

ESTABLISHING A BC METS SUPPORT GROUP – OPTION #1

GOAL: *Establish a metastatic breast cancer support group and meet regularly.*

OPTION #1: *Entirely Independent, Easy, Almost No Cost*

1. **STEP #1: Advertise (a flyer is your only cost for this easy-to-build support group)**
 - a. Build a Flyer: State you have metastatic breast cancer (BC mets) and wish to meet with others with the same diagnosis. Give a contact phone number and email address. Keep flyer gender free. Remember: Almost 500 men die annually of metastatic breast cancer. They are out there and need help too.
 - i. Use keywords such as “advanced”, “metastatic”, “stage IV to attract the right group. Be aware that some people classify stage III breast cancer as “advanced” breast cancer so query responders as to location of spread to ensure they are stage IV.
 - b. Distribute Flyers: Hand fliers to personal doctors, support person at breast cancer organizations, centers for oncology, chemo nurses, breast surgeons, physical therapists, social workers, etc. FIRST ask permission, preferably in person, and attach a cover letter for the staff explaining what you are trying to do.
 - c. Word of Mouth: Tell friends, neighbors, and everyone you meet about your project. When people ask: “How are you?” Answer: “Very busy trying to establish a support group.” Voila ... subject opened!
 - d. Some metastatic patients visit their oncology center only once a month, so be patient waiting for responses.
2. **STEP #2: Strike While the Iron is Hot**
 - a. Meet as Soon as Possible: Once you have one or two persons respond, discover where each person lives and what days/times are convenient. Exchange phone numbers and e-mail addresses. Follow up.
 - b. Keep it Simple: Meet at a coffee shop, bookstore, a city park or other location where you can simply show up ... and leave if you have a no show. Give people at least 30 minutes grace time.
 - i. If you prefer an office atmosphere, try hospitals and businesses with meeting rooms. Libraries, realties, mortgage companies, economic development offices, etc. offer rooms gratis to local groups -- or ask your local American Cancer Society for ideas.
 - c. Chat: Compare notes on the disease, treatments tried, facilities visited, handling side effects, etc. Get to know each other on a personal basis as well - family, work, etc. Take a group photo!
 - d. Spread the Word: Give attendees extra fliers. Encourage them to inform others.
 - e. Solidify Contact: Email everyone. Attach photo if you took one. Thank them for coming. Remind them of next meeting and getting the word out.
 - f. Formalize: At second meeting, ask everyone to fill out a contact form with name, email and home address, home and cell phone numbers, birthday (to send cards), whether or not they have young children at home, husband’s name and best days/times to meet. Get their permission to share list within the group – remind everyone that the list goes no further. **IMPORTANT: Never divulge personal information outside the group.**
3. **STEP #3: Setting Meeting Times.** Determine how often and where to meet. Consider everyone’s schedule. If advisable, rotate location, meeting time and day of the week, to accommodate your members. Publish a schedule. Send email reminders prior to meetings.

CONGRATULATIONS -- You now have a support group !!

You can stop here or scroll down to the section entitled “POSSIBLE ADD-ONS”

ESTABLISHING A BC METS SUPPORT GROUP – OPTION #2

GOAL: Establish a metastatic breast cancer support group and meet regularly.

***OPTION #2: Set Up a Support Program in Conjunction with a Local Support Facility
-- A Bit More Start Up Prep BUT Some Important Advantages to Consider --***

1. STEP #1: Weigh Advantages/Disadvantages of Operating Under Someone Else's Umbrella.

- a. Carefully consider your options and do what seems best for you. Keep your options open. Don't sign an agreement that might preclude a change if you decide things are not working.
- b. Pros: An organizational umbrella can open many doors. It gives you immediate legitimacy in the community. The organization will help spread the word, offer a meeting place, perhaps give you a desk, email account, phone line/free advertising and/or financial advice or assistance, free photocopying, free mail service, etc. If you collect donations for your group and your umbrella agency is a 501 (c) (3) charitable organization, your donors' gifts are tax deductible. This really helps with donations of goods and money.
- c. Cons: Anything you do could impact the organization's reputation, thus they will likely have guidelines you are to follow. They may oversee your media contact, review, approve/disapprove verbiage on flyers and business cards, require that their logo appears on your printed matter, etc. And they may consider the program theirs and make decisions that impact your group without consulting you. The relationship should be clarified to the extent possible prior to committing.

IF YOU CHOOSE TO WORK WITH A LOCAL FACILITY, GO TO STEP #2. OTHERWISE, RETURN TO OPTION #1.

2. STEP #2: Select Your Target Organization.

- a. Possible Partners: Oncology and therapy centers, medical facilities, universities, etc. Determine who in your area is most likely to lend support, who is good to work with and where you have contacts.
- b. Make an Appointment with the Appropriate Person. This is not always the decision-maker; it might be an approachable person who has influence with the decision-maker.
- c. Prepare: Go with your key points ready. Take a one-page paper (bullet points preferred) describing the what gap in the local area you are trying to fill, how you wish to fill the gap, what assistance you wish the organization to provide, and what benefit the organization will derive. (Normally this is increased positive publicity in the local area.) Be sure your contact information is on your paper.
 - i. Include information on what, if any, non-medical support exists locally for BC mets and how many are diagnosed annually in your area. (Ask your oncologist for estimates ... or revert to the national 2008 figures: 49,000 newly diagnosed and 41,000 deaths every year.
- b. Presentation: Verbally explain what you wish to do. Hand over your paper. Ask if there are other people (or if there is a Board) to whom you should present your plan. If you have the opportunity to present to a Board, do it! This help makes you and your program known.

3. **STEP #3: PROCEED WITH ALL STEPS FROM "OPTION #1", BUT TAKE FULL ADVANTAGE OF THE BENEFITS OFFERED BY YOUR LOCAL FACILITY.** Use their copier, ask them to help spread the word, ask their assistance in arranging media coverage, use their office email account and phone line if offered, use their facilities for storage and for meetings if possible ... especially for formal programs, workshops, etc., if you do those.

**CONGRATULATIONS -- You now have a support group !!
You can stop here or scroll down to the section entitled "POSSIBLE ADD-ONS"**

POSSIBLE ADD-ONS

IMPORTANT NOTE: If you've gotten this far, you have already created a very viable, helpful, important support group. If you wish to do more, we offer the ideas below. Remember, the more you do, the more time and energy it takes. Be careful not to take on more than you can handle and be sure you have help and people who can fill when needed.

1. **Spouses/Significant Others.** Invite partners to periodic get-togethers and/or parties. It is good for them to be involved and meet other partners. They may or may not decide to organize a partners' group. Leave the decision and the work up to them.
2. **Plan special events**
 - a. Send birthday cards. If possible give a small gift donated by craft guilds, local merchants, kind persons, others.
 - b. During the holidays and other special occasions have a party. If at a home, keep it simple. Try a potluck or progressive dinner party. If you do gifts, keep it simple and inexpensive -- white elephants or homemade gifts.
3. **Make Yourself Known Locally and Elsewhere.**
 - a. Locally: Re-contact all local agencies where you left initial fliers. Update fliers – you can do this simply by making labels and sticking them on the existing fliers. Pass information on your group to the local chapter of the American Cancer Society (ACS) and other local cancer referral services. Every community has its own way of advertising local support programs. Explore your own community and take advantage of available options.
 - b. Nationally: Pass information on your group to www.mbcnetwork.org and www.metavivor.org. If we are contacted by persons looking for a support program, we will pass along your information.
 - c. Online Groups: If you belong to any online groups such as Team Inspire or Facebook, mention your program. Post info on your group on www.bcmets.org and www.advancedbreastcancercommunity.com. Check www.advancedbc.org for a list of all message boards for metastatic breast cancer.
 - d. Conferences: Attend relevant conferences and mention your group. Encourage others to start their own groups.
4. **Involve Others.** To ensure the longevity of your program, don't be dependent upon one person.
 - a. Solicit Support Group Help: Most of your members will likely only attend functions and not become further involved; however, some will want to help. Encourage the latter to participate. Possible tasks: Getting the word out; keeping fliers updated and distributed; consolidating information on treatment facilities, doctors, social workers, clinical trials, and other support options; scheduling meetings; planning group parties; keeping in touch with housebound members and/or helping them with meals, transportation, etc. The more people become involved, the more they will identify with the group. And having different people take charge of various activities and/or responsibilities will not only reduce the work load on the lead individual, but it will also bring new ideas to the program and help it grow and thrive.
 - b. Other Volunteers: Friends, family and others might volunteer to help. Let them. Have a growing number of volunteers? Pick a lead volunteer to organize assistance. Possible help for individual members: Driving members to appointments and meetings, running errands for them when they are unable to do so themselves, fixing meals. Possible help with program: Arranging speaking opportunities with local clubs like Rotary and Kiwanis, helping with advertising, keeping files organized, arranging meeting rooms, planning parties, soliciting/providing items, including birthday gifts, for members.

5. **Phone Line:** If finances allow, consider getting a separate phone line or a cell phone to use strictly for your support program. This ensures that you receive every call and that every message left on the answering machine is retrieve by you.
6. **Collect/distribute information and items to your members**
 - a. Collect and share information on drugs, research, local support options, cancer facilities, trials, advocacy organizations (www.MBCNetwork.org, www.lbcc.org, www.breastcancer.org, etc). Include website addresses and other contact information for these groups. Several have hotlines, although these are not always manned by someone with a working knowledge of BC mets.
 - b. Obtain multiple copies of free pamphlets, booklets, brochures, etc. from organizations such as www.lbcc.org and www.cancercare.org and pass copies to each member. Encourage people to sign up for their own magazine subscriptions (i.e. CURE), newsletters (i.e. LBCC's Insights), etc.
 - c. Ask local merchants to donate items for members such as blank journals, photo albums, small books, etc. Ask scrap booking groups to donate supplies and host scrap booking workshops to create "legacy books". These events are also a great way to learn more about each other.
 - d. Ask local crafters to make and donate scarves, throws, or other items for members.
 - e. Give each new member a tote bag filled with information and donated items.
7. **Give your group an identity**
 - a. Create a name and logo and use it on group literature, tote bags, stationary, etc.
 - b. Get business cards – everyone asks for these. They are quick and easy advertising for your group and are helpful when soliciting donations, assistance, etc. .
 - c. Give members tote bags with your logo that are filled with information and donated items.
8. **Invite Guest Speakers.** Contact oncologists, social workers, surgeons, naturopaths, metastasis researchers, directors of clinical trials, etc. and ask them to speak to your group. Clarify that speakers are not paid or reimbursed for expenses. Ask hospitals, local businesses, etc., for gratis use of a meeting room for these events.
9. **Support Metastatic Breast Cancer Research.** Research focused on BC mets is paltry at best. National funds and most breast cancer organizations focus on early detection and prevention of recurrence. Far more funding is needed for research that specifically targets metastatic breast cancer. Initiate a fundraising campaign to support research that is endeavoring to transition BC mets from a terminal illness to a controlled, true chronic disease.

Please feel free to contact us at any time with questions. Email cj77@comcast.net or call "CJ" at 410-263-3340.

Keep us informed of groups you start, how the groups evolve, and new ideas that YOU implement. Feedback on the usefulness of our tutorial as well as suggestions for improvement would be greatly appreciated.

Make YOUR program your own and do whatever works for YOU.
