



Saudi Arabia

**Susan G. Komen/BHGI Assessment Visit:
SCS Breast Cancer Early Detection Program**
Chairman and Director, Breast Health Global Initiative (BHGI)
Fred Hutchinson Cancer Research Center
Director, Breast Health Clinic, Seattle Cancer Care Alliance
Professor of Surgery, University of Washington School of Medicine

Riyadh, Saudi Arabia
October 21-22, 2009

PROGRAM GOAL

To facilitate and support the visit of U.S. expert to provide advice and consult towards the development of a breast cancer early detection program in Saudi Arabia.

Executive Summary

In response to a request from the Saudi Cancer Society, Dr. Ben Anderson, a breast surgeon and Director of the Breast Health Global Initiative (BHGI), accompanied US-Middle East Partnership representative Chris McKallagat (ICF International) to Riyadh to provide a clinical assessment of existing services and systems and provide recommendations towards the development of a national breast cancer early detection program. Dr. Anderson was hosted by Saudi partners King Fahad Medical City (KFMC) and the Saudi Cancer Society (SCS). The assessment visit included a visit to KFMC tertiary care facilities related to the treatment of breast cancer, a meeting with the directors of oncology at the major Riyadh cancer referral hospitals, and a tour of the Abullatif Cancer Screening Center.

The visit demonstrated that KFMC is well equipped with high quality equipment in a beautiful, large and modern facility that would be the envy of any major city around the world. Despite the center's size and impressive equipment furnishing, the breast imaging equipment is notably underutilized for the population served and number of patients seen in the center. While the brief visit did not permit time to perform a complete analysis of patient characteristics, beliefs or of patient flow, observations suggest that major obstacles exist to breast cancer early detection in this population. Patients come to KFMC with advanced stage disease while no outreach programs directed from the center currently exist to change this pattern. Contributing to late-stage presentation of breast cancer patients are social and cultural beliefs among Saudi women as well as the lack of patient triage protocol to draw in women with early stage or clinically occult disease from the Riyadh community. Formal protocols linking early detection to breast cancer diagnosis are largely not employed in an organized, institution-wide program.

Treating physicians at KFMC spoke about the need to better establish the referral and diagnosis system in Riyadh. There appears to be a dichotomy between high levels of resource investment for equipment with relatively little investment in human resource allocation to educate women about breast cancer early detection and implement patient triage protocols. In particular, it was

noted that breast cancer screening was provided externally by an NGO, the Saudi Cancer Society, and was not integrated within KFMC itself. A referral network for diagnostic work-up of breast abnormalities is ill-defined at present. It was speculated that the current system would not provide a sustainable framework for managing breast cancer patients as new cancer cases are increasingly diagnosed based upon public education emphasizing the value of early detection.

These observations were discussed during the meeting among leaders from the major oncology centers in Riyadh. It was concluded that a significant need exists to improve coordination across centers and design strategies for achieving mutual goals to reduce the impact of breast cancer and building high-achieving cancer centers. It was suggested that the major centers develop a collaborative plan for coordination in managing breast cancer early detection and treatment. A follow-up meeting has been proposed among leaders at KFMC/SCS potentially to include other stakeholders in Riyadh in March 2010 at the time of Dr. Anderson's next visit to the region.

ICF's role on behalf of the Partnership was to provide introductions for Dr. Anderson and help gather information and shepherd additional meetings necessary to meet the goals of the visit. The following is a summary of the assessment visit and outcomes:

Wednesday, October 21, 2009

Event: Tour of King Fahad Medical City (KFMC)

Duration: 09:30-11:00 a.m.

Presenters: Department Heads: Prince Sultan Hematology/Oncology Center (Dr. Abdulaziz Al Humaidi), Lab, Radiology (Dr. Sven Anderson), Pharmacy, Rehabilitation

Because Dr. Abdullah Al Amro (CEO, KFMC) was out of the country, the overall assessment visit and meetings at KFMC were hosted by Dr. Abdulaziz Al Humaidi, Director of the Prince Sultan Hematology/Oncology Center at KFMC and a member of the board of the Saudi Cancer Society. Dr. Humaidi greeted Dr. Anderson formally in the VIP visitors' room and spent time discussing KFMC's overarching mission and structure – 4 hospitals and 4 specialty treatment centers, 1.5 Billion Riyals annual budget, focus on tertiary care.

Additional points:

- KFMC services are provided free of charge to Saudi nationals, KFMC workers, MOH employees who carry MOH insurance per their contract, and non-Saudis by royal order. However, patients entering the system must have received a referral for care and unable to self-refer for evaluation.
- The majority of breast cancer cases are detected at advanced stages (III/IV); early stage (I/II) cancers are uncommonly diagnosed.
 - Cultural beliefs can create significant obstacles to standard breast evaluation and diagnosis, especially in the setting where treating physicians or surgeons are male. It is considered socially unacceptable for male physicians to perform a standard clinical breast examination (CBE) of women with breast pathology. A standard CBE necessarily includes direct visualization of both

breasts with the patient in an upright position, palpation of axillary lymph nodes and direct palpation of both breasts without gloves. CBE is fundamental to breast cancer early detection and diagnosis; omission of CBE can be predicted to markedly hamper proper breast evaluation, even if screening mammography is available.

- Cultural beliefs can further make psychosocial aspects of patient care difficult to address. It is shameful to discuss marital/sexual problems with a stranger and there is no culture of therapy or psychiatry. Dr. Anderson noted that breast cancer has an emotional and spiritual impact on the patient that must be addressed, since these factors have been noted in essentially all cultures to cause women to conceal disease until it is so advanced that seeking care is unavoidable. Founder of Susan G. Komen for the Cure, Ambassador Nancy Brinker, observes, “You can’t fight a disease you can’t talk about.”
- Breast cancer cases are primarily managed by breast surgeons. The average patient undergoing surgery will spend 3 inpatient days recuperating from breast surgery. This stands in contrast to breast cancer surgery provided in the United States where patients typically are discharged home on the same-day or with a single overnight admission less than 24 hours.
- There are 24 beds open to breast cancer patients, attended by physicians.
- Radiology: Dr. Sven Anderson, head of Radiology, commented that he came to KFMC because of the clear investment in cutting edge technology.
 - Equipment includes: 2 CTs, 2 MRIs, 1 Mammography unit, and one ultrasound.
 - There are plans to build a breast imaging corner next year - a cordoned off area specific to breast imaging and early detection, a development which Dr. Al Amro supports.
- Pharmacy: KFMC has 9 pharmacies throughout the large facility, and patients must come to the hospital to receive their medications. Herceptin is available for treatment of Her-2/neu positive cancers.
- Rehabilitation: Physical therapy services for breast cancer patients most often relates to surgical complications (i.e. frozen shoulder, lymphedema).
 - At KFMC, physical therapist provides basic education regarding potential complications of surgical intervention. In the United States, dedicated surgical or oncology nurses provide education regarding procedure and follow-up.
 - There is a need to update the system to routinely feed patients into physical therapy. Delay in receiving physical therapy following surgery increases likelihood for potential complications. Often times, patients are not referred to physical therapy until after they are experiencing complications.
 - Rehab requested assistance from Fred Hutchinson Cancer Center with training for staff and best practices. Dr. Anderson is not directly involved with that part of Fred Hutchinson, but willing to make introductions.

Event: Meeting w/ KFMC Senior Staff

Venue: KFMC

Duration: 11:00 a.m. – 12:00 p.m.

Participants: Dr. Abulaziz Al Humaidi (KFMC/SCS); Dr. Ben Anderson (BHGI); Chris McKallagat (ICF)

Hosted by Dr. Humaidi, the topic of the meeting was “What kind of tertiary care can KFMC provide to breast cancer patients?” Discussion included an overview of the services available at KFMC and the systems in place to provide top-level treatment to patients from throughout the Kingdom. There was a focus on the need to establish a diagnostic center where patients requiring further workup on an irregular mammogram can be seen. Currently the system is setup so that all irregularities are referred to a tertiary care facility, such as KFMC. The facilities become bogged down with cases that either do not require evaluation within a cancer center and could have been triaged on the basis of history and CBE, or at the other extreme, patients who do not seek medical evaluation until their disease is locally advanced or metastatic due to fear and lack of education about their potential condition.

Dr. Anderson noted that patient triage issues can be addressed through the establishment of multidisciplinary management teams. At the Breast Health Clinic at the University of Washington (UW), specialty trained Nurse Practitioners (NPs) work-up patients and funnel those needing surgery to breast cancer surgeons, who are able to focus their work on patients who require surgical intervention. Following surgery, NPs provide primary follow-up care, accessing specialists and physicians on an as needed basis. Essential to the success of this model is well established clinical screening and diagnosis protocols that are closely followed across the board such as those developed by the National Comprehensive Cancer Network (NCCN) in the United States.

Additional points:

- KFMC and King Abdulaziz City for Science and Technology (KACST) are collaborating on a project to set up the top floor of the College of Medicine at KFMC for basic medical research. KFMC has put in a request to include labs for cancer research.
- KFMC is working on a long-term plan to achieve international accreditation as a premier cancer center through all stages of care: diagnosis to palliation.
- KFMC is the largest MOH hospital and the CEO reports directly to the Minister of Health, as opposed to the regional health director as most other MOH hospital chiefs do.
- By the numbers: 1 digital mammography machine (plans for future equipment purchase); 600-800 mammograms annually; 400-500 ultrasounds for breast imaging annually; 100-150 biopsies per year; 90-100 new breast cancer cases annually.
- National Cancer Registry is housed at King Faisal Specialists Hospital
- Regional Cancer Registry at King Khalid Hospital (Plans to move to KFMC)

- Future plans include having a building at KFMC that can handle more primary patients and become regional cancer referral center; increase capacity for handling all stages of disease; focus on getting patients in at earlier (more treatable) stages.

Event: Meeting w/ female breast cancer specialists

Venue: Abdullatif Cancer Screening Center

Duration: 1:30 p.m. – 2:30 p.m.

Participants: Dr. Huda Abulkareem (KFMC/SCS); Dr. Um Al Khair Ubu Al-Khair (National Guard Hospital); Dr. Ben Anderson (BHGI); Chris McKallagat (ICF)

Dr. Huda Abdulkareem, KFMC/SCS, and Dr. Um Al Khair Abu Al-Khair, Head of the Department of Tumors at the National Guard Hospital in Riyadh, are two of the leading physicians focusing on treatment of breast cancer patients in Riyadh. Both doctors volunteer at the Abdullatif Center and spoke about the need to improve the referral and diagnosis system in Riyadh. Dr. Um Al Khair commented that most patients referred to National Guard from Abdullatif have been screened by Dr. Fatin Tahan, a Radiologist at National Guard Hospital and also a volunteer at Abdullatif. Due to her affiliation with National Guard, she naturally sends most of her referrals to National Guard for further check-up. This system, or lack-there-of, is unsustainable especially as new cancer cases are expected to rise with increased education and greater emphasis on screening.

It was noted that screening for breast cancer is not just about installing mammography machines, but about establishing systems to support the screening and diagnosis that result from having machines. Initiating mass screening before building the necessary structures to handle the influx of patients is ineffective in improving the treatment of breast cancer patients and ultimately reducing mortality.

Additional points:

- There is no formal training for a breast imaging sub-specialty in KSA.
- There is a feeling that physicians in Saudi are underpaid for the level of work and training that is required. Salaries are set by the government and do not compete with other high-valued professions (i.e. engineering, finance, etc.). Also, there is no increased compensation for specialization within medicine.
- Rapid turnover creates a QA/QC problem. Quality of services is variable.
- Dr. Um Al Khair is on a regional committee working on clinical guidelines for breast cancer, part of a larger initiative to adapt NCCN guidelines for the Middle East.
- The Saudi Society of Medical Oncology is working on guidelines for physicians seeing oncology patients, from screening, through staging workup, treatments, etc.

Event: Tour of Abdullatif Cancer Screening Center, including meeting with

Duration: 2:30 p.m. - 4:00 p.m.

Participants: Dr. Huda Abdulkareem (KFMC/SCS); Breast Cancer Survivors; Dr. Ben Anderson (BHGI); Chris McKallagat (ICF)

The tour included an overview of Abdullatif Center's history and mission – to provide quality, accessible cancer screening services. Dr. Anderson and Chris were allowed permission to tour the women's screening area on the first floor, including meeting with the newly hired women's health education and outreach coordinator. Dr. Anderson commented that the facility was top notch in terms of equipment. It was also discussed that a defined triage and referral system is needed to direct necessary follow-up care were needed, i.e. systems that will ensure that women with abnormalities who require further diagnostic workup can be referred to receive this care.

Dr. Anderson noted that screening does not appear to be part of the major medical system in Saudi Arabia, which is very different from how it works in the United States. Instead, screening in Saudi Arabia is led on a voluntary basis by charitable organizations as opposed to medical institutions. Only when there is a pre-identified need is referral is made to an institution within the healthcare system. Lack of coverage for screening programs and/or limited public education about the value of breast cancer early detection is also seen in middle income countries in Latin America. These countries suffer from the same problem as Saudi Arabia, women presenting with late stage disease at diagnosis.

For the visit, Abdullatif gathered breast cancer survivors to provide their perspective on the system to Dr. Anderson. The breast cancer survivors gathered included women who had been diagnosed inside and outside of Abdullatif. One woman, Haifa, was diagnosed early (Stage I) and treated successfully with lumpectomy and no chemo-therapy. Most others gathered were diagnosed with advanced stage disease, and some were still undergoing treatment. All agreed that talking with fellow survivors was cathartic. Dr. Anderson commented although he could not understand the language, the scene in the waiting room with the survivors talking and finishing each others sentences, appeared like any other meeting of survivors in the United States. This observation points to an finding previously published by BHGI, that the experience of breast cancer is largely a universal experience among women around the globe regardless of cultural, social or racial background (*Errico KM, Rowden D. Experiences of breast cancer survivor-advocates and advocates in countries with limited resources: a shared journey in breast cancer advocacy. Breast J. 2006 Jan-Feb;12 Suppl 1:S111-6.*)

Additional points:

- Since opening in Oct. 2007, Abdullatif has provided 3,000 mammograms in 2 years.
- Recent education and outreach initiatives have succeeded in raising awareness in targeted populations and drawing in women for screening, however more widespread campaigns will be necessary to increase the visibility of the center.
- Focus up until now has been on high-risk populations so as not to overwhelm the system; patients receive calls and texts to follow-up, remind them to screen again one year later.

- Radiologists: currently, there are 2 paid, part-time radiologists and 2 volunteer radiologists; Abdullatif does have plans to hire a fulltime radiologist to cover the center during operating hours.
- Ultrasound is available on site 3 days/week when tech is working.
- Further sampling and biopsies must be done at hospitals.
- National Guard Hospital women’s care unit has a fulltime physiotherapist.
- Zahara Breast Cancer Association provides wigs, prosthesis, and access to a support group.

Thursday, October 22, 2009

Event: Meeting with Heads of Oncology

Venue: Riyadh Radisson SAS Hotel

Duration: 1:30 p.m. – 2:30 p.m.

Participants: Dr. Abdulrahman Jazieh (Chairman, Department of Oncology, King Abdulaziz Medical City – National Guard Hospital); Dr. Mohammed Mohiuddin (Director, Oncology Centre King Faisal Specialist Hospital & Research Centre); Dr. Abdulaziz Al Humaidi, Director of the Prince Sultan Hematology/Oncology Center, KFMC); Dr. Mushabab Al Siri (National Guard Hospital Eastern Province/Saudi Cancer Society); Dr. Huda Abulkareem (KFMC/SCS); Dr. Ben Anderson (BHGI); Catherine Schweitzer (Public Diplomacy Officer, U.S. Embassy); Chris McKallagat (ICF)

This landmark meeting brought together, for the first time, the heads of oncology for the three main cancer centers in Riyadh, along with additional key specialists focused on breast cancer early detection and treatment. The meeting focused on the need to improve coordination across centers and design strategies to achieve mutual institutional goals of reducing the impact of breast cancer and building high-achieving cancer centers. Dr. Anderson presented his work with the Breast Health Global Initiative (BHGI), challenging the doctors to think outside the walls of their respective centers for solutions that will create coordination amongst various stakeholders and be held together by strong, collaborative systems of care. The discussion was lively and thoughtful, particularly regarding a visual Dr. Anderson presented that linked cyclically Early Detection-Diagnosis-Treatment-Survivors-Advocacy-Awareness. Upon adjourning, the group planned a follow-up meeting to be attended again by Dr. Anderson when he is in Riyadh in March 2010 for a previously scheduled trip to present at the Arab Cancer Initiative conference.

Additional points:

- Saudi MOH has not decided whether to advocate for annual mammography across the board beginning at 40, as in U.S. There is a fear that screening could be oversold and lead to a false sense of security (i.e. if you get your mammogram, you’ll never die of cancer).

- Dr. Asiri noted that in KSA, “the problem is early detection and advocacy.” At Abdullatif, they are beginning to conduct more public education in schools and communities.
 - Of the 61 cases detected at Abdullatif (no time frame given) almost all had come in already with symptoms. There is no need for mammography when there is a clear palpable or even visual finding.
 - Dr. Anderson noted that you can downstage disease quicker in KSA than was the experience in the U.S. because you already have evidence based practices that can be implemented. The trick is effective cultural adaptation.
- The National Guard and their dependents include up to 2 million Saudis.
- Recognition among the doctors that more patient data of all kinds (i.e. personal history, tumor tissue, treatment plans, etc.) is necessary; doctors discussed developing a unified system for data collection.
- Dr. Humaidi proposed an idea to build screening centers directly tied to tertiary care facilities, such as KFMC, that would also include on-site follow-up diagnostics.
 - For example, KFMC would have its own screening facility where patients would go to receive mammography and also be able to have ultrasound, biopsy, and other necessary follow-up care. KFMC staff would run the center and if there was a cancer diagnosis the patient would be transferred internally for treatment.
- The doctors agreed that the diagnostic and referral systems are not meeting the needs of patients in Saudi and certainly are not set-up for the anticipated influx of patients. They must be redesigned in order to meet future needs.
- All of the doctors affirmed a willingness to continue trying to collaborate to resolve these issues moving forward
- Future meetings could address:
 1. Patient Care
 2. Referral
 3. Research
 4. Guidelines
 5. Protocols
- Dr. Anderson offered to help facilitate a future meeting on guidelines development – how to adopt/create guidelines to apply evidence in Saudi setting.
- Dr. Jazieh commented, “The way Saudi [Arabia] is paying attention to healthcare system is second to none.”
 - No country has limitless resources, but there is a real desire (and support from the government) to try and get it right.

Saturday, October 24, 2009

Event: Meeting with Dr. Samia Al Amoudi

Venue: Grand Hyatt Hotel (Cairo, Egypt)

Duration: 1:30 p.m. – 2:30 p.m.

Participants: Dr. Samia Al Amoudi (King Abdulaziz University/SCS); Dr. Ben Anderson (BHGI); Chris McKallagat (ICF)

Dr. Anderson also met with Dr. Al Amoudi in Cairo during the Komen regional advocates meeting to include her viewpoint in his overall assessment. The discussion focused on the need for a better understanding of how to overcome the cultural and societal barriers present in the Kingdom. There is a new term, "implementation science," that denotes research into how to most effectively deliver interventions in a particular society. This works encompasses epidemiology and sociology and often focuses not necessarily on what's possible, but what makes the most sense. This is essentially the framework for BHGI, and Dr. Samia was very interested in this approach, particularly for her new Center of Excellence.

Dr. Samia invited Dr. Anderson to Jeddah to visit King Abdulaziz University for further discussions in March, which Dr. Anderson accepted.

Outcomes:

- Further joint collaborations proposed: Follow-up meeting w/ heads of Riyadh cancer centers; consultative visit to King Abdulaziz University/Sheikh Al Amoudi Center of Excellence for Breast Cancer (March 22 -24, 2010).

Next Steps from the Assessment Visit for ICF and the Partnership:

- Help facilitate development and delivery of assessment report.
 - Dr. Anderson is working on an assessment report to include recommendations for steps that can be taken to improve systems related to breast cancer screening and follow-up care in Riyadh.
 - ICF will assist with content editing and also engaging Dr. Al Amro and Dr. Humaidi on a draft version prior to finalization.
 - Dr. Al Amro previously mentioned that he would like to submit this report to the new Minister of Health for review and to engage his support.

APPENDIX – Dr. Ben Anderson Assessment Visit Meeting Agenda (Provided by KFMC/SCS)
DR ANDERSON'S VISIT WEDNESDAY, OCTOBER 24TH 2009

TIME	ACTIVITY	SITE	STAFF INVOLVED	IN-CHARGE/COMMENTS
08:30	PICK UP FROM HOTEL	HOTEL LOBBY	ANDERSON AND CHRIS	PUBLIC RELATION TO ARRANGE TRANSPORTATION FROM HOTEL TO KFMC
09:00 - 09:30	RECEPTION & KFMC MODEL EXPLANATION	AT KFMC ADMIN GATE	HUMAIDI	
09:30 – 11:00	TOUR AT KFMC	PSHOC,LAB,RADIOLOGY,PHARMACY,REHAB	DEPARTMENT HEADS	PUBLIC RELATIONS/EACH 15-20 MIN
11:00 – 12:00	CLOSED MEETING: WHAT KIND OF TERTIARY CARE KFMC CAN PROVIDE TO BREAST CA PATIENTS	RADIATION SEMINAR ROOM	ANDERSON, , CHRIS, HUDA, LARSON, HARTHY & HUMAIDI	HUMAIDI
12:00 – 14:00	BUSINESS LUNCH	AT SHAIKH /ABDULLATIF SCREENING CENTER	ANDERSON, CHRIS, HUDA, UMALKAHIR, OTHERS	PUBLIC RELATION TO ARRANGE TRANSPORTATION FROM KFMC ADMIN GATE TO SHAIKH ABDULLATIF SCREENING CERNTER
14:00 – 16:00	TOUR AND BUSINESS MEETING	SHAIKH /ABDULLATIF SCREENING CENTER	ANDERSON, HUDA UMALKHAIR AND ? OTHERS	HUDA
16:15	BACK TO HOTEL	PICK UP FROM SHAIKH /ABDULLATIF SCREENING CENTER	US GUESTS	PUBLIC RELATION
18:30 – 21:00	DINNER	ALFAISALIA BUILDING, 11 A RESTURANT	ANDERSON, CHRIS, HUDA, JAZIAH, MOHIUDDIN,ASIRIR, UMALKAHIR, ?Azar AlSayed, HUMAIDI	PUBLIC RELATION TO ARRANGE TRANSPORTATION OF THE US GUESTS FROM HOTEL TO 11 A AND BACK TO HOTEL
21:10	BACK TO HOTEL	FROM ALFAISALIA GATE	US GUESTS	PUBLIC RELATION

**DR ANDERSON'S VISIT
THURSDAY, OCTOBER 22ND 2009**

TIME	ACTIVITY	SITE	STAFF INVOLVED	IN-CHARGE/COMMENTS
10:00 – 12:00	PRESENTATION OF DR ANDERSON AT AND MEETING WITH DIRECTOR AND CONCERNED STAFF OF BREAST CANCER CENTERS AT KFMC, KFSH&RC, NGH, AND RKH	RADISSON SAS MEETING ROOM #??	ANDERSON, MUHIUDDIN, JAZIAH, ASIRI, UMALKAIR, BAZERBASHI, HUDA, HUMAIDI	PUBLIC RELATION TO ARRANGE THE MEETING ROOM
12:00 - 14:00	LUNCH	AT RADISSON SAS HOTEL	ANDERSON, MUHIUDDIN, JAZIAH, ASIRI, UMALKAIR, BAZERBASHI, HUDA, HUMAIDI	PUBLIC RELATION TO ARRANGE THE LUNCH FOR (8) PEOPLE
14:00 – 16:00	US GUESTS REST RADISSON SAS HOTEL			
16:00 – 20:00	TOUR : VISIT OF THE NATIONAL MUSEUM, DOWNTOWN SOOQ, ETC...	RIYADH	ANDERSON, , CHRIS, PUBLIC RELATION REPRESENTATIVE	PUBLIC RELATION TO ARRANGE THE TRANSPORTATION
20:00 - ...	FREE TIME			
FRIDAY, OCTOBER 23RD 2009				
FREE TIME TO VISIT US EMBASSY AND OTHERS				