

FY2004 COMMUNITY BENEFITS REPORT
DANA-FARBER CANCER INSTITUTE

February 28, 2005

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I. ABOUT DANA-FARBER CANCER INSTITUTE

Name / Address of Hospital:

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Boston, MA 02115

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Community Benefits Mission Statement:

In 1995, the Dana-Farber Cancer Institute Board of Trustees formally adopted a Community Benefits Mission Statement. This mission statement affirms the Institute's commitment to support community-based programs, participate in outreach activities aimed at the reduction of cancer incidence, morbidity and mortality, and conduct community-based research. (See Section II).

Description of the Institute:

Since its beginning in 1947, Dana-Farber Cancer Institute (DFCI) has committed itself to multidisciplinary activities that encourage collaboration between laboratory scientists and clinical oncology practitioners leading to the development of comprehensive integrated programs in basic and clinical research, training, and patient care.

The National Cancer Institute (NCI) named DFCI as one of the country's seven original comprehensive cancer centers in 1973. Dr. Sidney Farber, who founded DFCI, played an integral role in developing the concept for such centers. Today, NCI recognizes 39 comprehensive cancer centers, including DFCI, which is a member of the Dana-Farber/Harvard Cancer Center. All comprehensive cancer centers are dedicated to the research, prevention, diagnosis, and treatment of cancer and related diseases.

In 1989, DFCI was designated as a Center for AIDS Research in recognition of DFCI's growing commitment to high quality, multidisciplinary research devoted to the pathogenesis, therapeutics, and prevention of AIDS.

In 1996, the formation of DFCI and Partners marked a new era in adult oncology. This collaborative program including DFCI and the founding members of Partners HealthCare System – Brigham and Women's Hospital (BWH) and Massachusetts General Hospital (MGH) – is committed to ensuring that its patients receive the finest adult cancer care available. The program is based at two sites – the Dana-Farber/Brigham and Women's Cancer Center site, where inpatient care is based at BWH and most outpatient care at DFCI,

and MGH Cancer Center where both inpatient and outpatient services are provided. DFCI and Partners coordinate 12 disease programs focused on endocrine, breast, gynecologic, gastrointestinal, genitourinary, head and neck, and thoracic cancers, hematologic malignancies, melanoma, brain tumors, sarcoma, and benign hematology. The goal of the disease programs is to share practice guidelines for clinical care and common research strategies under the direction of the best clinicians, surgeons, medical oncologists, radiation therapists, and supporting specialists in cancer care.

DFCI's Division of Pediatric Oncology is part of the Children's Oncology Group (COG), which formed in 2000 as a result of the merger of several children's cancers cooperative groups. The Division has successfully exported innovative trials to the national group and has provided leadership in designing protocols for various leukemias, bone tumors, brain tumors, and lymphomas. Approximately 7500 children are diagnosed with cancer each year and are enrolled in clinical treatment protocols. The majority of children in Maine diagnosed with cancer are treated on DFCI protocols, and their tissues and tumors are studied in DFCI laboratories under the auspices of the Maine Children's Cancer Program. Moreover, children with acute lymphoblastic leukemia from central and western Massachusetts, Maine, Puerto Rico and eight collaborating institutions are all treated on DFCI protocols and have their cells evaluated in DFCI laboratories.

In 1998, DFCI joined with Harvard Medical School, four of its affiliated hospitals, and Harvard School of Public Health to create the collaborative entity Dana-Farber/Harvard Cancer Center (DF/HCC). The DF/HCC, which also includes Beth Israel Deaconess Medical Center, Children's Hospital, BWH, and MGH, unites the major basic, clinical, and population cancer research efforts of the member institutions. The DF/HCC links more than 800 cancer scientists into an organizational structure designed to foster interaction and collaboration that will lead to new, more effective approaches in cancer prevention, diagnosis, and treatment. Research is carried out in 12 disease-based programs and 17 discipline-based programs that cross institutional and scientific boundaries. The DF/HCC also provides infrastructure for 23 core facilities that provide shared resources to Center members, facilitating scientific progress. The DF/HCC also supports the infrastructure for a unified system of clinical trials.

In 2000, DFCI and Children's Hospital formalized the close working relationship the two hospitals have had for the past 50 years to create the Dana-Farber/Children's Hospital Cancer Care (DF/CHCC). The formation helps to create a seamless patient care experience for children whose illness requires the full spectrum of inpatient and outpatient hematology or oncology pediatric services. DFCI's Jimmy Fund Clinic delivers outpatient pediatric oncology care, and Children's Hospital provides inpatient oncology care. Children's Hospital also offers both inpatient and outpatient hematology services.

In 2002, DFCI and HealthCare Dimensions Hospice formed a collaboration, which provides high-quality, comprehensive end-of-life care to patients with advanced terminal cancer and services to their families. HealthCare Dimensions is committed to serving low-income and underserved communities.

II. DANA-FARBER CANCER INSTITUTE COMMUNITY BENEFITS MISSION STATEMENT

Dana-Farber Cancer Institute's community outreach mission is to:

- establish quantifiable and sustainable programs in cancer and AIDS prevention focusing on at-risk and underserved populations in Massachusetts
- provide expertise in cancer care to city and state health departments, community-based agencies and health care providers
- increase accrual of minorities into clinical trials.

Revised: January 1996
Approved: September 1995

III. COMMUNITY BENEFITS PLANNING MECHANISMS

As a National Cancer Institute-designated comprehensive cancer center, DFCI has a mandate to serve the residents of Massachusetts and Maine. In keeping with its mission, DFCI defines its community using an illness-specific approach focusing on cancer prevention and risk assessment targeted to underserved and at-risk populations.

The DFCI **Board of Trustees Community Programs Committee** oversees the development and implementation of DFCI's Community Benefits Plan. In their advisory capacity, Committee members have provided leadership and direction to community benefits staff in several areas. Co-chaired by Mr. David Auerbach and Dr. Hubert Jones, the Committee meets semi-annually to review progress and prioritize program initiatives.

Internally, the community benefits staff meets quarterly with the **Community Benefits subcommittee**. Chaired by DFCI's Community Benefits Administrator, the committee is comprised of physicians, nurses, other clinicians, and administrators who bring a unique blend of technical expertise and outreach experience to the Community Benefits program.

In 1997, DFCI established an **External Advisory Committee** that consists of representatives from community organizations, neighborhood health centers, and city and state health departments who share DFCI's commitment to educate and outreach to communities most in need. To ensure the success of our efforts, the External Advisory Committee members serve as advocates for their respective communities, and assist DFCI in developing effective and sustainable programs in cancer prevention, education, and awareness. The committee, chaired by DFCI's Chief of Staff Stephen Sallan, M.D., meets twice a year.

The DFCI Community Benefits Program is involved in community benefits planning through the following activities:

Massachusetts Department of Public Health (MDPH): Through ongoing partnerships with MDPH's Center for Chronic Disease Prevention, several cancer control priorities have been identified in collaboration with DFCI. Programs in colorectal, prostate, skin, and women's cancers have been established in partnership with MDPH and community agencies across the Commonwealth. Participation in statewide coalitions, such as the Massachusetts Comprehensive Cancer Control Coalition, and working groups, sponsorship of health information forums and symposia, development and implementation of cancer educational initiatives, material and resource development, and provision of technical assistance have enhanced DFCI's outreach efforts.

To ensure **ADA compliance**, the Community Benefits Program is committed to providing access to all individuals interested in attending cancer education programs and makes every reasonable effort to accommodate all forum participants.

United Way/Jimmy Fund Collaboration: Now in its eleventh year, this collaborative program was established to provide direct support to community-based agencies that provide cancer prevention, education, and outreach services to low-income, underserved, at-risk

communities. Several partnerships have evolved from this collaboration that have enhanced DFCI's ability to reach communities most in need.

Center for Community-Based Research (CCBR): CCBR conducts cancer prevention research with the goal of developing effective intervention strategies to reduce the risk of cancer. CCBR works extensively with neighborhood health centers, low-income housing, unions, small businesses, faith-based organizations, health departments, and community-based agencies. Community Benefits and CCBR continue to explore more avenues to expand these collaborative relationships.

Dana-Farber Cancer Institute/Partners HealthCare Systems (Partners): DFCI and Partners continue to work together on cancer control outreach activities in the Greater Boston area. In collaboration with Partners-affiliated health centers, a number of initiatives have been further developed this past year.

Dana-Farber/Harvard Cancer Center (DF/HCC): DFCI and DF/HCC's Initiative to Eliminate Cancer Disparities are working together in the areas of minority faculty and staff recruitment, community engagement, cultural competency, and research in health disparities. There are ongoing efforts to attract more ethnically and culturally diverse clinicians and staff, as well as to establish and implement cultural competency courses for faculty and staff in all disciplines. Other initiatives include partnering with diverse organizations such as faith-based organizations to provide opportunities for access to care, participation in clinical trials, and community-wide education about cancer prevention, screening, and treatment.

DFCI Health Disparities Committee: Chaired by DFCI's President, the Health Disparities Committee provides oversight and coordination of initiatives in research, clinical care, and outreach at DFCI that focus on eliminating cancer-related health disparities. The committee works to foster opportunities to collaborate with various partners, seek grant opportunities, and increase resources addressing health disparities.

DFCI Diversity Committee: Through its Diversity Committee, DFCI is working to achieve its mission more effectively. By promoting diversity among patients, staff, volunteers, trustees, and friends, DFCI is better able to provide more compassionate and respectful care to patients and families and is viewed as a welcoming resource to the broader community.

National Black Leadership Initiative on Cancer (NBLIC): DFCI is actively involved in the Boston Chapter of NBLIC. NBLIC, a coalition of community-based agencies, cancer survivors, health professionals, and concerned individuals, works to mobilize and educate communities of color in the fight against cancer.

Boston's Crusade Against Cancer: DFCI works closely with the Boston Public Health Commission (BPHC) to implement initiatives as part of Boston's Crusade Against Cancer. Among other programs, DFCI and the BPHC have worked together to address the need for more cancer prevention education, increased screening services, and available transportation, and will continue to partner on future cancer prevention programs.

Boston Mayor's Task Force to Eliminate Health Disparities: As a member of the Mayor's Task Force to Eliminate Health Disparities, DFCI worked alongside fellow health care institutions and other task force partners to address the serious racial and ethnic disparities in health that exist not only in Boston, but throughout the region and the nation.

Center for AIDS Research (CFAR): The DFCI/Beth Israel Deaconess Medical Center/Children's Hospital Center for AIDS Research is working closely with the Harvard Medical School Division of AIDS and the Partners CFAR in the newly formed Harvard Medical School Center for AIDS Research (HMS CFAR). The CFAR engages in HIV and AIDS-related basic and clinical research, and in addition, is building its community outreach efforts. DFCI is working collaboratively as a member of the CFAR Networking Committee and is involved in developing initiatives to raise community awareness about clinical trials.

IV. COMMUNITY BENEFITS PROGRAMS

A. Education, Outreach, Screening, Advocacy, and Research

DFCI is committed to educating the community about cancer through its collaborative work in local neighborhoods and through statewide public and professional education initiatives. DFCI has been an active partner in a wide range of programs and community events to help raise awareness about the importance of cancer prevention, outreach, screening, early detection, and research.

1. Community-Based Cancer Control Initiatives

Boston's Mammography Van (BMV): In May 2002, DFCI launched Boston's Mammography Van (BMV), which provides critical breast cancer screening, education, and follow-up tracking for underserved and uninsured women throughout the City of Boston, regardless of ability to pay. By providing these timely, high quality, and convenient services, BMV aims to increase the survival rates of women diagnosed with breast cancer. The BMV is currently the only mobile mammography program in the Commonwealth.

In 2004, the BMV provided breast health education and mammography services to over 3,000 women in the Boston area, 80% of whom are uninsured or publicly insured and 90% of whom are of ethnic minority backgrounds, including African-American, Caribbean, Latina, Eastern European and Asian. More than 50% speak a first language other than English. Priority populations include women who are uninsured, underserved, elderly, immigrant, non-English speaking, and of ethnic/racial minority backgrounds; priority neighborhoods in Boston include Roxbury, Mattapan, Jamaica Plain, Dorchester, South End, Roslindale, and Hyde Park.

Each van screening day is the result of tremendous collaboration between DFCI, BPHC, Encore Plus/YWCA, the MDPH's Women's Health Network (WHN) and one or more community groups or centers within Boston. Community partners include neighborhood health centers, churches/faith organizations, social service agencies, public housing, a prison, and others. Relying on their relationships with community members, DFCI's neighborhood partners conduct extensive outreach, recruitment, scheduling, promotion, and planning of the van day. DFCI provides the clinical services and breast health education on the van day, and manages the patient registration, billing, reporting of results to provider and patient, and follow-up tracking as needed. Skilled, licensed technologists perform mammography screenings, and films are interpreted by Board-certified radiologists from DFCI, clinicians with extensive experience dedicated to mammography. For those women who are not connected to the health care system, DFCI works with community providers to help connect the women to regular primary care. DFCI is also responsible for the licensing, maintenance, and all operational costs of the van.

Approximately 6% of the women screened on BMV needed diagnostic or follow-up services. BMV staff track abnormal results and work closely with the community partners, area hospitals, primary care providers, and WHN to ensure that, when necessary, every woman receives timely follow-up services and receives assistance with referrals, keeping appointments, and insurance coverage.

Breast and Cervical Screening Collaborative (BCSC):

Screening Services

In July of 2004, the Breast and Cervical Screening Collaborative began its seventh year of a grant with the Women's Health Network (WHN) program from the MDPH. The WHN provides funding for breast and cervical health services for uninsured women. Through the program, fourteen community health centers in the Greater Boston area, along with DFCI and Partners, work collaboratively to promote and enhance the early detection of breast and cervical cancer. DFCI and Partners have provided significant supplemental funding to support the BCSC's central administration, outreach and inreach activities, and additional fundraising efforts.

During FY04, the BCSC provided screening services for nearly 1,400 women from diverse cultural, linguistic, and socioeconomic backgrounds. The following offers a statistical description of the women served:

- 55% were new to the program
- 87% between the ages of 40-64
- 38% White, 26% Black, 3% Asian and 32% refused to respond in a self report
- 45% self report as Spanish, Hispanic or Latina
- 65% reported a primary language other than English
- 38% did not have a high school diploma
- 28% had a screening finding which required further evaluation
- 7 women were diagnosed with breast cancer, 2 with cervical cancer

The BCSC engaged in three expansion initiatives in FY04:

- Breast and Cervical Cancer Treatment Program (clinical)
- North Shore development (program)
- Inreach via technology enhancements (technology)

Beginning in January of 2004, the Massachusetts Division of Medical Assistance enacted the Breast and Cervical Cancer Treatment Program. Through this program, women who had been enrolled in WHN when diagnosed with either breast or cervical cancer or a precancerous cervical lesion that required further diagnostic evaluation may be enrolled in MassHealth. If a woman is enrolled in MassHealth under the treatment program and continues to meet the requirements of the program, she will continue to receive MassHealth benefits as long as she remains in treatment. The BCSC enrolled 10 women in this program during the 6 months of operation in FY04.

In FY04, the Collaborative began the development phase of expanding the WHN program on the north shore. Although the BCSC had been working with health centers in Salem and Peabody for three years, the program was not available in the City of Lynn, a diverse community with a significant low-income population. The BCSC partnered with North Shore Medical Center and Lynn Community Health Center to develop the structure and clinical and administrative processes for identifying and enrolling women in need of care. The program began on July 1, 2004 and anticipates serving over 500 women during the first year of operation. Combined with North Shore Community Health, Inc., the north shore initiative anticipates serving 900 women in FY05.

Over the past two years, many of the health centers have upgraded their technological capacity with advanced practice management programs and electronic medical records. The BCSC has worked with many of the health centers to identify the application of these systems for enrolling new patients in the WHN, tracking and follow up. Technological improvements have enhanced patient care and, in the long term, will improve the overall management of the program.

Boston Mayor's Task Force to Eliminate Health Disparities: The City of Boston launched the Mayor's Task Force to Eliminate Health Disparities in 2003 and mobilized leaders and organizations from the health care and public health communities to partner in citywide efforts. As an active member of the full Task Force and the Hospital Working Group, DFCI was involved in initiatives in data collection and measurement, workforce development, cultural competency, and community outreach. A few examples of DFCI's involvement includes:

- Financial support for facilitation and evaluation of task force initiatives
- Participation as one of two hospitals sites piloting collection of expanded ethnicity data on patients
- Serving as an internship site for minority Boston Public School students
- Participation in the Boston REACH 2010 Breast and Cervical Cancer Coalition (see below)
- Operation of the Boston's Mammography Van throughout Boston's multiracial and multiethnic neighborhoods.

Racial and Ethnic Approaches to Community Health (REACH) 2010: DFCI has been an active member of the REACH 2010 coalition since its inception in 2000. REACH 2010, spearheaded by the Boston Public Health Commission (BPHC), is a 4-year program funded by the Centers for Disease Control and Prevention. The program aims to eliminate racial and ethnic disparities in breast and cervical cancer screening and management among Black women and women of African descent in Boston.

The initiative is comprised of multiple components – a case management/outreach model in place at six health care sites in Boston, a public education campaign, a Women's Health Ambassador outreach program, a radiology technologist scholarship program, and a faith-based outreach component.

DFCI was actively involved in:

- Promoting opportunities for community-based screening on Boston's Mammography Van
- Development of the public education campaign on breast and cervical health
- Providing educational resource materials to faith-based organizations and other community-based organizations
- Providing support for coalition building and staff recruitment.

Boston's Crusade Against Cancer: In 2004, DFCI continued its active involvement and support of the Boston Crusade Against Cancer. DFCI partnered with BPHC in a number of initiatives including:

- The BPHC-led REACH 2010 Breast and Cervical Cancer Coalition (see above);
- Boston's Mammography Van (see page 9) – providing mobile mammography services throughout all Boston neighborhoods;
- Distribution of cancer prevention and early detection information at health fairs throughout Boston; and,
- Contributions to a taxi-voucher program that helps ensure that Boston residents, who are undergoing cancer treatment, can access transportation to and from appointments.

National Marrow Donor Program (NMDP)

In 2004, the National Marrow Donor Program continued to strengthen its community partnerships. NMDP established a working relationship with the Boston Police Department's Area B3 Community Service Office and educated area residents on the importance of marrow donation in the minority community. NMDP collaborated with Asian Spectrum, a local Asian cable access channel, and recorded a video at DFCI that is geared to educating the Asian community on marrow donation.

There has been an increase in patient-focused marrow drives, which has enabled NMDP to recruit potential donors in the surrounding towns of Metropolitan Boston. Aggressive recruitment efforts have allowed NMDP to give several bone marrow transplant recipients a second chance of life.

Also in 2004, NMDP introduced a marketing campaign with the slogan "Are You My Type", which has been very successful. There has been a significant increase in awareness and in the number of walk-in potential donors. In 2004, 18% of new registrants were Black/African American, while 65.1% of new registrants were Asian. NMDP will continue its outreach efforts to reach minority communities.

Community Education and Health Fairs: In spring 2004, DFCI launched a billboard campaign in the neighborhoods of Roxbury, Dorchester, and Mattapan to communicate that people of color can survive cancer and that DFCI is available to help. This effort endeavors to increase awareness of DFCI in the African-American

community and support institutional efforts to reduce cancer disparities in Boston. The billboard campaign will continue in 2005.

Throughout 2004, DFCI participated in numerous community events and distributed cancer prevention and screening information. Below is a partial list of events DFCI has supported and attended:

- Boston Race for the Cure
- Making Strides Against Breast Cancer
- Raise Your Racquet to Good Health – Breast and Prostate Health
- Men’s Health Summit
- Mission Hill Walk for Health
- Mattapan Health Care Revival

2. Statewide Initiatives

Massachusetts Comprehensive Cancer Control Coalition (MCCCC)

As a member of the Massachusetts Comprehensive Cancer Control Coalition and its Executive committee, DFCI worked with coalition members in FY04 to develop a comprehensive cancer control plan to be submitted to CDC for federal funding. DFCI helped identify cancer control priorities and opportunities for greatest impact in addressing cancer incidence, morbidity, mortality, and survivorship issues. Development of the cancer control plan is currently underway.

Colorectal Cancer

Education: DFCI, as a member of the Massachusetts Colorectal Cancer Working Group, promoted colorectal cancer awareness across the state. The Working Group’s mission is to reduce colorectal cancer incidence, morbidity, and mortality in Massachusetts by increasing public and professional awareness of risk factors, prevention strategies, and the need for timely and appropriate screening. In FY04: DFCI continued to work with members including the Harvard Center for Cancer Prevention and the American Cancer Society to build an advocacy network. Advocacy efforts were aimed at educating state legislators on the importance of colorectal cancer screening.

Prostate Cancer

Education and Screening: DFCI partnered with the MDPH’s Men’s Health Partnership Program to promote educational workshops on prostate health and screening with particular emphasis on reaching audiences of men of color. The Men’s Health Summit in June 2004, co-sponsored by DFCI, MDPH, Whittier Street Health Center, and others featured keynote speaker Judge Greg Mathis, civil rights activist and television personality. Judge Mathis described the challenges he overcame in order to succeed personally and professionally and highlighted the challenges of connecting men to primary care for prostate health screening and other issues.

Also in FY04, DFCI began developing a prostate cancer education and screening program utilizing a new DFCI Blum Resource Van. The program, which is aimed at reaching underserved men, utilizes an informed decision making model. The program will provide prostate health education for all men and will offer screening for those men who decide they would like to receive services.

Massachusetts Prostate Cancer Symposium: The seventh annual statewide Prostate Cancer Symposium was held in May 2004 in Marlboro, Massachusetts. DFCI joined the Massachusetts Prostate Cancer Coalition, MDPH, and others in co-sponsoring the event. DFCI helped organize symposium logistics, selected speakers and topics, and offered continuing education credits for nurses. Attended by about 300 individuals, the symposium featured experts who discussed diagnosis, treatment, and quality of life issues. Workshops covered topics such as nutrition, genetics, treatment complications, and sexuality.

Skin Cancer

Education: DFCI supported initiatives of the Massachusetts Skin Cancer Prevention Collaborative (MSCPC). The MSCPC is a statewide coalition comprised of more than 25 members, which is committed to promoting the prevention, early detection, and treatment of all types of skin cancer. DFCI is developing a skin cancer education and screening program utilizing a new DFCI Blum Resource Van. The program will take place at parks and beaches and will offer education on skin protective behaviors, as well as offer screening opportunities on the van.

3. NCI-Sponsored Activities

Asian-American National Cancer Awareness, Research, and Training

(AANCART): In 2000, NCI awarded a national consortium grant to six centers to work on eliminating disparities in cancer outcomes among minority and underserved populations, including Asian-Americans. DFCI's Dr. Frederick P. Li serves as the AANCART National Director of Research. In this capacity, Dr. Li worked with young investigators to develop pilot projects to investigate the disparities in cancer care that exist among different Asian American groups.

Cancer Information Service (1993-2004): The NCI's Cancer Information Service (CIS) is a national information and education program that provides accurate, up-to-date information on cancer to patients and family members, health professionals, medically underserved audiences, and the general public. The CIS operates an Information Services Program that includes a toll-free telephone line (1-800-4-CANCER), a Health Communications Research Program, and provides program development assistance to organizations reaching medically underserved audiences through its Partnership Program. The CIS Partnership Program for New England was based at DFCI, in collaboration with the New England Region CIS Project Office at the Yale Cancer Center in New Haven, CT.

In 2004, the CIS Partnership Program provided over 7,200 informational and material updates to health professionals and organizations working to reach ethnic minority and medically underserved audiences throughout New England. It also provided program planning, development, implementation, and evaluation assistance on over 200 occasions for state, regional, and local cancer-concerned organizations to help enhance their capacity to conduct cancer education and outreach programs. Priority topics for the CIS Partnership Program include breast and cervical cancer screening and early detection, education about the risks of tobacco and on smoking cessation, cancer clinical trials, and general cancer awareness for special populations.

National Black Leadership Initiative on Cancer (NBLIC): DFCI has been actively involved in the Greater Boston Chapter of the National Black Leadership Initiative on Cancer since its inception in the mid 1990's. NBLIC is a coalition of community-based organizations, health professionals, cancer survivors, and concerned individuals that works to mobilize and educate communities of Black and African descent in the fight against cancer.

In 2004, DFCI and NBLIC continued its collaboration on the African-American Male Prostate Cancer Education Initiative. The goals of the multi-phase project are to understand the perception of prostate cancer and the barriers to screening and health care in the African-American community, develop and pilot a prostate health education and screening program, and then implement the program broadly among organizations such as churches, men's groups, athletic associations, and others. The initiative is still ongoing. In addition to this project, DFCI provided financial and in-kind support for NBLIC's infrastructure to expand its board and membership and to establish firmly its community programming.

DF/HCC Initiative to Eliminate Cancer Disparities – In collaboration with the DF/HCC Initiative to Eliminate Cancer Disparities, DFCI is engaged in multiple initiatives to address health disparities in cancer. Examples include:

Cancer Disparities – Program in Development

In 2001, the DF/HCC leadership established a program-in-development (PID) in Cancer Disparities. The overall purpose of this PID is to stimulate inter-institutional and inter-programmatic collaborative research related to social disparities in cancer, across the cancer continuum. The program in development currently has over 26 members, who are conducting over 25 projects in the area of cancer disparities. The program members have grants and have recently collaborated on responses to three large center grants: (1) Community Networks RFA; (2) patient navigator RFA; and (3) Transdisciplinary Research on Energetics and Cancer RFA.

The PID held its first program-wide event in January 2004, a workshop designed to set its research agenda in cancer disparities, which drew over 100 participants. Nine papers resulted from the work prepared for this workshop, and all are now in press as a

special section on cancer disparities in *Cancer Causes and Control*, to be published in February/March of 2005 (Vol. 16 (1)).

Community Involvement in Setting the Research Agenda: Including the community in setting the research agenda is critical in order to conduct relevant research, and if the community is to feel that the DF/HCC is responsive to its needs. DFCI has partnered with DF/HCC in hosting several activities to provide the community with a voice (e.g. hosted a series of Community Dialogues for community leaders, hosted a Public Health Grand Rounds at community health centers, sponsored events in honor of National Minority Cancer Awareness Week, and collaborated with faith-based organizations to conduct a needs assessment). In addition, a well-attended legislative breakfast was held in May 2004, co-sponsored by the chairs of the Health Committee, Senator Richard Moore and Representative Peter Koutoujian. The purpose of this event was to educate the legislative community on the impact of cancer disparities in Massachusetts and how the cancer center is responding. In conjunction with DF/HCC, DFCI will look to create a similar forum in 2005.

Cultural Competency - The goal of the emerging field of cultural competence in health care is to improve providers' ability to understand, communicate with, and care for patients from diverse backgrounds. During the past year, DFCI has been committed to developing, implementing, and evaluating a cultural competency curriculum for clinical staff. A four-part training series was piloted with the breast and pediatric oncology clinicians. This training curriculum will be delivered to the remaining medical oncology staff in 2005. In addition, a state of the art e-learning tool will be made available for clinical providers. Lastly, training only physicians will not result in the desired changes in cultural awareness within the DF/HCC institutions—DF/HCC's goal is that all components of the workforce are equally sensitized to the issues. DFCI will expand the training program to involve non-clinical researchers.

B. Center for Community-Based Research

The Center for Community-Based Research (CCBR) at DFCI conducts research aimed at cancer prevention and control, with a particular emphasis on the development and evaluation of effective interventions designed to modify behaviors, policies and practices to reduce cancer risk, and to provide increased access to and comprehension of cancer risk information. This research program has a special focus on reducing racial/ethnic and socioeconomic disparities in cancer risk.

These interventions ideally are evaluated in randomized, controlled studies, with the intent that the tested models will ultimately be applied broadly through community and health organizations nationally. These public health approaches that target organizations or communities are an important complement to the clinical and basic research also being conducted at DFCI.

To test the effectiveness of community-based educational and policy interventions within defined populations, solid partnerships with community organizations are necessary. Community organizations act as collaborators in our research, providing both study populations, and shaping the interventions.

Another priority of CCBR is to place and mentor students from a range of academic levels and including many from racial and ethnic minorities.

Examples of completed studies and accomplishments include:

Development of a Worksite Intervention Protocol to Increase Informed Decision-Making For Prostate Cancer Screening: (2003-2004) The purpose of this exploratory study was to develop and pretest an educational intervention protocol to promote informed and shared decision-making (IDM/SDM) among employed men ages 50-65. Formative research was conducted to assess men's knowledge, attitudes and behaviors regarding prostate cancer and screening; their preferences for shared decision-making; and the feasibility and acceptability of various educational strategies in worksites. The intervention employed multiple educational strategies, including group education sessions, one-to-one counseling, and print materials. Completed in the Fall of 2004, this study demonstrated the feasibility of conducting prostate cancer education in worksites. Findings will inform the development of intervention and evaluation methods for the upcoming Computer-Based Prostate Cancer Education in Worksites study (see below, page 20).

Barriers and potential solutions to the delivery of effective prostate cancer care to African American men (2001-2003): The study examined the barriers and potential solutions to the delivery of effective prostate cancer care to African American men in the city of Boston. The initiative was a collaboration between DFCI and the Greater Boston Chapter of the National Black Leadership Initiative on Cancer. The study employed key informant interviews and focus groups with healthy men and survivors. Study results will inform efforts to perform feasible and culturally acceptable patient outreach, and develop materials and recruitment strategies for prostate cancer screening, treatment and clinical trials.

Project Watch (2000–2003): Funded by the Massachusetts Tobacco Control Program, the study was an evidence-based critique of the Master Settlement Agreement’s (MSA) restrictions on advertising and promotion of tobacco products. The MSA restricts, but does not prohibit, sponsorship of events, outdoor advertising, and brand and company name advertising. This study observed and documented tobacco industry advertising and promotion strategies over a two-year period in six Massachusetts communities. The study’s findings will inform policy recommendations for countering the industry’s emerging advertising and promotion strategies.

Current projects include:

Special Interest Project (SIP-02) Massachusetts Cancer Prevention and Control Network (2002-2004): CCBR, in collaboration with the Harvard Prevention Research Center (PRC) and the Boston University PRC, received funding from the Centers for Disease Control to establish the Massachusetts Cancer Prevention Community Research Network (the Network.). The purpose of the Network is to foster partnerships among community collaborators and public health researchers. The Network focuses particularly on addressing disparities in cancer risk by socioeconomic status and race/ethnicity, fostering partnerships with a broad range of community organizations, including those not traditionally engaged in cancer prevention and control, and will provide an important resource for the DF/HCC Risk Reduction Program.

Cancer Prevention for Unionized Blue-Collar Workers (2000-2005): This project is a collaboration with the Laborers Health and Safety Fund of North America, which is a joint labor-management organization. The partnership provides unique access to the Laborers International Union of North America (LIUNA). A large background survey, qualitative research, and worksite observations have been carried out with LIUNA members around the country. The data have been used to develop a tailored telephone-based tobacco cessation and nutrition program specifically for laborers. The study is designed to test the effectiveness of a program to help workers quit smoking and make dietary changes. The program has been completed and final analysis and manuscript preparation are underway.

Health Promotion for Mobile Workers (2004-2007): This study is a collaboration with the Motor Freight Carriers’ Association and the International Brotherhood of Teamsters. This study will test the effectiveness of a program to promote tobacco use cessation and weight management in motor freight workers, including truck drivers and dockworkers. DFCI will survey motor freight workers in eight trucking terminals and invite respondents to participate in a telephone-delivered motivational interviewing health promotion program that includes tailored educational materials and five telephone counseling calls delivered over four months. All survey respondents will be surveyed after the program is completed.

Organized Labor and Tobacco Control Network (2001-2005): The Organized Labor and Tobacco Control Network, in cooperation with labor unions and tobacco control organizations seeks to reduce health disparities due to high levels of tobacco use and exposure among working people and their families. The research component aims to find the most effective methods of working with labor unions to reduce tobacco use and promote tobacco control

policies in worksites and communities. The first research study, funded by the American Legacy Foundation, tests a pilot intervention to reduce tobacco use in one Boston-based building trade union apprenticeship program. The Massachusetts AFL-CIO assisted in recruiting Ironworkers Local 7 to the study.

Physical and Social Hazards: Jobs, Race, Gender and Health (2001-2004): Funded by the National Institute for Occupational Safety and Health, the goal of this study of a population of unionized workers is to generate new knowledge about the distribution of physical and social hazards at work, their patterning by race/ethnicity, gender, and wage level, and their contribution to social inequities in health. The study additionally explores whether the distribution and impact of adverse working conditions are modified by workplace policies.

Weight Control, Physical Activity and Cancer Risk Reduction Among Racially Diverse Obese Women in an Urban Community Setting, (2003-2005): This study represents a new and growing collaboration between DF/HCC and the University of Massachusetts, Boston, a designated Minority-Serving Institution. This study has been designed to provide needed pilot data for an expected future collaborative R01 grant submission. This study responds to an urgent need to develop, test, and implement cancer prevention interventions to promote physical activity and behavioral weight control strategies, particularly among ethnically diverse and low-income populations. The study will pilot-test a weight management program at the Greater Worcester YMCA focused on nutrition and physical activity.

Colon Cancer Prevention through Low Income Housing (2003-2008): The goal of this project is to evaluate an intervention designed to address colorectal cancer prevention (CRC) through low-income housing sites. This study is a randomized controlled trial that will be conducted in 10 diverse low-income housing sites; eligible residents will be enrolled in a cohort and followed; housing sites will be the unit of randomization and intervention. The intervention conditions are: (1) a social contextual, housing site-based intervention, that addresses individual, organizational, and systems-level factors that influence participation in CRC prevention activities; or (2) minimal treatment control. The primary outcomes are physical activity and participation in colorectal cancer screening. Of note, both interventions will offer equivalent access to CRC screening.

A web-based smoking intervention for cancer survivors (2004-2009): DFCI recently completed Partnership for Health (PFH), a peer-delivered telephone-based counseling intervention among childhood cancer survivors. The PFH intervention resulted in a doubling of smoking quit rates in the treatment group compared to a self-help control group. A key issue is now how to disseminate smoking interventions to this population. The aim of this randomized controlled trial is develop and evaluate the efficacy of a Web-based intervention for smoking cessation among this group, compared to a Materials-only condition. This study will make significant contributions toward increasing the reach of a tested intervention. Additionally, this study will make significant steps toward dissemination of tested smoking cessation interventions among cancer survivors.

Decision-making about prostate cancer screening (2004-2006): Funded by the NCI, this is an observational study exploring the factors that influence the decision of whether not to

undergo prostate cancer screening and what men experience during the decision-making process. This decision is a difficult one that men are increasingly expected to make for themselves, yet little is known about the factors that influence their decision or how their decision is influenced by the extent to which their thoughts about the decision fluctuate. This study represents the first step in a rigorous research program exploring the decision-making processes for difficult, value-laden medical decisions to inform the development of interventions to facilitate these difficult decisions for patients.

Computer-Based Prostate Cancer Education in Worksites (2004-2007): Men are advised to make a decision about prostate cancer screening through a discussion with their physician of the potential risks and benefits. The purpose of this study is to develop and pretest an educational intervention method that will promote informed and shared decision-making (IDM/SDM) among employed men ages 50-65. In the first phase, a Decision Aid (DA) currently under development will be adapted so that it is appropriate for a multi-ethnic audience of employed men. Formative research will be conducted to assess men's needs and preferences for prostate cancer education. In the second phase, a randomized controlled trial will be conducted to assess the efficacy of the computerized DA tool for promoting IDM related to screening among employed men. A process evaluation system will assess intervention reach, dose, and cost-effectiveness.

Factors Associated with Follow-Up of Abnormal Mammograms Among Low-Income Ethnic Minority Women (2002-2005): The purpose of this study is to identify factors associated with delay in receipt of diagnostic follow-up of abnormal mammography results among low-income minority women. In-depth interviews are ongoing with women and key community informants to describe factors that hinder or facilitate follow-up. A survey of women, who have had an abnormal mammogram, is ongoing to identify the individual, socio-cultural and institutional factors related to timely diagnostic follow-up. Available educational materials have been assessed, and new materials are being developed for a field trial. Study findings will inform efforts to reduce disparities in breast cancer survival by improving the delivery of diagnostic and treatment services.

Increasing Cancer Screening Through the Use of Small Media Interventions:

Evaluation of Materials for Mammographic Abnormalities (2004-2005): The first aim of this study was to identify and review extant educational materials designed for patients on the topic of abnormal mammograms requiring follow up. Secondly, these materials were assessed for suitability in regard to women from low-income, multi-ethnic communities, including the extent to which extant materials are: (a) culturally acceptable; (b) linguistically appropriate; (c); comprehensible; and (d) persuasive. In the final phase, adaptations were identified and recommended to enhance the degree to which existing materials meet the needs of women.

Smoking Cessation Intervention with Building Trade Unions (2004-2007): This study builds upon a recently completed pilot study in collaboration with 3 building trade union apprenticeship programs. The pilot study confirmed that this population of workers is at very high risk of smoking in comparison to the general US population and that the planned interventions are feasible and result in positive changes in smoking behavior. The aim of this randomized, controlled trial is to assess: (1) the *efficacy* of a smoking cessation intervention

among unionized apprentices in the building trades; (2) the *determinants* of smoking cessation including intention to quit smoking, self-efficacy to quit smoking, knowledge and concern about the dual threat posed by the combination of occupational hazards and smoking, and perceived organizational and social support for quitting; (3) the *adoption* (recruitment into the trial) among eligible apprenticeship programs, *reach* of the intervention among potential participants, elements of successful *implementation and best processes* of intervention activities delivered; (4) *cost-effectiveness* of the intervention.

Identifying Facilitators and Impediments to Adopting US Public Health Service Guidelines for Smoking Cessation Treatment Among Labor-Management Health and Welfare Funds (2004-2007): The purpose of this study is to investigate and describe the nature and extent of coverage of smoking cessation by health and welfare funds through a nationally representative sample of funds. In addition, the study will compare coverage for smoking cessation to treatment of addiction to alcohol and drugs and prevention-related services by health and welfare funds and identify factors that impede and facilitate compliance with national guidelines for benefits coverage for smoking cessation treatments. Also, cost-benefit estimates will be developed for smoking cessation coverage in the context of a health and welfare fund using state-of-the-art economic modeling; and disseminate findings to health and welfare fund decision makers, labor unions, and the general public.

C. United Way/Jimmy Fund Collaboration

During its eleventh year in 2004, the United Way/Jimmy Fund Collaboration awarded funds to nine community-based organizations that provide culturally appropriate cancer prevention, education, and outreach services for at-risk populations in low-income communities. The United Way of Massachusetts Bay (UWMB) and DFCI work together to develop ways to strengthen the Collaboration and support the unmet needs of the organizations. In the coming year, UWMB and DFCI will work with the organizations to enhance their ability to measure program outcomes and their ability to describe the impact that their work has on the communities in which they serve.

The following nine community-based organizations received grant awards in 2004:

Federated Dorchester Neighborhood Houses/Kit Clark Senior Services

Senior Cancer Outreach Prevention and Education (SCOPE) Program – cancer education program that targets low-income, immigrant senior men and women of color, many of whom are originally from Cape Verde, Haiti, other Caribbean countries, Vietnam, and Central America. The program seeks to educate about cancer and provide preventative information on topics such as smoking cessation, healthy eating, exercise, and cancer screening.

Haitian Multi-Service Center

Breast Cancer Prevention Program – program is designed to educate Haitian women age 40 and over, who live in Dorchester, Mattapan, and Roxbury, about breast health. Program components include: workshops, home visits, educational materials, and referrals for mammography.

Latin American Health Institute

Cancer Initiative – a bilingual (Spanish-English) breast, cervical, and prostate cancer education program specifically tailored to Latino women and men in Boston. Program components include: a public information media campaign, a toll-free health information hotline, community-wide events, and organizing *charlas* (small discussion groups at homes).

Massachusetts Alliance of Portuguese Speakers

Chronic Disease and Cancer Prevention Program – a program that teaches Portuguese speakers in the Somerville/Cambridge area about the cancer-prevention benefits of exercise and other related healthy behaviors. Components include outreach, newspaper articles, and public service announcements.

The Medical Foundation, The Boston Area Tobacco Control Coalition (BATCC)

Not in Mama's Kitchen – an education program to address and educate Latino residents regarding environmental tobacco smoke through planned outreach to the Latino population in local churches in Boston, Cambridge, and Somerville.

Mujeres Unidas en Acción

Cancer Education and Prevention Workshops – a bilingual (Spanish-English) initiative that includes cancer prevention and education courses for Latina women, who range in age from

16-65. Topics such as prevention, screening, and breast health are interwoven into weekly women's health workshops.

Sociedad Latina

Tobacco Prevention and Education Program – program utilizes trained peer leaders to conduct outreach and education to youth through workshops and street outreach. Program aims to increase knowledge and awareness on the dangers of tobacco products, reach out to the public and educate about tobacco industry marketing tactics, and inform current smokers of smoking cessation methods.

YWCA Boston

Encore Plus Program – a breast cancer education, early detection, and survivorship program for women most at-risk of late cancer diagnosis, including women of color, women over 40 years, and women who are under-or completely uninsured. Services include education sessions, transportation, translation, appointment facilitation, and follow-up.

YWCA Malden

Encore Plus Program – a breast and cervical cancer education and outreach program, which targets African-American, Haitian, Latina, and Asian women ages 50 and older in the communities of Malden, Everett, Medford, Chelsea, and Somerville. Services include education sessions, transportation, translation, appointment facilitation, and follow-up.

D. Services to Patients, Families, and Communities

DFCI offers a variety of services to patients, families, and the wider community ranging from support groups, workshops, seminars, and educational and referral resources. These services are facilitated and provided by social workers, nurses, and other DFCI staff and are designed to help people cope with the challenges that accompany a cancer diagnosis.

Examples include:

Pediatrics

- Bereavement Day
- Brain Tumor Support Group
- Inpatient Parent Support Group
- Yoga for Kids
- Sibling Day
- Making Music
- Back-to-School Program
- Specialized Support Groups for Childhood Cancer Survivors

Adults

- Prostate Cancer Support Group and Workshops
- Bereavement Support Group
- Post Bone Marrow Transplant (BMT) Patient and Family Education Support Group (for newly discharged patients)
- Breast Cancer Support Group
- Look Good/Feel Better (presented by American Cancer Society)
- One to One: The Cancer Connection (Peer Support)
- Stepping Stones (BMT) {for patients who have undergone bone marrow transplant at least 6 months previously and their families}
- Spirituality in Health and Illness

Eleanor and Maxwell Blum Patient and Family Resource Center and Satellites: The Blum Patient and Family Resource Center, which was established in 1996, is located in the DFCI lobby and houses brochures, computers, videotapes, compact discs, and over 550 books in its loan library. The Blum Resource Center provides patients, families, and anyone from around the country and the world seeking services with the most current and useful educational materials available, as well as support, resources, and referrals. The Blum Resource Center and its 4 satellite rooms boast more than 10,000 visits annually. The 4 satellite resource rooms include:

- The Houghton Mifflin Patient and Family Resource Room, based in the Gillette Center for Women's Cancers since 1997, offers resources that are specific to women and families coping with cancer.

- The DF/BWCC Inpatient Resource Room, which opened in 1998 on the 6th floor of the Tower building of BWH, serves inpatients of Dana-Farber/Brigham and Women's Cancer Center and their families.
- The Betty Ann Blum and Marjorie Blum Pediatric Resource Room, which opened in 1999, serves parents and families of children receiving care at the Jimmy Fund clinic.
- The Pediatric Inpatient Satellite Room, located at Children's Hospital Boston since 2001, serves pediatric oncology and hematology inpatients.

A Clinical Nurse Specialist in Patient Family Education and a team of volunteers are available to assist patients, families, and visitors access cancer information, identify supportive care services, and provide referrals to housing, hospice, and complementary therapies.

DFCI commissioned the new **Blum Family Education and Resource Van** and launched the mobile unit program in October 2004. Committed to tackling the issues of health disparities in cancer incidence, morbidity, mortality, treatment, and quality of life, and the pressing need for more participants in clinical trials, the Blum Van enables DFCI to expand its mission and share its expertise with the larger community. The Blum Van offers a unique and innovative way to bring cancer education, prevention, and screening to people directly in the communities where they live, work, and play. The Blum Van is equipped with state-of-the-art technology and has been designed to accommodate the multiple needs of the community, ranging from space for small groups to private space for individual needs. The following is a selected list of initiatives that will take place on the Blum Van:

- Prostate cancer education and screening targeting African-American men and other men at elevated risk of the disease
- Sun protection awareness and skin cancer prevention and screening in collaboration with the Massachusetts Dermatological Nurses Association. Target sites include local beaches, parks, and community fairs
- Outreach and education in the African-American community regarding sickle cell disease
- Education on the National Marrow Donor Program and the critical need to recruit potential donors from different racial and ethnic backgrounds
- Education and workforce initiatives – recruitment of students and residents of underserved communities and assist them in seeking career paths in the healthcare professions. Provide mobile space for employment team to host job fairs, career education, and recruitment interviews.

Interpreter Services: The DFCI Interpreter Program provides interpreting services to patients and families with limited or no English proficiency and healthcare providers to ensure proper communication and understanding across languages and cultures. In FY04, nearly 3,800 interpreting encounters were made, representing 3,150 interpreting hours. The most requested languages were Spanish, Russian, Portuguese, Cantonese, and Arabic, representing 83% of interpreting encounters and 72% of interpreting hours.

The Leonard P. Zakim Center for Integrated Therapies: The Zakim Center is a multidisciplinary program that provides complementary therapies to adult and pediatric patients and families; education to patients, families, and staff; and research studies to test the efficacy

of complementary therapies in cancer patients. In 2004, the Center offered over 2,000 individual treatments (acupuncture, massage and reiki) to patients and expanded clinical services to include meditation, dance and music classes, and complementary therapy medical consultations and a fellowship program. The Center offered educational programs, which were all open to the public. Examples of lectures included “Music Therapy and Your Health: Theory, Practice and Research” and “Massage with Care: A New Look at an Ancient Art”. The Fifth Annual Lenny Lecture was held in November and featured two lectures; one on integrating complementary therapies with traditional cancer care and the other lecture was on research trends in integrative medicine.

The Center also received funding for several research studies looking at the effectiveness of various interventions on white blood cell recovery, immune changes and quality of life for patients undergoing cancer treatments. Results of these studies will help provide the foundation for seeking insurance coverage for integrated therapies, which would have a major impact for patients everywhere who chose to use complementary therapies in conjunction with traditional cancer therapies.

The Wellness Community: Financial support is provided annually to The Wellness Community, a not-for-profit organization that provides psychosocial support to cancer patients and their families, at no cost. DFCI clinicians lend support by leading educational workshops and serving on the organization’s advisory board.

Survivorship Conferences: DFCI continues to play a major role in sponsoring and/or participating in the planning of cancer survivorship conferences. In 2004, DFCI provided financial support and staff consultation for the 2nd Annual “Young Adults Affected by Cancer Symposium” scheduled for April 2005. Workshops throughout the day will provide time for participants to share with one another and to establish networks for on-going support.

Schwartz Rounds: DFCI began Schwartz Rounds in 2001. The Schwartz Center Rounds are a multidisciplinary forum where caregivers discuss important emotional and social issues that arise in caring for seriously ill patients. Participants engage in an interactive discussion about the issue presented and share their experiences, thoughts and feelings. In 2004, select topics included: “End of Life Decisions in the Elderly Patient – When Conflicts Arise” and “Caring for the VIP Patient.” DFCI is now providing facilitator assistance and guidance at hospitals throughout the area that are just beginning Schwartz Rounds.

E. Pediatric Programs

DFCI programs focus on the patient and family and support the belief in “total patient care” for the body, mind, and spirit. Programs are divided into the following categories:

1. **Patient and Family Activity Program** is designed to meet a wide range of developmental and emotional needs for patients that range in age from infancy to young adulthood. A full-time patient activity coordinator works with volunteers to engage patients and families in activities to reduce anxiety and stress through creative expression and communication. Activities are provided within the clinic and in the community. Examples of activities include:
 - Teen Red Sox Weekend at Camden Yards, Baltimore, MD
 - Outward Bound
 - Family Day at Fenway Park
 - Summer and Winter Festivals
 - Variety of craft and creative activities

2. **Patient and Family Education Program** is an important aspect of providing care to patients and families. When a child has cancer, family members want as much information as possible about the disease, treatment options, and what to expect during treatment. Through the Blum Family Pediatric Resource Room, patients and families have access to computers, as well as written and audiovisual materials. Specific educational materials developed by DFCI staff are available to help explain treatment, manage side effects, and provide care at home, among others. Several major programs are run out of the Pediatric Resource Room including:
 - Pediatric Entertainment Program: Tickets to local venues, such as museums, Duck Boats, and the Aquarium, are distributed to patients and families in order to provide some diversion from the rigors of treatment.
 - Teen Look Good Feel Better: This program, which is jointly sponsored by DFCI and ACS, provides teen cancer patients with tips about health coverings, make-up, and nutrition during treatment. Sessions are offered for both male and female patients.
 - “Making Music” Program: a licensed music therapist runs weekly classes for pediatric patients using music as a form of healing.
 - Parent Education Classes: Weekly parent education classes are held to teach parents about caring for a central line, managing side effects, pediatric nutrition, home care, and blood counts.

Patient and Family Support Groups and Programs offer a wide range of services for patients and their families. Examples include:

3. **The David B. Perini, Jr. Quality of Life Clinic** is in its 12th year of operation as a multidisciplinary pediatric survivorship program. The Perini Clinic works to meet the unique medical and psychosocial needs of childhood cancer survivors through

biweekly clinic sessions. Evaluation is provided by a multidisciplinary team of experts in childhood cancer survivorship in collaboration with other sub-specialists. The clinic also serves as a source of information and support for survivors of childhood cancer and their families through many educational programs held throughout the year. The Perini Program's research efforts are designed to reduce and eliminate harmful late effects of treatments for past, current and future patients.

Highlights of the Perini Clinic's 2004 educational and support programs are:

- **Facing Forward: Adult Challenges for the Childhood Cancer Survivor**
To help survivors of childhood cancers face the emotional, physical, and social challenges that come with hearing "You're cured," the Perini Clinic again held Facing Forward, its fall support group series for survivors' aged 20 to 40. The workshops explored the aspects of everyday life affected by cancer and survivorship, like self-image, relationships, health worries and school or work. Grouped by diagnosis and age at diagnosis, the participants focused on how best to cope with the realities of survivorship. The program was offered one evening per week over the course of six weeks in the fall of 2004.
 - **Survivor Weekend at The Hole in the Wall Gang Camp**
The Fifth Annual Perini Clinic Survivors' Weekend was held at The Hole in the Wall Gang Camp in April 2004. Attended by 38 survivors, the weekend served as a valuable forum for survivors from the Perini Clinic and other New England cancer centers. The well-rounded weekend program featured survivorship lectures accompanied by a variety of social and recreational events.
4. The **Island of Hope** program is designed to empower youth and their families to face their lives with cancer. The mission is accomplished through experiential-based, outdoor activities reinforced by regularly scheduled follow-up activities. In its sixth year, DFCI provided staff nurses, social workers, and child life specialists to support the campers based at Thompson Island.
 5. **The Stop & Shop Family Pediatric Brain Tumor Clinic** has been addressing the many medical and psychosocial concerns of children with brain and spinal cord tumors for over a decade. The multi-disciplinary team, comprised of highly trained clinicians and allied health professionals, focuses on the complex needs of these patients. The program spans diagnosis and management, including surgery, radiation therapy, chemotherapy, and other components that address the needs of patients and families. The **Neuro-Oncology Outcomes Clinic** provides specialized care for children who have completed brain and spinal cord therapy and may be experiencing late effects of treatment.

Additionally, the Brain Tumor Program routinely has parent, teen, and young adult groups that focus on educating patients and families about late effects, provide psychosocial support, and opportunities for building relationships between families

facing similar life long issues as a result of the patient's tumor and treatment. An example is:

- **11th International Symposium on Pediatric Neuro-Oncology**

The event was held June 13-16, 2004 in Boston and provided a comprehensive overview of all aspects in the understanding, treatment, and care of children with central nervous system tumors. The foremost researchers in Neurosurgery, Oncology, Neurology, Pathology, Radiation Oncology and Nursing and Quality of Life clinicians presented their latest findings.

6. **The Division of Pediatric Psychosocial Services** is a multidisciplinary group of psychologists, social workers, resource counselors, and a special educator who provide comprehensive psychosocial services to patients and their families. The mission of the division is to reduce the potential emotional and psychosocial complications of pediatric cancer and to maximize the child's and family's psychological and emotional adjustment to the illness. An assessment is done for each family at the time of diagnosis. Individual, family, couples therapy, and behavioral work can be provided. Crisis intervention and triage are also available. The division has several educational and support programs to meet the diverse needs of patients and their families. Some examples are:

- **School Liaison Program** is designed to assist children after treatment whose cancer or cancer treatment has resulted in learning difficulties or other problems related to attending school. Services include: educating school personnel about cancer, its treatment and long-term effects; facilitating neuropsychological evaluations; consultation with families and school systems to address educational needs; and, educating communities about long-term effects of childhood cancer and treatment.
- **The School Workshop** is offered annually by the School Liaison Program for school personnel who are directly involved with our patients. The workshop focuses on increasing understanding and communication between the child, family, and school personnel. The long-term challenges faced by children treated for cancer and their siblings are also addressed.
- **Parent Night Series** is a series of educational forums where parents receive important information regarding school issues, such as neuropsychological assessment, parent skill-building in collaboration with schools, and relevant facts about the Special Education Laws as they pertain to pediatric patients. The program both educates and empowers parents to help their children succeed in school.
- **Sibling Programs** are designed to provide group support for siblings of patients. A one-day outward-bound program for teens, age 11-19, was held in the spring 2004 at Thompson Island. Other groups, both inpatient and at the clinic are being planned for the rest of the year. With the use of puppet shows and group activities, the special needs and concerns of siblings are addressed.

- **Bereavement Day** is an annual workshop for bereaved parents to provide them support, to help them network with one another, and to offer psycho-education about the bereavement process. There is also a one-day parent group offered during the holidays to help parents find and use coping strategies to support them in getting through a potentially difficult time.
7. **Pediatric Advanced Cancer Team** is a multidisciplinary team that promotes quality care at the end-of-life. The team facilitates discussion of end-of-life issues among hospital caregivers, home care, hospice, and the family, and it works collaboratively with them to organize a plan for end-of-life care.
 8. **The Back To School Program:** is a program developed in 1997 to assist the patient, family, and school community with the sometimes difficult transition from active treatment back to the school. Nurses, social workers, psychologists, and child life specialists travel to the child's school and provide age appropriate education about pediatric cancer to the child's classmates, teachers, and parents. These visits alleviate anxiety and encourage sensitivity and support for the child experiencing cancer.

F. Center for AIDS Research

In 2004, the DFCI/Beth Israel Deaconess Medical Center/Children's Hospital Center for AIDS Research (CFAR) worked closely with the Harvard Medical School Division of AIDS and the Partners CFAR to form the Harvard Medical School Center for AIDS Research (HMS CFAR). Similar to the formation of the DF/HCC, the HMS CFAR formation enables the institutions to share scientific and clinical expertise and resources to advance the knowledge of HIV/AIDS prevention, diagnosis, and treatment. The CFAR Networking Committee (CNC) was created to:

- Support clinical research through the education and recruitment of patients for clinical trials
- Educate the public on the importance of clinical research
- Reach out to all communities affected by HIV, particularly those that lack resources (including underserved populations outside of Boston), and inform them about available treatments/trials
- Bring together community leaders and “gatekeepers” in order to strategize on educating/empowering the community/consumer.

In 2004, the newly created CNC focused its early efforts on identifying opportunities to collaborate with community organizations, in order to educate the broader community about HIV/AIDS research and clinical trials. DFCI will work with other CFAR/CNC members on developing initiatives in the coming year.

G. Community and Workforce Development Programs

Community/City of Boston Support

Fenway and Mission Hill Neighborhoods: Financial support is provided annually to community health centers and community development corporations in Boston's Fenway and Mission Hill neighborhoods. DFCI also participates in the Longwood Medical Area Forum to discuss ongoing community needs and concerns.

PILOT: DFCI made payments in lieu of taxes and housing linkage payments to the City of Boston.

Housing: DFCI provides support to housing programs for cancer patients and their families. Programs include:

- Ronald McDonald House – a home away from home for pediatric oncology patients at DFCI and Children's Hospital, Boston
- Shannon McCormack House – a residence for out-of-town cancer patients undergoing cancer treatment in the Longwood area and their families
- Hospitality Program – provides lodging for cancer patients and their families through its network of more than 180 volunteer hosts in the Greater Boston area.

DFCI participates in a variety of other community activities. Examples include:

- James F. Condon Elementary School – 150 new and gently used books were donated to the James F. Condon Elementary School. DFCI's President served as Principal for a day during Spring 2004.
- Annual food drive sponsored by MASCO. Contributions to the food drive are donated to the food bank operated by Action for Boston Community Development in Mission Hill.
- Caps for Kids Program – Along with BWH, DFCI participates in the annual program, which provides knitted hats for Tobin Elementary School, BWH newborn intensive care, and various community centers.

Career, Employment, and Training Initiatives

DFCI maintains educational partnerships with Boston area high schools and colleges to provide underrepresented students of color internship opportunities to explore and pursue careers in health and science. DFCI works closely with the following schools to place students who have a specific interest in health and science.

Educational Partnerships

- Boston Latin School Science Mentorship Program
- Fenway High School
- Madison Park Technical Vocational High School – Allied Health and Human Services Academy

During the 2003-04 academic year and summer 2004, more than 90 Boston Public Schools students from diverse backgrounds worked at DFCI in clinical, research, and administrative departments. A number of students participated through the Boston Mayor's Summer Jobs Program. Students had opportunities to receive CPR certification, participate in presentation skills and PowerPoint classes, engage in site visits at biotech companies, and attend educational seminars. In addition to the schools noted above, students hailed from the following Boston Public Schools:

- Boston Community Leadership Academy
- Boston Latin Academy
- Brighton High School
- Codman Academy Charter School
- English High
- Health Careers Academy
- John D. O'Bryant School of Math and Science
- West Roxbury High School

DFCI actively participates in school-to-work programs with the Boston Private Industry Council (PIC). PIC programs include:

- Classroom at the Workplace – DFCI provides paid internships for high school students who had not passed one or both sections of the statewide test MCAS. Students work up to 40 hours per week with two hours of classroom instruction per day.
- Groundhog Job Shadow Day – Students shadow DFCI employees learning about their job responsibilities, as well as the skills and training needed for their position. One example – a young man via Bridge Over Troubled Waters attended Shadow Day, acquired an unpaid internship in Nuclear Medicine, enrolled in DFCI Medical Terminology course, and now has a full-time, paid position at DFCI.

DFCI participated in the **Southern New England Junior Science and Humanities Symposium (JSHS)/Biomedical Science Career Program (BSCP)**, both of which are programs operated by Harvard Medical School. They are designed to promote increased recruitment, retention, and advancement of underrepresented minority and female physicians and scientists. DFCI hosted a site visit where 60 JSHS students toured research labs and learned more about careers in the health and sciences. DFCI supported the BSCP and mentored minority students ranging from high school to graduate school.

In addition to working with youth and young adults, Dana-Farber offers career development opportunities for its staff through the following programs:

Black Achievers: As a 2004 sponsor of the Black Achievers program, DFCI joins the Black Achievers in recognizing African-Americans in Boston for their accomplishments and demonstrated excellence in their profession. Through the partnership, DFCI and two staff members, who have been among those recognized as this year's Achievers, have provided youth with opportunities to explore their interests, develop skills, and broaden their access to information and resources.

Boston Health Care and Research Training Institute: In collaboration with community-based organizations, educational institutions and other health care and research institutions, DFCI provides comprehensive training and educational programs for entry and mid-level employees. Courses allow employees to build upon existing skills, while helping them to advance along career pathways. DFCI and the Training Institute currently are working on a proposed course of study in nursing or clinical assistants. DFCI will provide space, release time, tuition for employees, and clinical instructors. In addition, DFCI is working with the Training Institute to develop specialized pre-employment trainings in Science and in billing/financial work. In 2003-2004, 22 DFCI employees enrolled in training courses.

Bunker Hill Community College: In 2003, DFCI began a joint program with Bunker Hill Community College. At the end of seven courses (two years), staff will be eligible for a Medical Coding Certificate.

English as a Second Language (ESL): In collaboration with nearby health care institutions, DFCI offers ESL classes to its staff. Currently, nearly forty employees are in the program representing nine cultures/languages.

The Partnership: DFCI is a corporate sponsor of The Partnership. The Partnership works in collaboration with the Boston Chamber of Commerce and its members to increase the number of people of color in leadership roles in the Boston community. In 2004, DFCI participated in two of The Partnership's Leadership Development Programs, the Senior Executive Program and the Boston Fellows Program. These programs support DFCI strategies to effectively attract, retain, and develop leadership among professional staff members of color.

University of Massachusetts at Boston: In 2004, Dana-Farber entered into a new affiliation with the University of Massachusetts at Boston (UMass). Eight UMass Boston nursing students from diverse backgrounds completed their community health rotation at DFCI during the fall of 2004. Dana-Farber plans to hire several of the students into a soon-to-start new graduates nursing program.

V. COMMUNITY BENEFIT EXPENDITURES

TYPE	ESTIMATED TOTAL EXPENDITURES FOR FY03	APPROVED PROGRAM BUDGET FOR FY05*
COMMUNITY BENEFITS PROGRAMS	(1) Direct Expenses [\$1,016,380] (2) Associated Expenses [\$] (3) Determination of Need Expenditures [\$40,000] (4) Employee Volunteerism [\$] (5) Other Leveraged Resources [\$ 2,663,261]	[\$TBD] *Excluding expenditures that cannot be projected at the time of the report.
COMMUNITY SERVICE PROGRAMS	(1) Direct Expenses [\$ 122,121] (2) Associated Expenses [\$] (3) Determination of Need Expenditures [\$] (4) Employee Volunteerism [\$] (5) Other Leveraged Resources [\$]	
NET CHARITY CARE or UNCOMPENSATED CARE POOL CONTRIBUTION	[\$ 4,640,559]	
CORPORATE SPONSORSHIPS	[\$ 197,170]	
	TOTAL [\$ 8,679,491]	

<p>[Hospitals]: TOTAL PATIENT CARE-RELATED EXPENSES FOR FY04: [\$133,802,939]</p> <p>[HMOs]: MASSACHUSETTS PLAN MEMBERS [# - N/A] [FOR PROFIT/NOT-FOR-PROFIT]</p>

VI. FUTURE INITIATIVES

DFCI is committed to developing and supporting culturally and linguistically appropriate cancer and HIV/AIDS education, prevention, outreach, and screening programs in collaboration with health care, community, and government partners. DFCI is also dedicated to addressing the pervasive and growing cancer-related health disparities affecting its surrounding communities and across the nation. Initiatives include:

- Expansion of the mobile mammography screening service in partnership with the City of Boston throughout all Boston neighborhoods.
- Supporting the Breast and Cervical Screening Collaborative program and its efforts to reach and provide services to hard-to-reach, underserved women.
- Expansion of education and outreach initiatives utilizing the new Blum Family Education and Resource Van; initiatives include:
 - ✓ Prostate cancer education and screening targeting African American men
 - ✓ Skin cancer prevention and education and screening services
 - ✓ Human papilloma virus (HPV)/cervical cancer education
- Establishing a patient navigator program to help underserved patients access care and support services and maneuver through the health care system.
- Supporting the National Black Leadership Initiative on Cancer, Boston Chapter and its efforts to expand its board and membership and promote greater awareness on cancer and clinical trials in communities of color.
- Incorporating the recommendations of the Boston Mayor's Task Force to Eliminate Health Disparities into DFCI's ongoing Health Disparities program.
- Continuing work with the Dana-Farber/Harvard Cancer Center member institutions in areas such as cultural competence and community engagement.
- Continuing our efforts with Partners-affiliated health centers to improve and expand cancer control and prevention programs.
- Generating more opportunities for underrepresented youth and young professionals to engage in mentorship and career development activities in health care and research.
- Collaboration on community outreach with fellow members of the newly formed Harvard Medical School Center for AIDS Research.
- Building an advocacy network, in collaboration with the Colorectal Cancer Working Group, to promote awareness about colorectal cancer screening and prevention.
- Strengthening the connection between the DFCI hospice program and the community.

- Strengthening the United Way/Jimmy Fund Collaboration by providing resources and training for capacity building and impact measurement.
- Sustaining our ongoing collaboration with MDPH, Partners-affiliated health centers, the BPHC, American Cancer Society, and other community organizations.

VII. REVIEW/EVALUATION OF COMMUNITY BENEFITS PLAN

DFCI has evaluated the appropriateness and effectiveness of its programs through the following approaches:

- Data collection through Massachusetts Department of Public Health, Boston Public Health Commission, hospital tumor registries, focus groups, and other available data sources assist DFCI in designing, monitoring, and evaluating our community outreach programs.
- DFCI staff serve on various statewide and regional committees including the Massachusetts Comprehensive Cancer Control Coalition, Colorectal, Prostate, and Skin cancer task forces, and Boston-based groups such as the Mayor's Task Force to Eliminate Health Disparities and the REACH 2010 Breast and Cervical Cancer Coalition.
- DFCI has established a number of committees to assist in program evaluation including the Board of Trustees Community Programs Committee, the External Advisory Committee, DFCI Internal Subcommittee, Health Disparities Committee, and Diversity Committee.
- DFCI is working with Partners to conduct neighborhood health center-based data collection. The data are used to set baselines, monitor performance, and measure progress against appropriate cancer control performance objectives.
- DFCI leadership serve on the Community Benefits Committee of the Conference of Boston Teaching Hospitals and the Attorney General's Community Benefits Task Force.