



TISSUE BANK AT THE
IU SIMON CANCER CENTER

SUSAN G. KOMEN® TISSUE BANK AT THE IU SIMON CANCER CENTER MINORITY DONOR RECRUITMENT MANUAL

The Komen Tissue Bank (KTB) is the only repository in the world for normal breast tissue and matched serum, plasma and DNA. By studying normal tissue, we accelerate research for the causes and prevention of breast cancer. To more deeply understand the evolution of the disease, it is necessary to compare abnormal, cancerous tissue against normal, healthy tissue. The KTB staff appreciates your support as our community partner in the collection of healthy breast tissue. This document is intended to be used as a resource when recruiting women from diverse populations to donate healthy breast tissue to the Komen Tissue Bank.

This manual includes information to help you plan a successful recruitment event for your area. You will find information on:

1. How breast cancer affects women of different races and ethnicities
2. Identifying cultural beliefs that may affect participation by women of color
3. Community Partner Involvement
 - a. The Need for Tissue Donations from Women of Color
 - b. Organizing a Minority Recruitment Team
 - c. Cultivating Community Partners
 - d. Developing a Communications Plan
4. Effective Recruitment Strategies
5. Komen Tissue Bank staff and support

HOW BREAST CANCER AFFECTS WOMEN OF DIFFERENT RACES AND ETHNICITIES

Some facts about how breast cancer affects minorities (*Source: <http://ww5.komen.org>*)

- **Breast cancer is the most common cancer among African-American women.** They develop breast cancer at a younger age. Breast cancers in African American women are more likely to be Triple Negative (Cancer test shows Negative results for Estrogen Reception, Progesterone Reception and HER-2). In 2011 (most recent data available), the breast cancer mortality was 44% higher among African American women than in white women. Controlling for grade and stage of tumor, native African women have higher percentages of Triple Negative Breast Cancer than White- or African-Americans.
- An estimated 17,100 cases of breast cancer were diagnosed in U.S. **Hispanic women** in 2012, with more than 2,400 deaths, making breast cancer the leading cause of cancer death among Latina women in the U.S. Breast cancer in Latinas is more often diagnosed at a later stage (when the disease is more advanced) than when found in non-Hispanic women.
- Breast cancer is the 2nd leading cause of death among Asian American and Pacific Islander women. Breast cancer is the most common cancer in **Korean, Chinese, Filipino and Japanese women** in the U.S. **Among Asian American and Pacific Islander women, Native Hawaiian and Japanese women** have the highest rates of breast cancer. **Native Hawaiian and Samoan women** have the highest rates of breast cancer death, exceeding even rates among African American and white women.

IDENTIFYING CULTURAL BELIEFS THAT MAY AFFECT PARTICIPATION BY WOMEN OF COLOR

Cultural beliefs, norms, and attitudes held by racial/ethnic and disadvantaged groups may affect their decision to donate tissue

- It is important to work with leaders from racial/ethnic groups to identify strategies to successfully increase the interest and participation of women of color.
- There are several documented research studies in history that were conducted unethically and negatively impacted trust in research participation. Today, some people are not aware of the protections that have been put into place. Familiarize yourself with this barrier to develop appropriate messages to reach women of color.

(Sources: <http://iccnetwork.org>; <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2702151/>)

COMMUNITY PARTNER INVOLVEMENT

The Need for Participation by Women of Color

Today, people everywhere benefit from research-based discoveries. In fact, more than 10 million cancer survivors are alive today because of the remarkable advances made through cancer research. Since breast cancer affects minority women differently, it's particularly important to offer them opportunities to participate in research. Without adequate representation of racial/ethnic groups, researchers cannot be certain that advances will be beneficial to them.

Organizing a Minority Recruitment Team

Set up a diverse minority recruitment team (suggested minimum of 8 people – mix and match from these categories) Work with this group to determine your approach to the community, how to promote the tissue bank event and to identify outreach strategies.

- Representative from the affiliate/event partner
- Key spokespeople: health professionals, survivors
- Representatives from community partner organizations: Hospitals, breast related organizations
- Leaders from target groups: Faith based organizations, organizations serving minority groups
- Media representative(s)

Cultivating Community Partners

Work with this team to identify community partners that can assist in reaching out to potential tissue donors and volunteers. Create a list of minority-owned, operated, or serving groups in the area of the event location, such as churches and /or service organizations that predominately serve minority populations, minority focused academic groups, affinity groups at universities, sororities and fraternities.

Suggested opportunities for involvement include:

- Distributing literature about the Komen Tissue Bank
- Posting event details in their newsletters or to their websites
- Representing their organization on the KTB Event steering committee
- Setting up opportunities drive women to sign up on the Interested Donor List on the KTB website
- Participating in ongoing communications or about the KTB project

COMMUNITY PARTNER INVOLVEMENT (CONT.)

Identify members from the community who could serve as spokespersons for the event. Using KTB materials, develop talking points for potential spokespersons. Let them know that they may be able to see the event before it comes to your area. This will most likely necessitate travel to Indianapolis or another city where an event is scheduled.

- Contact, engage, and confirm 2-3 Spokespeople/public activators
- Ideas – prominent female athletes, or wives of prominent athletes, female mayors or mayors wife, television personality/news anchors, radio personalities, minority female company presidents or CEOs , survivors, faith-based leaders as well known minority community leaders
- Oncologists, physicians, who are familiar with the KTB event, or research
- Try to use people who look like those you want to recruit

DEVELOPING A COMMUNICATIONS PLAN

Any communications materials not supplied by the KTB must be submitted to the KTB for IRB approval (PSA’s, brochures, PowerPoint presentations, fliers, postcards, posters.) **FOR CLARITY, PLEASE NOTE – ABSOLUTELY ALL RECRUITMENT MATERIALS MUST EITHER BE ISSUED BY THE KOMEN TISSUE BANK, OR MUST FIRST BE SUBMITTED TO US FOR IRB APPROVAL BEFORE USE.** This approval can often take a month or more, so an early start is especially important if you intend to devise a flyer or handout to promote the tissue collection. Be sure to share materials with the host site and local Komen office as well.

1. Create a minority recruitment timeline
 - a. Adjust the timetable to fit parameters of your local activities
 - b. Start recruitment efforts early – if possible, at least 12 months ahead of the scheduled tissue collection event date.
 - c. SUGGESTED TIMELINE:

# of months before collection event	To Do
12 months – 9 months	<ul style="list-style-type: none"> • Begin monthly conference calls with the KTB. • Meet with your local Komen Office to discuss the KTB event • Identify and reach out individuals to serve on the Minority recruitment team. • Determine when the Minority Recruitment Team will meet
6 months – 9 months	<ul style="list-style-type: none"> • Schedule speaking engagements for this period (churches, sorority meetings, etc.) • Work to set up groups and identify group leaders who will be your contacts. • Consider planning at least one community awareness event to educate the community about tissue donation • Make contact with minority-focused media (newspaper & radio) to inform and ask for an interview. • Continue to contact large business; ask about the existence of any minority-focused affinity groups to distribute event recruitment materials • Monthly conference calls with the KTB. • Monthly meetings with the Minority Recruitment Team
3 months – 6 months	<ul style="list-style-type: none"> • Schedule speaking engagements for this period. • Distribute KTB Donor recruitment materials to community partners • Fine-tune or replication community awareness event • Monthly calls with the KTB • Monthly meetings with the Minority Recruitment Team

<p>6 weeks – 3 months</p>	<ul style="list-style-type: none"> • Identify Key Spokespeople: 2 – 3 high profile minority spokespeople (athletes, news anchors, business leaders, etc.) and ask for commitment. Make calls to local large minority churches and other establishment to try to arrange presentations. • Look for schools and universities which target minority communities. • Distribute brochures and posters to churches, community centers, clinics • Reach out to minority-focused media (newspaper & radio) to ask for support • Contact group leaders with written instructions (including info as to how to have their members register) • Monthly calls with the KTB • Monthly meetings with the Minority Recruitment Team
	<p>Recruitment needs to be completed when registration opens, 6 weeks prior to collection date</p>
<p>2-4 weeks</p>	<ul style="list-style-type: none"> • Schedule speaking engagements, radio announcements, print articles, social media promotions • Continue to secure volunteers • Ask all Minority Recruitment Team Members to register/volunteer • Monthly calls with the KTB • Monthly meetings with the Minority Recruitment Team

2. Start working ASAP to schedule speaking / recruitment engagements
 - a. All speaking engagements are best placed between 3 months and 6 months prior to the collection date.
 - b. All speakers should have some KTB knowledge training beforehand so that they have familiarity with their topic. Please communicate with the KTB about how to make this happen.
3. Engage Media support
 - a. Identify local mass and minority media outlets – print, television, and radio.
 - b. Contact television stations and newspapers. Work to arrange an interview.
 - c. Contact local radio talk shows – these are often looking for interesting area happenings.
 - d. Provide media outlets with materials and press releases. Inquire about PSAs.

EFFECTIVE RECRUITMENT STRATEGIES

- Use KTB materials to educate your Minority Recruitment Team and community
- Work with your team to help you reach your donation goals
- Make a list of community events in which your team may be able to promote the KTB event
- Drive volunteers and potential donors to the KTB website as soon as recruitment codes are provided
- Involve breast cancer survivors on your Minority Recruitment Team
- Work closely with your local Komen Chapter and host site
- Plan a community awareness event and invite media to attend
- Develop a church packet explaining KTB and ways in which churches can assist in recruitment
- Involve student groups in the dissemination of information and volunteer recruitment
- Identify an activity in which all Minority Recruitment Team Leaders can participate (appearance on a local morning show)

Each city and state is different in regards to where minority population concentrations can be found, and which groups or organizations are present. Look to your Minority recruitment team to identify groups who could help reach recruitment goals. It is always best to have guided information from those who live locally, in the city where the event will be held, however, here are some general suggestions which may help in the effort to initiate contact.

- For African Americans, identify: sororities (Alpha Kappa Alpha, Delta Sigma Theta, Sigma Gamma Rho, and Zeta Phi Beta); mothers' groups, Jack & Jill, Links, other national organizations, major churches.
- For Asians, look for: partner with Filipino nurses group, Chinese school, university groups, employer affinity groups, festival organizers, Asian student organizations.
- For Hispanics, partner with: churches, festival organizers (identify as spokespeople), Hispanic student organizations, schools.
- For Native Americans, identify: national tribal organizations, First Nations, local reservations, and community groups.

KOMEN TISSUE BANK RESOURCES AND SUPPORT

Become very familiar with the KTB website, and review promotional materials to learn about the KTB and the process. Below is a list of items to assist you in familiarizing yourself and, your outreach team and the community about the Komen Tissue Bank and determine which materials you will use. All are accessible on KTB website www.komentissuebank.iu.edu:

- What's It Like video
- Why Should I Donate?
- KTB Power Point Presentation
- How to sign up, including the eligibility criteria and exclusions

The KTB staff will be responsible for:

- Coordinating with the host site
- Scheduling planning calls with the Minority Recruitment Team
- Providing promotion and recruitment materials
- Facilitating volunteer orientation sessions
- Event day logistics

KTB STAFF & RESOURCES:

Komen Tissue Bank staff contacts:

Kathi Ridley-Merriweather, keridley@iupui.edu, 317-274-2366

Amy Trullinger, ajtrull@iupui.edu, 317-274-4051

Komen Tissue Bank Resources:

KTB Brochures (contact the KTB to arrange to receive these)

KTB Videos – Why Should I Donate? What's it like? Asian video, Hispanic Video

All accessible on KTB website www.komentissuebank.iu.edu

KTB PowerPoint presentation (contact the KTB to discuss this)

Susan G. Komen® affiliates can look to their grantees as a resource – us grantees as a way to connect with / access minority groups and communities.