based Approach. Principal Investigator: Joan R. Bloom, PhD.</p>		

APPENDIX B: Sample Budgets

SAMPLE PRE-PLANNING BUDGET: 6 MONTHS

I. EXPENSES**A. PERSONNEL**

1. Executive Director or other Staff (20%, 6 months)	\$6,500
2. Payroll expense and benefits	1,430
3. Subtotal Personnel	7,930

B. PROFESSIONAL FEES

1. Grant Writer (contracted)	2,000
2. Facilitator Training Stipends	600
3. Subtotal Professional Fees	2,600

C. OTHER EXPENSES

1. Telephone	100
2. Postage and Delivery	100
3. Printing and Duplication	150
4. Miscellaneous	120
5. Subtotal Other	470

D. TOTAL PRE-PLANNING EXPENSES \$11,000**II. INCOME**

A. CONTRIBUTED [planning or technical assistance grants]	8,500
B. IN-KIND (Support from Sponsoring Agency)	2,500
C. TOTAL INCOME	\$11,000

SAMPLE ONE-YEAR OPERATING BUDGET

I. PROJECTED EXPENSES**A. PROFESSIONAL FEES**

1. Two Co-Facilitators (10 hrs/wk @ \$30/hr)	\$31,200
2. Grantwriter	3,000
TOTAL PERSONNEL	\$34,200

B. OTHER EXPENSES

1. Printing and duplication (including brochures and flyers)	500
2. Postage	600
3. Travel and Parking (\$70/mo)	840
4. Group Expense (refreshments)	650
5. Books and subscriptions	250
6. Meeting Space	1,200
7. Insurance (Liability & Worker's Comp)	1,325
8. Office Supplies	480
9. Telephone	420
10. Miscellaneous Program Expense	500
11. Administrative Overhead (15%)	6,145
TOTAL OTHER EXPENSES	\$12,910

C. TOTAL PROJECTED EXPENSES: YEAR ONE **\$47,110**

II. PROJECTED INCOME**A. FOUNDATIONS**

1. ABC Foundation	5,000
2. XYZ Foundation	5,000
3. City/Regional Community Foundation	5,000
TOTAL FOUNDATIONS	\$15,000

B. CORPORATIONS

1. Area Hospitals (2)	5,000
2. Local Banks	7,500
TOTAL CORPORATIONS	\$12,500

C. COMMUNITY SUPPORT

1. Individual donations/ Special Events	15,000
2. Hispanic-owned and local small businesses	5,000
3. In-Kind donations (e.g., rent, refreshments, printing, etc.)	2,500
TOTAL COMMUNITY SUPPORT	\$22,500

D. TOTAL PROJECTED INCOME: YEAR ONE **\$49,000**

APPENDIX C: Role and Membership of the Advisory Committee

The advisory committee for the Spanish language cancer support program is a voluntary association of professionals from within the field of cancer, as well as members of the Latino, social services, business and religious communities. It is ideal if the committee can meet monthly for an hour and half while the program is in development. After the program is up and running, the committee can set a new schedule.

The committee's primary role is to assist the sponsoring agency with the following:

- Identifying donor prospects.
- Recruiting candidates for the positions of support group facilitators, as well as other advisory committee members.
- Conducting outreach in the community.
- Providing entrée to oncologists, radiologists, oncology social workers, etc., all of whom will be important sources of patient referrals to the support group.
- Serving as 'ambassadors' who help publicize the need for this program in the community and get the word out about the project.
- Assisting the facilitators with locating a venue for the support group and securing other donations such as food, furniture, books, etc.
- Ensuring that the project is culturally appropriate, sensitive, and accessible.

The advisory committee should include a diverse mix of people from the Latino, medical and business communities. The composition might include physicians who treat Latino cancer patients, religious leaders, representatives from local hospitals and cancer early detection programs, business women and men, social workers, Latino cancer patients, and media experts. The majority of these should be bilingual.

APPENDIX D: Sample Press Release

Agency Letterhead

FOR IMMEDIATE RELEASE

CONTACT: Name
Company
Address
Phone Number

"LAS ISABELAS", A CANCER SUPPORT GROUP FOR SPANISH SPEAKING WOMEN IN SANTA CLARA COUNTY, EXPANDS TO INCLUDE MORE LATINAS AND MORE RESOURCES

San Jose, Calif. (March X, 2000)—A diagnosis of breast cancer is frightening for any woman, but it is especially difficult for individuals who do not speak English or for whom English is their second language.

Breast cancer is the leading cause of cancer in all women in all ethnic and racial groups (except Laotian) in California. The Northern California Cancer Center anticipates that Santa Clara County will have more than a 1,000 new breast cancer cases this year, a county with a large population of Spanish-only speakers.

"This program is essential to strengthening community resources with the expertise and compassion that is needed in the area," explained _____, of Gardner Health Care Services, the sponsor and fiscal agent for Las Isabelas, a community based support group for Latinas who have breast cancer. "It takes time to sort through and process the emotional turmoil that comes with a diagnosis of breast cancer. Support groups help women talk about their concerns -for themselves, their families, and their future."

Las Isabelas, a support group developed by a coalition of Latina women and agencies, works closely with Gardner Family Health Care Corporation, Las Isabelas' fiscal agent and sponsor.

Las Isabelas has been meeting for two years, providing sensitive and appropriate psychosocial support, educational resources, comfort and guidance to Latinas diagnosed with breast cancer in Santa Clara County. Most support groups have a limit of 10 people in a group. Las Isabelas has seventeen and the number is rising.

The Northern California Cancer Center (NCCC), based in Union City, is working with Las Isabelas in the expansion of their program. Bilingual facilitators are being trained by NCCC to lead additional cancer support groups in Spanish. NCCC is also help Las Isabelas to develop financial resources for the project. Extensive community outreach to make one-on-one contacts in local hospitals and clinics with patients, social workers, oncologists, surgeons and radiologists is also part of the project. The support group sessions are held at Gardner Health Care Center on East Virginia Street, San Jose.

The Northern California Cancer Center also operates the Cancer Information Service of California (1.800.4.CANCER), a bilingual (Spanish/English) program which provides information about cancer sites, side effects, resources and clinical trials. The CIS offers free written materials in Spanish and English, as well. The Cancer Information Service is an important resource for Las Isabelas participants.

A community-based Advisory Committee serves as the managing and oversight committee for Las Isabelas. Additional members for the Advisory Committee are being sought among local business and philanthropic communities.

This partnership is currently seeking community and corporate help to meet its goal of offering permanent cancer support services including free support groups, counseling, and education.

The Advisory Committee is working to raise \$40,000 from local businesses and residents. Donations to the project can be mailed to _____ .

Many Latinas avoid early detection and screening because they believe they will not find the acceptance and support they need if the diagnosis is positive. To increase trust and to reduce the mortality rate, Latinas must have greater access to information—in Spanish—about cancer, how it progresses, and its treatment. Culturally sensitive psychosocial and educational support must be available to help patients and their families understand the disease and treatment options, as well as to offer compassion, companionship, guidance, and support. Numerous studies show the enormous benefits of on-going support groups for women with cancer. These benefits include increased longevity, greater understanding of the patient’s diagnosis, treatment options and compliance with treatment, as well as better communication with physicians. But groups in Spanish in areas where there are large Latino communities have been generally unavailable.

Gardner Health Care Corporation was established in ____, to _____

_____.

Founded in 1974, the Northern California Cancer Center's mission is to reduce the burden of cancer by determining who gets cancer and why, how best to find and treat it, and how to enhance the patient’s quality of life. NCCC is nationally recognized for its work in community-based research and education, with a special emphasis on medically underserved people and communities of color. NCCC operates the Bay Area Cancer Registry for nine counties, the Family Registry for Breast Cancer, the Cancer Information Service (1.800.4.CANCER) for all of California, and the Breast Cancer Early Detection Program information service (831.769.8680).

For more information on NCCC visit its web site: www.nccc.org.

APPENDIX E: Sample Job Descriptions

The following job descriptions can serve as blueprints for the sponsoring agency and can be easily modified to accommodate the agency's employment policies. The descriptions will also be useful for defining the facilitators' scope of work if they are being hired on a contracted basis.

JOB DESCRIPTION: SUPPORT GROUP CLINICAL FACILITATOR

NATURE OF THE WORK

Under the supervision of the [Sponsoring Agency Program Supervisor], this position will be responsible for the development and facilitation of a Spanish language cancer support group for Latina cancer patients and will perform both clinical and outreach functions related to providing psychosocial support for this population. The Support Group Facilitator will work closely with a co-facilitator to develop educational presentations on breast cancer for community centers, senior centers, church groups, etc., and will develop and implement in concert with the lay co-facilitator a comprehensive outreach plan.

EXAMPLE OF DUTIES

- Coordinates outreach plan.
- Develops relationships with oncology and other social workers in area hospitals and neighborhood health centers and clinics.
- Co-facilitates biweekly cancer support group in Spanish for Latinas with cancer.
- Responsible for client intakes and assessments.
- Conducts crisis and/or individual counseling for group members as needed.
- Makes home and hospital visits.
- Makes client referrals to appropriate agencies such as mental health, social services, etc.
- Conducts phone follow-up for group members who miss a session due to illness.
- Works with host agency and co-facilitator to promote the group in the community and media; helps prepare public service announcements and other materials.
- Supervises lay co-facilitator.
- Develops with co-facilitator a simple internal resource guide for phone referrals.
- Completes all necessary documentation of group meetings, intakes and assessments.
- Works with the project advisory committee to promote the program and help identify potential donors for the program.
- Meets periodically with advisory committee.
- Represents host agency in professional community affairs.
- Develops a confidentiality policy for support group members if one does not already exist.

MINIMUM QUALIFICATIONS

1. Masters Degree in clinical psychology or social work.
2. Preferably licensed: MFC, LCSW, PhD, or PsyD If not licensed, clinical experience in psychology and demonstrable experience facilitating groups. (If licensed, must have insurance.)
3. Knowledge and/or experience with cancer patients.
4. Must be bilingual (Spanish/English) and bicultural.
5. Cancer survivor preferred.
6. Must be comfortable working with people of different socioeconomic backgrounds and religious beliefs.
7. Must have excellent listening skills.

KNOWLEDGE, ABILITIES AND SKILLS

- Knowledge of cancer-related issues including treatment, death and dying issues.
- Knowledge of body image and sexuality, etc.
- Knowledge of local mental health, cancer resources and social services.
- Knowledge of Latino community interdependence.
- Comfortable working in a team.
- Respect for Latino culture and spiritual diversity.
- Comfortable talking about spiritual/existential issues.
- Understanding of Latino family-centered approach to crisis.

JOB DESCRIPTION: SUPPORT GROUP CO-FACILITATOR/OUTREACH WORKER

NATURE OF THE WORK

Under the supervision of the [Sponsoring Agency Program Supervisor], this position will be responsible for community outreach for the program and will serve as the support group co-facilitator. The Co-Facilitator, working closely with the Clinical Group Facilitator, will make home and hospital visits for current and prospective support group members. She will also develop and conduct periodic educational presentations on breast cancer for community centers, senior centers, church groups, health fairs, etc.

EXAMPLE OF DUTIES

- With the Clinical Group Facilitator, develops ongoing relationships with oncology and other local social workers.
- Conducts outreach for the program, including individual mailings to agencies, hospitals, clinics, cancer resource agencies, social workers, oncologists, radiologists and patients.
- Works with sponsoring agency and Clinical Group Facilitator to promote the group in the community and media; helps prepare public service announcements and other materials.
- Makes home and hospital visits and telephone referrals.
- Helps group members problem-solve around basic issues such as transportation to and from the treatment and doctors' offices, etc.
- Conducts intakes and assessments under supervision of the Clinical Group Facilitator.
- Assists Clinical Group Facilitator with client phone follow-up and group documentation.
- Makes presentations on breast cancer and the role of psychosocial support to the public at community centers, health fairs, churches, etc.
- Serves as liaison with other Spanish language cancer support groups in the area.
- Develops an internal resource list for phone referrals.
- Meets periodically with advisory committee.

(continued on next page)

MINIMUM QUALIFICATIONS:

1. Two years college education, preferably in health or social sciences.
2. Two years of verifiable experience working with a culturally diverse population providing health education, intake and/or referral services or participating in health promotion and health education activities.
3. Knowledge of the cancer field.
4. Must have excellent listening skills.
5. Must be bilingual, bicultural.

KNOWLEDGE, ABILITIES AND SKILLS

- Knowledge of local mental health, cancer resources and social services.
- Respect for Latino culture and spiritual diversity; must be comfortable talking about spiritual/existential issues.
- Comfortable working in a team.
- Understanding of Latino family-centered approach to crisis.
- Knowledge of Latino community interdependence.
- Ability to listen without offering advice.

APPENDIX F: Sample Monthly Reporting Form

The report form that follows assumes the group is meeting biweekly. The form is filed monthly with the facilitators' supervisor and covers two meetings each month.

CONFIDENTIAL DOCUMENT

Monthly Group Progress Report

Group: _____

Facilitator/s: _____

Report Month: _____

Meeting Date: _____

Group Members	Individual Issues/Notes
Major Group Issues	

APPENDIX G: Sample Patient Intake and Referral Form

The Intake Form should be used by the facilitators each time they speak with a patient by phone or in person. This not only helps the facilitators assess the patient's needs, but also serves as an accurate record of how many women are using the service, even if they never join the group.

CONFIDENTIAL DOCUMENT

Telephone Intake and Referral

Date _____

Name _____

Address _____ City _____ Zip _____

Age _____ Ethnicity _____ Phone _____

Reason for calling _____

Type of cancer, date of diagnosis, treatment history _____

Current treatment _____

Support System/Family _____

Name of Doctor and Hospital _____

Referred by _____

Other important information _____

Plan and disposition _____

Referral to other services _____

Income level

- Under \$20,000 20,000-40,000 Above \$40,000

This intake form completed by _____

To the reader of this guide...

COMMENTS AND FEEDBACK

We value your input and hope you will take a few minutes to let us know if this Guide was of use to you and/or your organization.

Was it helpful? _____

Was it easy to use? _____

Are there additional resources/references that you can recommend? _____

Additional remarks? _____

Your name (optional): _____

Agency/Organization: _____

Address: _____

Phone/Fax/e-mail: _____

Please return to:

Community Education
Northern California Cancer Center
32960 Alvarado-Niles Rd., Suite 600
Union City, CA 94587
Tel: (510) 429.2500
Fax: (510) 429.2550
E-Mail: education@nccc.org

FOR ADDITIONAL COMMENTS AND FEEDBACK

Community Education
Northern California Cancer Center
32960 Alvarado-Niles Rd., Suite 600
Union City, CA 94587



For More Information

NCCC is a nationally recognized leader in community-based cancer research and education. NCCC studies cancer causes, trends, prevention, detection, quality of life and survival.

For more information about NCCC or to make a contribution:

NORTHERN CALIFORNIA CANCER CENTER

32960 Alvarado-Niles Road, Suite 600

Union City, California 94587

Tel: 510.429.2500

Fax: 510.429.2550

www.nccc.org

For information about cancer treatment, resources and publications:

CANCER INFORMATION SERVICE

(in English and Spanish)

1.800.4.CANCER