New York State Department of Health
Community Service Plan—Comprehensive Three-Year Format

Advancing the Prevention Agenda: Hospital for Special Surgery Priorities Promote Healthy Communities

The 2009 Comprehensive Three-Year Community Service Plan offers Hospital for Special Surgery (HSS) the opportunity to harness its knowledge, experience working in New York's multicultural arena, far-reaching professional affiliations, and its skilled health care leadership to the cause of strengthening the implementation of New York State Department of Health's (DOH's) *Prevention Agenda Toward the Healthiest State* initiative. The Hospital's contributions will be to the Priority Areas of: **Physical Activity and Nutrition,** and **Chronic Disease**, where HSS concentrates on musculoskeletal and rheumatic disorders, its expertise areas. The five programs presented under these two Priority Areas will also help to advance progress in addressing additional Priority Areas, including **Healthy Mothers, Healthy Babies, Healthy Children**, and particularly, **Access to Quality Health Care**, which is a major underlying theme of all HSS community programs.

1. MISSION STATEMENT

Hospital for Special Surgery's commitment to implement integrated and focused initiatives that provide the highest quality care to its patients and improve the health of its varied communities is articulated in its *Mission, Vision, and Values* statement, which is reviewed annually by the Hospital's Board of Trustees. It remains unchanged from the previous year.

Key principles include:

- Providing the highest quality patient care, improving mobility, and enhancing the quality of life for all and advancing the science of orthopedic surgery, rheumatology, and their related disciplines through research and education— regardless of race, color, creed, sexual orientation, or ethnic origin.

- Leading the world as the most innovative source of medical care, the premier research institution, and the most trusted educator in the fields of orthopedics, rheumatology, and their related disciplines.

- Setting and adhering to the highest possible standards based on Excellence, Integrity, Compassion, Respect, Teamwork, Quality, Safety, Innovation, Education, and Efficiency.

The Hospital's *Mission, Vision, and Values* propel Special Surgery's efforts to provide the highest quality patient care—inclusively, with cultural sensitivity and without discrimination. HSS extends this commitment outward—improving public health, empowering communities through information and services to act in their own interests, leveraging resources through effective partnerships, and strategically linking to other health care providers and government agencies.

2. SERVICE AREA

Special Surgery's immediate community lies within the boundaries of New York City's Community Board #8, which extends north from 59th Street to 96th Street and east from Fifth Avenue to the East River; more generally, its primary service area consists of the five boroughs of New York City. The suburban counties surrounding New York City, including those in New Jersey and Connecticut, comprise its secondary service area. However, the institution assists its many communities, whether in New York City neighborhoods, in the tri-state area, or around the world.

Investing in improving New York City's public health will pay substantial state dividends: in 2008, the percentage of the State's population that resides in New York City increased to 42.9 percent. Moreover, given the fact that immigrants remain attracted to New York City (in 2007-2008, 73,000 immigrants moved to the City) while the City's elderly population continues to grow (the NYC Department of Planning projects that the City's elderly population will rise 44.2 percent between 2000 and 2030), the need for focusing on prevention programs in Special Surgery's areas of specialty is more important now than ever before.

HSS musculoskeletal expertise in joint diseases such as osteoarthritis, osteoporosis, and autoimmune diseases such as lupus, resonates with the health needs of many New Yorkers, particularly culturally diverse communities, children, and seniors, cross-cutting categories. For example:

- The growing percentages of older New Yorkers, their susceptibility to osteoporosis and arthritis that compromises mobility and can lead to devastating falls;
- The disproportionate prevalence and severity of lupus among Asian American, African American, and Latina women and girls; and,
- Skyrocketing obesity among New York's children, particularly among Latino and African American youth, contributing to elevated rates of diabetes, heart disease and joint damage seen for the first time in these age groups.

These traditionally medically underserved communities face challenges in accessing health care to optimally address these issues so that early diagnosis and treatment are not impeded by cultural and language barriers, financial constraints, and lack of access to health insurance.

As part of the health planning process, HSS has identified and engaged with specific communities based on available census data and New York City Department of Health and Mental Hygiene Community Health Profiles. This is inclusive of the five boroughs of New York City and beyond, given the Hospital's focus on arthritis/musculoskeletal care. In addition, for CSP planning purposes there is an identified focus based on issues related to health disparities in the following communities: the Lower East Side (encompassing Chinatown), the Hospital's immediate and adjacent communities of the Upper East Side and East Harlem, Inwood/ Washington Heights, and the Bronx. Although epidemiologic data is not available on arthritis for specific communities/zip codes, HSS has used census data, the New York State Report on the burden of arthritis, and its own patient population demographics to help inform the priority initiatives for the Prevention Agenda.

3. PUBLIC PARTICIPATION

Public participation is a key ingredient to shaping and informing HSS patient and public education and prevention programs. Special Surgery works to strengthen its extensive public health education and social work programs through its collaborations with community organizations, public schools, city and state agencies, universities, colleges and the private sector. The design of the **five programs** supporting the **HSS Prevention Agenda Priority Areas** presented in **Section 5. Three-Year Plan of Action** highlights the role of public participation, and the process of involvement and community engagement of collaborating organizations in arriving at mutually identified goals to move forward NY State's Prevention Agenda.

Complementing these partnerships is Special Surgery's **needs assessment** process, which incorporates relevant national, state and city health data and priorities related to the Hospital's areas of specialty in musculoskeletal disease. In addition, the institution's internal collaborative processes facilitate systematic, scheduled feedback from its varied constituents, which include community members, patients, physicians and staff. This provides invaluable insight into public and patient needs, which is utilized to identify gaps and future programming areas.

Special Surgery utilizes the U.S. Government report, *Healthy People 2010*, which sets broad based goals and objectives to expand Americans' access to care, and to eliminate health disparities by age, gender, race, or disabilities, and pays special attention to information regarding the needs of all New Yorkers. For example, HSS actively supports New York State's initiative to reduce and prevent osteoporosis, and to combat obesity in children. These needs and priorities are reflected in HSS public education outreach programs.

The Hospital routinely conducts needs assessments among key groups in its community. In 2006, to assess the public's healthcare needs, the Public and Patient Education Department conducted a broad-based needs assessment of the HSS community, distributing more than 10,000 questionnaires. The survey collected information on community priorities, probed attitudes on major medical concerns, solicited feedback on health and wellness, and gathered valuable demographic information. The nearly eight percent response rate provided targeted feedback in 2007 to shape Special Surgery's community programs and its affiliated institutions, including New York Presbyterian-Irving Sherwood Wright Center on Aging.

Other needs assessment data is gathered through a rigorous evaluation process of public and patient programs. All Special Surgery Public and Patient Education Department and Department of Social Work programs include participant questionnaires, and the feedback from these is tabulated, evaluated, and used in formulating new or refined offerings. In addition, focus groups and in-depth qualitative and quantitative evaluations by users inform and direct program models, to ensure that they are consistent with meeting the needs of the communities being served. In 2008, nearly 4,900 people participated in 131 hospital and community based Public and Patient Education public health programs. The Department of Social Work Programs had approximately 19,000 patient/client contacts during this time period, who participated in illness-specific support and education programs available free to patients and the community.

Further, Special Surgery's Service Excellence Council reviews Press Ganey monthly patient comments and quarterly reports, and along with departmental managers and multidisciplinary teams develops improvements in services based on this feedback of patients' needs. To sample the range of its constituencies, HSS incorporates findings from its Gallup Survey, measuring employee engagement to strengthen programs that enhance staff development and improve quality.

Finally, to ensure that the range of needs assessment information is interpreted at the highest level of management, Special Surgery's Board of Trustees receives and reviews ongoing reports that include results of patient satisfaction surveys and a summary of the Hospital-wide Quality Assessment and Performance Improvement Program.

INTEGRATED APPROACH FOR PREVENTION AGENDA RESULTS

4. ASSESSMENT OF PUBLIC HEALTH PRIORITIES AND 5. THREE-YEAR PLAN OF ACTION

Context: HSS Prevention Agenda Task Force—Review, Plan, Respond

Hospital for Special Surgery's Public and Patient Education Advisory Committee is comprised of representatives across the Hospital's Departments including Internal Medicine and Rheumatology, Department of Orthopedics, Osteoporosis Prevention Center, Rehabilitation Department, Nutrition and Food Services, Metabolic Bone Disease Service, Public and Patient Education Department, Department of Social Work Programs, Pastoral Care, and HSS Board members and Advisors. Meeting bi-monthly, the Committee assesses, coordinates, and prioritizes a range of HSS community initiatives, including public health education symposia and support and educations programs. Yearly strategic planning by this group enables the Hospital and its programs to respond to changes in the health care environment and link its programs and external trends.

In February 2009, this Committee formed a special Community Service Plan Task Force to: methodically review the DOH Prevention Agenda for the Healthiest State materials, analyze current initiatives and partnerships in light of data and statistics describing community needs and health care disparities, and respond to the public health challenge presented by DOH and its new Comprehensive Three-Year Format planning document. The assessment process, which included consultations with partners as well as with the highest levels of HSS management, ensured Hospital-wide ownership of the two HSS CSP Task Force-identified priorities—**Physical Activity and Nutrition** and **Chronic Disease**—and designed the blueprint for reaching our common goals. *The Three-Year Plan of Action developed from the assessment process is included at the end of each HSS initiative description, thus integrating Sections 4 and Section 5 for coherence and ease of reference*.

HSS data, generated specifically for aligning the Hospital's comparative advantage with the DOH Community Service Plan, showed the following 2008 HSS patients visits by diagnosis (primary or secondary):

- Osteoarthritis = 24,739
- Osteoporosis = 5,106

- Rheumatoid Arthritis = 8,452
- Lupus = 2,092

An aging population and a high percentage of ethnic representation are also reflected in this portrait. When HSS looked at the ethnic composition of people 60 years and older coming to its ambulatory care clinics (ACC), the single largest category was Hispanic, comprising 33% of the ACC population, followed by African American at 20%, and Caucasian at 14%.

HSS Prevention Agenda Priority One: Nutrition and Physical Activity

Known as a "specialist in mobility," HSS is acutely aware of the important role that physical activity and nutrition play throughout the life stages including the optimum development of bones and muscles; maintenance of a healthy weight, bone strength, and balance; and falls prevention. HSS shares the Prevention Agenda's concern about the devastating impact on New Yorkers from diminishing rates of physical activity among all age groups, poorly-informed nutrition choices, and skyrocketing obesity rates among young New Yorkers, particularly Latinos and African-Americans.

Data Confirms Need to Address Alarming Obesity Rates in New York City's Children

Obese children are beginning to develop illnesses of excess associated with people in their 40's and beyond, including type 2 diabetes, joint breakdown and heart disease. HSS, prepared and positioned by the institution's comparative advantage in these specialties, fields patient and public education programs—informed by the communities to meet their needs—to provide healthy alternative behaviors. These prevention investments encourage a more active, productive and healthier population and hold positive implications for our communities. Residents of low-income and medically-underserved neighborhoods are particularly hard hit by the obesity epidemic.

The Hospital's data review underscored the relevance of this Health Priority in the Community Service Three-Year Comprehensive Plan:

- According to NYS DOH, *55.5% of New York City's adults* are overweight or obese compared to the *statewide average of 25 %.*[1,2]

- Obesity rates in New York City climbed an alarming 17% between 2002 and 2004—compared to 6% nationally for the same time period.[3]

- Among New York City's elementary school children, *24% are obese and 19% overweight.* The problem starts young—21% of kindergarteners are obese and by fifth grade the number stands at 25%, according to a 2003 survey by the New York City Department of Health and Mental Hygiene.

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[1] (Obesity Statistics in New York City. New York State Department of Health http://www.health.state.ny.us/statistics/prevention/obesity/county/newyorkcity.htm

[2] US Obesity Trends: 1985-2007. Centers for Disease Control and Prevention. http://wwwcdc.gov/obesity/data/trends.html

[3] Van Wye G, Kerker BD, Matte T, Chamany S, Eisenhower D, Frieden TR, et al. Obesity and Diabetes in New York City, 2002 and 2004. *Preventing Chronic Disease* 2008;5(2)

- The same survey of 2,682 children reveals alarming racial disparities—obesity affected 16% of Caucasians, 23% of African Americans, 14% of Asians and 31% of Hispanics.

- The rate of obesity is *skyrocketing among Hispanic children*, rising from 21% in 1996 to 31% by 2003.[4]

- Drilling down to neighborhoods affected by obesity shows that according to the NYC DOH, "in adolescents and adults aged 45 to 64, the prevalence of obesity is greater in the South Bronx than in New York City overall." Additionally, the percentage of overweight and obese adolescents and adults in East and Central Harlem is higher than in Manhattan and New York City.[5]

HSS Prevention Priority One Program

Super Nutrition Education for All Kids to Eat Right (SNEAKER©): Lesson for Life

The SNEAKER© Project provides culturally-sensitive nutrition education information for New York City's English-, Spanish- and Chinese-speaking children and their families. The project grew out of a 2003 collaboration between HSS and the New York State Attorney General's Office when, as a result of a successful legal action resulting from the Indirect Vitamins Purchasers Antitrust Litigation Settlement, the AG's office awarded the HSS Education Division the resources to implement a program focused on "the improvement of the health and/or nutrition of New York State citizens and/or the advancement of nutritional, dietary or agricultural science."

The bilingual educational design of SNEAKER© teaches children, adolescents and their families to appreciate the importance and sources of calcium and Vitamin D intake, to understand the value of consuming whole grain and high fiber foods, to recognize the perceived versus the real amounts of sugar hidden in certain foods and beverages, to learn the definition of portion control and sizes, and to identify healthy food options in different situations—the school cafeteria, fast food restaurants, street stands and home—all accomplished through educational interactive workshops and website activities in order to prevent adult onset osteoporosis and to reduce obesity.

Obesity challenges growing bodies: bones and cartilage in the development process are not strong enough to bear excess weight. According to the Journal of Pediatric Physical Therapy, in childhood obesity, orthopedic problems can affect the lower limbs and joints. Hip problems and abnormal growth of the main bone of the lower leg below the knee, are most common; excess weight results in wear and erosion of weight-bearing joints.

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[4] Thorpe, Lorna E., Deborah G. List, Terry Marx, Linda May, Steven D. Helgerson, and Thomas R. Frieden. Childhood Obesity in New York City Elementary School Students." *American Journal of Public Health* 94 (2004): 1496-500.

[5] Matte T, Gordon C, Goodman A, Selenic D, Young C, Deitcher D. "Obesity in East and Central Harlem: A look across generations." New York, NY: New York City Department of Health and Mental Hygiene, 2007.

SNEAKER© targets some of New York City's most medically underserved communities such as East Harlem, Harlem, the Lower East Side, Manhattan's Chinatown, and sections of the Bronx. Children and their families in these areas are predominantly Asian Americans, Latinos and African Americans. HSS and its partners use a bilingual outreach model to maximize impact: the experienced HSS multilingual and multicultural public health staff demonstrates sensitivity and knowledge of religious and cultural beliefs, literacy and educational issues, and family practice. Since its inception in 2003, SNEAKER© has reached 2,855 children; 84% ranged in age from 4 to 13 years, 14% represented youth 14 to 18 years, and 2% were from 18 to 21 years old.

The Three-Year Program Plan projects leveraging relationships with current partners and expanding the program's reach with new partners. Current partners and activities include:

Girl Scout Council of Greater New York (GSCGNY) - The SNEAKER© Patch earned by troop leader nutrition sessions or a one-day workshop, is offered within NYC's five boroughs. HSS Public and Patient Education Department produced and continue to revise the patch program resources, including the Leaders Guides that outline the learning objectives and the Brownie and Junior Workbooks, annually reaching over 500 girl scouts.

New York State Osteoporosis Prevention and Education Program (NYSOPEP) - As one of five selected state regional centers, the HSS Education Division targets primary and secondary prevention of osteoporosis annually reaching over 2,700 community members through education programs and 40,000 through consumer health literature.

New York City Public Schools - HSS works with diverse cultures and medically underserved children and their families to screen children in East Harlem, Chinatown, the Lower East Side and Bronx public schools to catch orthopedic problems early, through its Pediatric Outreach Program (POP). As HSS physicians examine children for spinal or other orthopedic conditions, increasingly, nutrition issues figure prominently in the reason for medical referrals.

- HSS will leverage existing partnerships with NYC public schools to promote SNEAKER project goals and raise awareness of joint damage due to excess weight.

Charles B. Wang Community Health Center (CBWCHC) - HSS works with Chinatown's largest community based ambulatory health care facility to provide pediatric orthopedic specialty care. The collaboration with CBWCHC has established a valuable connection to the Chinatown Asian-American neighborhood, particularly as the community has experienced rapid growth and endured economic, linguistic, and cultural barriers to health care access.

- HSS will leverage this relationship to explore a SNEAKER expansion focusing on calcium and Vitamin D education due to the increased risk of osteoporosis within the Asian American population.

Weill Cornell Clinical Translational Science Consortium Community Engagement Core -The mission of the CTSA Community Engagement Core is to improve the health status of the community through research. The specific aims are designed to create a framework for efficient research/community collaboration and include integration, research, outreach and education. The role of HSS is to engage diverse communities in understanding research in musculoskeletal medicine and to involve and share research findings with the community.

- HSS will partner with members of the Community Engagement Core to promote the goals of SNEAKER within medically underserved communities.

New program partnerships are also projected with the following organizations and programs: Community Health Worker Network of New York City, School-based Health Centers, and Special Surgery's Charla de Lupus program.

To accomplish the Three-Year Plan of Action, HSS will roll out SNEAKER's © bilingual public health tools, including SNEAKER © educational workshops, activity book and award winning Cookbook, working on the primary and secondary levels to prevent and respond to escalating rates of childhood obesity. A key program element is to teach the benefit of good nutrition, particularly the importance of including adequate calcium and Vitamin D in diets, essential to prevention of the onset of osteoporosis.

THREE-YEAR PLAN OF ACTION

Prevention Agenda Priority One: Physical Activity and Nutrition Program

SNEAKER© in Action

HSS will implement SNEAKER©, through its existing partners and new collaborators, to reach children, parents, caregivers and teachers to help children and adults change their eating patterns by engaging in the interactive program to learn essential facts and strategies about nutrition and physical activity. The expanded program will focus on the overall goal of reducing childhood and adult obesity by teaching the benefits of good nutrition—lowering sugar intake, controlling portion size, and increasing consumption of whole grains, calcium and Vitamin D.

Specific program goals include:

- Increasing awareness in children and adults that obesity is a key health concern,
- Helping children and adults adopt healthier nutrition patterns in any setting, and
- Training teachers, health care workers, caregivers and parents in the SNEAKER© program model.

The Sneaker© Three-Year Plan in brief follows.

Three-Year Plan: Priority Area Number One/Physical Activity and Nutrition
SNEAKER©: Lessons for Life, Primary and Secondary Prevention

HSS Aligns with Prevention Agenda Goals:

- Reduce the % of obese children
- Reduce the % of obese adults

SNEAKER© Participants will Learn:

- Importance of calcium and vitamin D intake
- Understand value of whole grain and fiber-rich foods
- Recognize real versus perceived amounts of sugar in foods and beverages
- Learn portion control by understanding portion sizes
- Identify health food options in different settings

Program Implementation:

- Assess educational gaps through needs assessments or focus groups
- Organize educational workshops within the community by HSS health educators
- Organize trainings of trainers—core group of community health workers to expand SNEAKER© within communities
- Disseminate nutrition and exercise information for consumers and via website

Supportive Community Partnerships Deepen:

- NYC Public Schools
- GSCGNY
- NYSOPEP
- International Center for Disabilities
- Charles B. Wang Heath Community Health Center
- Safe Kids International
- Pediatric Health Care Coalition
- NYC DOH
- Clinical and Translational Science Awards (CTSA), Community Engagement Core to improve health through research
- NYC Public Libraries

Reach Extended through New Partnerships:

- Community Health Worker Network of NYC
- School-based health centers
- HSS lupus program for Spanish speakers, Charla de Lupus/Lupus Chat®

Measuring Program Outcomes and Benchmarks

Year 1

- Assess gaps in nutritional education knowledge and practice in partners, such as Charla de Lupus, school-based programs such as POP, through focus groups and needs assessment
- Use SNEAKER© curriculum to address nutrition education and practice gaps
- Develop specific outcomes measures based on needs assessment using qualitative community-based participatory research, working with collaborators for example, pre- and post- survey questionnaires, focus groups, pre- and post- intervention and key informant interviews
- Collect process data such as number of participants, number of trained SNEAKER© community health care workers, number and location of programs offered
- Discuss findings and initial feedback with partners and community

Year 2

- Implement programs
- Apply agreed-on outcomes measures to targeted populations and communities
- Organize and analyze data
- Continue collecting and applying outcomes measurement instruments, adapt if necessary
- Develop new collaborations
- Share findings with community

Year 3

- Implement programs
- Train community health workers
- Continue collecting and applying outcomes measurements
- Continue collecting quantitative data
- Present 3-year totals and analysis
- Discuss with partners and community
- Present findings/next steps

HSS Prevention Agenda Priority Two: Chronic Disease

Context: Interlinking Programs Advance Prevention Agenda

The DOH Prevention Agenda initiative presents HSS an opportunity to strengthen public and community efforts to combat chronic musculoskeletal diseases that align with this specialty Hospital's comparative advantage. **Under this DOH-identified priority, HSS is focusing on improving the health and reducing health care disparities among populations affected by arthritis and lupus.** The **four programmatic interventions** require distinctly designed programs for the Latino, African-American and Asian communities, as well as tailored outreach to adults 60 years and older. Together, these four programs address the inter-linkages of promoting good health through education, support, access to care, and the importance of exercise and sound nutrition. Each is central to Special Surgery's mission and commitment to improving community health. They are: Osteoarthritis Awareness and Prevention, VOICES 60+ Senior Advocacy Program, Charla de Lupus/Lupus Chat ®, and LANtern ® (Lupus Asian Network). Following a brief description of how the Hospital addresses this priority, each of the four programs will be separately described.

HSS Mission: Investing in Mobility and Community

Arthritis is a disease of the joints that causes pain, swelling and limits joint movement; it affects the surrounding as well as the body's other connective tissues. While there are more than 100 types of arthritis, osteoarthritis is the most common type and results in the wearing down of cartilage, restricting motion, causing pain and disability.

Fulfilling the Hospital's Mission Statement, "*To provide the highest quality care, improve mobility, and enhance the quality of life for all to advance the science of orthopedic surgery, rheumatology, and their related disciplines through research and education*," points the way to program priorities. The data concerning osteoarthritis (OA) and its prevalence, along with information gained from community needs assessments, partners and health agencies, motivated HSS to *design a new program specifically focused on osteoarthritis*. The initiative benefits from long-standing partnerships with the National and New York Chapter of the Arthritis Foundation, New York Presbyterian Hospital (NYPH) Greenberg Academy for Successful Aging, HSS Division of Rheumatology, the Charles B. Wang Community Health Center (CBWCHC) in Chinatown, New York Public Library, Baruch Elder Service Team (Best), East Side Council on Aging (ESCOTA), NYC DOH and others.

As the nation's leading specialty hospital for orthopedics and rheumatology, HSS treats thousands of patients from all parts of the State and from around the world for arthritis. Among the public, arthritis ranks high on the list of health concerns. According to a Community Program Interests and Needs Assessment Survey conducted in 2003 by the NYPH Greenberg Academy for Successful Aging, 63% of respondents ranked arthritis at the top of their interest list. More recently, Special Surgery's Public and Patient Education Division conducted a 2007 Community Healthcare Needs Assessment of 759 community members and the highest percentage, 54%, indicated a concern about arthritis.

HSS Community Outreach Programs

To address community concerns, HSS offers a range of programs that provide arthritis-related information in workshops, lectures and exercise wellness classes—Yoga, Pilates and TaiChi—designed for all ages and abilities to help people diagnosed with arthritis to manage this chronic disease and empower them to keep active and maintain a healthy lifestyle.

Communities benefit from Special Surgery's engagement with the Clinical and Translational Science Awards (CTSA) Community Engagement Core formed to improve health status of the community through research. Under the CTSA grant, the HSS-led Greenberg Academy implemented the Arthritis Foundation Exercise Program in a Naturally Occurring Retirement Community (NORC) Lower East Side Branch. The long-standing partnership between the National Arthritis Foundation and HSS benefited community residents who accessed the Arthritis Foundation Self-Management Programs. To date, 182 community members have completed this 8 week intervention program. To sustain and further expand the Hospital's reach into the community, an additional four HSS staff are trained program instructors.

According to the Arthritis Foundation, program participants report that they have increased knowledge about their arthritis, use exercise and relaxation techniques more frequently, demonstrate higher levels of self-confidence and less depression, experience less pain and make fewer doctors visits. A national strategy to diminish this disease's toll on Americans and the health care system is an investment in mobility and health care savings.

Data Confirms Need to Address Osteoarthritis Challenge

- Arthritis poses a **national** challenge to America's health with an estimated 46 million American adults (about 1 in 5) annually reporting doctor-diagnosed arthritis according to the CDC report, *Arthritis—Meeting the Challenge—At a Glance 2009.*

- Arthritis is the country's most common cause of disability with <u>nearly 19 million Americans reporting activity limitations because of arthritis each year.</u>

- Immense costs result from the staggering 992,100 arthritis hospitalizations and 44 million outpatient visits. In 2003, the total cost of arthritis amounted to $127.8 billion, including $80.8 billion in direct medical costs and $47 billion in lost earnings.

- Although the disease is more common among adults 65 years or older, people of all ages can be affected; nearly two-thirds of people with arthritis are younger than 65, and the recent CDC study indicates that some form of the disease affects 1 in 250 children.

- While arthritis affects all racial and ethnic groups, it is more common among women (24.4%) than men (18.1%) in every group.

- The CDC projects that by 2013—just 20 years from the start date of the Prevention Agenda—the number of adults with doctor-diagnosed arthritis will increase to 67 million, limiting the activity of more than one-third of those affected. Under the direction of the Osteoarthritis Alliance Leadership Group, which includes HSS, in 2010 the Ad Council will launch a public health campaign on osteoarthritis.

- In **New York** for the year 2005, this chronic disease affected approximately 3.7 million adults, which amounts to more than 26% of the State's adult population.

- 56%, or 1.4 million of those age 65 or older experience arthritis. Additionally, 7.4% of younger New Yorkers aged 25 to 34 cope with arthritis.

- The number for **New York City** residents of all ages with arthritis totals 21.7%.

- Nearly one third of New Yorkers with arthritis are poor, with annual household incomes of less than $15,000.

- The **statewide total cost** from this chronic disease in 2003 amounted to $8.7 billion, with $5.6 billion in medical costs and $3.1 billion in lost wages.

- In 2008, the Hospital treated more than 7,800 patients diagnosed with OA and more than 5,500 of them required a partial or total knee replacement.

Prevention Agenda Priority Two Program

Osteoarthritis Awareness and Intervention in Action

This HSS Prevention Agenda Priority Two Program emerged from the Hospital's review of its patients and their concerns, combined with a number of key inputs such as: an analysis of national, state and city data on arthritis incidence and cost—particularly osteoarthritis, conversations with partners, local and state health departments. Increasingly, health policy makers and authorities recognize the urgency of increasing public awareness of OA and the need to understand the toll of this chronic disease and targeted interventions. OA has moved firmly onto the national agenda.

- OA identified as one of five priorities in the chronic disease category by newly appointed head of CDC.
- Substantial funding to address OA Prevention and Early Diagnosis appears in the Recovery Act, even in the midst of economic downturn.
- The Advertising Council responds to the OA crisis by planning launch of a national OA public health media campaign in 2010.
- Both the NIH and DOD announce OA research funding for 2010 or 2011.

This changing context presents a new opportunity for HSS to leverage its expertise and ongoing community partnerships to advance the Prevention Agenda's focus on chronic disease through its proposed **Osteoarthritis Awareness and Intervention in Action** program. In concert with the Ad Council's upcoming OA media effort, the HSS program will expand non-surgical patient options through the OA risk assessment screening tool, as well as contribute through prevention efforts, improved treatments resulting from research and establishing registries.

OA risk factors can be modified through life style changes. For example, losing weight relieves pressure and wear on knees and other joints. Teaching good sports techniques, warm up exercises, and training coaches and athletes can reduce potential OA sports-related injuries.

Similarly, expanding OA understanding among medical professionals will lead to sharper diagnoses, for example, the connections between trauma and possible OA-related impact. Looking at the implications of certain occupations that bring with them joint stress from hard physical labor, heavy lifting, knee bending and repetitive motion can help workers protect themselves from potential joint damage. These working conditions affect men working in construction and home improvement, agriculture, blue collar manufacturing jobs and engineers. Women involved in similar employment or in cleaning, restaurant work or in small and retail businesses are also at risk.

To accomplish the Three-Year Plan of Action, HSS will launch a new public intervention and awareness program that will make a significant contribution to the Prevention Agenda by focusing on this emerging and under-resourced area.

THREE-YEAR PLAN OF ACTION

HSS Prevention Agenda Priority Two: Alleviating Chronic Disease Osteoarthritis Awareness and Intervention in Action

Together with its partners, HSS will implement Osteoarthritis Awareness and Intervention in Action using its broad network of existing partners and new collaborators, leveraging experience of working with underserved communities, maximizing its expertise through newly emerging initiatives directed at combating OA and improving New Yorkers' health. The new program will focus on the overall objective of addressing *modifiable risk factors* by *raising awareness of OA and providing OA patients with life style management strategies*.

Specific program goals include:

- Increasing public awareness of OA as a priority public health concern,
- Educating the public about the spectrum of treatment options for OA from non-surgical to surgical,
- Helping people with OA increase their knowledge of the disease,
- Offering people with OA techniques to better manage the impact of the disease, and
- Implementing OA life style and behavior management programs.

The Osteoarthritis Awareness and Intervention in Action Three-Year Plan in brief follows.

Three–Year Plan: Priority Area Number Two/Chronic Disease
Osteoarthritis Intervention and Awareness in Action: Enhancing Mobility, Primary and Secondary Prevention

HSS aligns with Prevention Agenda Goals:

- Highlight modifiable risk factors
- Raise public awareness of OA

Osteoarthritis Intervention and Awareness in Action will:

- Partner with Arthritis Foundation on their 2010 OA Awareness Campaign
- Teach life style management strategies
- Educate the public of spectrum of OA treatment options, non-surgical to surgical
- Help OA patients better understand and manage the disease
- Implement OA life style behavior management programs

Program Design:

- Survey and analyze factual and clinical information
- Assess knowledge gaps in OA treatment options through needs assessments or focus groups of patients, new and existing partners and the community
- Develop program elements based on revealed gaps

Program Implementation:

- Build relationships with new and existing partners
- Determine target populations and locations
- Roll out evidence-based Arthritis Foundation life style management programs

Supportive Community Partnerships Deepen:

- National Arthritis Foundation
- CBWCHC
- NYSDOH
- NORCs
- Chinese American Planning Council
- Greenberg Academy for Successful Aging

Reach Extended through New Partnerships:

- United Federation of Teachers
- New York Road Runners Club and other possible training clubs.

Measuring Program Outcomes and Benchmarks

Year 1

- Assess gaps in OA knowledge and treatment in community, partners and health care providers
- Identify new and existing partners
- Identify outcomes measure (such as SF 36 and others)
- Develop specific outcomes measurements based on knowledge gap assessment; design pre- and post-survey questionnaires
- Implement OA program
- Collect process data such as number of participants in programs, number of programs offered
- Discuss with partners and community

Year 2

- Continue implementation of programs
- Apply agreed-on outcomes measures to targeted populations and communities
- Organize and analyze data
- Continue collecting and applying outcomes measurement instruments, adapt if necessary
- Develop new collaborations
- Discuss findings and feedback with partners and community

Year 3

- Continue implementation of programs
- Train community health workers
- Continue collecting and applying outcomes measurements
- Continue collecting quantitative data
- Present 3-year totals and analysis
- Discuss findings and feedback with partners and community
- Present findings/next steps with community

Prevention Agenda Priority Two Program

Improving the Medical Care Experience and Home Safety/Support for Culturally Diverse Older Adults with Arthritis

HSS continues to be a leader in caring for older people with arthritis through its wide ranging clinical services, support groups, self-help programs, and patient and public education. Recognizing the challenge that many older people find in accessing medical care and social supports, HSS launched VOICES 60+ to help seniors, many from low-income and Spanish-speaking communities.

The growing number of Americans age 55 and older presents an extraordinary opportunity to apply the Prevention Agenda and improve health. HSS proposes to meet the Prevention Agenda's challenge to reduce health care disparities through a targeted program that enhances the medical care experience of low income, ethnically diverse patients in its Ambulatory Care Center clinics and in the Upper East Side and East Harlem communities. Research affirms that these groups have experienced significant health disparities in terms of access to care, doctor-patient communication, and treatment adherence.[6]

Data Confirms Need to Address Prevention and Increase Access for Culturally Diverse Older Adults

- Nationally, by 2030, the number of people 55 and older will almost double, rising from 60 million (21% of the total U.S. population) to nearly 108 million (31%).
- During that same period, the number of Americans over 65 will more than double, expanding from 34.8 million in 2000 (12%) to 70.3 million (20% of the total population.)
- Hispanics are the fastest growing ethnic group in the country, growing from 22 million in 1990 to 44.3 million in 2006; by 2050, it is estimated that Hispanics will total 102 million.
- The number of Hispanic/Latino elderly is also growing at 3.9% annually and by 2020, they are expected to total 9% of all people 65 and older; by 2050, they will increase to 16.4%.
- In **New York City**, the number of Hispanic elderly has increased by more than 26% from 1990 to 2000 (Source: US Bureau of the Census).

Communication Improves Outcomes

Findings from a focus group HSS conducted in Spanish with older Hispanic HSS patients attest to the importance of linguistically and culturally appropriate communications to improve participants' health care experience. The group underscored how important it is to them that: health care is offered in a language they understand and with which they are comfortable, takes into account health literacy concerns, and that providers convey respect and interest in their

[6] Institute of Medicine Report, "Unequal Treatment", 2003

personal well-being, and their cultural/spiritual beliefs, including complementary medicine modalities. Enhancing doctor-patient communication is especially critical in managing the impact of arthritis and its complex treatment regimens, and in falls prevention, which is closely linked to mortality in older adults and the frail elderly.

- Research has shown that level of health literacy and the quality of doctor-patient communication are critical to health care outcomes and medical adherence.[7]

- Older adults receive less health education and counseling than younger patients, ask fewer questions, and doctors spend less time on psychosocial issues during medical appointments.[8]

- Medical literature recognizes that the relationship with the medical team is essential in enhancing patient adherence and that as many as 40% of patients do not adhere to treatment regimens: "Nonadherence to medications causes 125,000 deaths annually and accounts for 10% to 25% of hospital and nursing home admissions. This makes nonadherence…one of the most expensive disease categories."[9]

- Language is perhaps one of the most significant barriers to accessing optimal health care. This has a direct impact on Hispanic patients who are monolingual in Spanish, and bilingual patients who prefer to receive health care services in Spanish.[10] Bilingual and bicultural staff and volunteers are essential to bridge the language and cultural divides.

Prevention Agenda Priority Two Program

VOICES 60+ Senior Advocacy Program

The goal of VOICES 60+ is to enhance the medical care experience of low income, ethnically diverse (primarily Hispanic and African American) HSS patients 60 and older, by helping them to navigate and access the support, education, and community resources, they need to manage their rheumatologic or musculoskeletal disorders to improve their quality of life. To advance the Prevention Agenda, HSS will expand its existing program priorities to enhance doctor patient communication in two targeted communities, and create specific linkages with culturally appropriate community resources.

The program began in 2006 as a three-day a week pilot program, and moved to full-time status in 2007. In its first two years, the program had 9,239 patient contacts and an evaluation confirmed that 93% surveyed were satisfied with the program, with 85% saying they were "very" or "extremely" satisfied. A majority reported that the program "very much increased" their overall satisfaction with their medical care. However, Special Surgery's Spanish speakers reported that

[7] Adelman R, Greene MG. Psychosocial factors in older patient's medical encounters. *Research on Aging* 1996; 18:1, 84-102.
[8] Kinnersley P, Edwards A, Hood K, Cadbury N, Ryan R, Prout H, Owen D, MacBeth F, Butow P, Butler C. Interventions before consultation for helping patients address their information needs (Review). *The Cochrane Library*: 2007, Issue 3.
[9] Atreja, A, Bellam N, Levy SR. Strategies to enhance patient adherence: making it simple. *Med Gen Med*. 2005; 7 (1)
[10] Preciado, J. and Henry, M. (1997). Linguistic barriers and health education and services. In Garcia, J.G. and Zea, Maria Cecilia (Eds.). *Psychological intervention and research with Latino populations* (pp. 235-254). Boston, MA: Allyn and Bacon.

the program was less likely to improve communication with their health care team. This feedback highlighted the need to better address Hispanic patients' concerns and led to the development of tailored outreach strategies to address communication barriers.

Expanding VOICES 60+ through Community Partnerships

HSS will build on the success of VOICES 60+ in collaboration with leaders and agencies that serve older adults, particularly on the Upper East Side and in East Harlem. It is relevant to our intervention that, according to the NYC Department of Health and Mental Hygiene's Community Health Profile, the Upper East Side of Manhattan has the third highest rate of hospitalizations from falls, more than 40% higher than the City's overall rate. Additionally, the neighborhood's fall-related hip fracture hospitalization rate was 20% higher than the rest of the City. Furthermore, the National Osteoporosis Foundation notes that hip fractures are on the rise among Hispanics, with half of all Latinas older than 50 having low bone mass, a risk factor for falls. The average direct cost per fall is nearly $9,400 nationally (National Osteoporosis Foundation).

Currently, HSS works with a wide range of community organizations and continues to expand collaborations, which is essential to design and deliver this program. VOICES 60+ collaborates with the East Side Council on the Aging (ESCOTA) and East Harlem InterAgency Council on Aging, which are two consortiums of key community service providers for older adults in HSS' primary and adjacent communities.

The following are community partners with which VOICES 60+ has begun a dialogue regarding mutual goals. These include comprehensive community-based senior service programs, senior centers, and home care agencies. VOICES 60+ will actively engage these service providers to assess interest in educating culturally diverse older adults concerning ways to enhance their communication with their medical team about their arthritis, and its treatment, with a special focus on falls prevention.

- <u>Greenberg Academy on Successful Aging, HSS Education Division:</u> Identify and facilitate relevant public education seminars targeted to older adults and present our mutual programs at community health and senior fairs.
- <u>New York Foundation for Senior Citizens</u>: Provide a series of presentations on doctor-patient communication and health management to one of their senior housing facilities on the Upper East Side, with a focus on engaging the ethnically diverse residents of the program.
- <u>Burden Center on Aging, Lenox Hill Neighborhood Association</u>, and <u>Health Outreach, NewYork Presbyterian Hospital:</u> Work with these current community partners to assess opportunities for specific initiatives together.

Linking patients with agencies that provide language accessible individualized home care solutions may help to prevent falls, reduce isolation and improve overall quality of life. Toward this end, we have established relationships with the following organizations.

- <u>Senior Health Partners</u>**:** A coordinated home care plan with a variety of service providers in many languages, specifically for our Spanish speaking patients experiencing difficulty managing and navigating the health care system.

- Senior Companions, Henry Street Settlement: This is a federally funded program that offers free companion service for older adults, provided by older adult volunteers.
- RAICES, Spanish Speaking Elderly Council: Mental health clinics and senior centers predominantly serving the Hispanic community. HSS has just signed a linkage agreement with this community agency as a referral source.

Through community presentations in senior centers and collaborations with community agencies, the program will highlight areas of mutual interest and assist in raising awareness to reduce the multiple health disparities patients' face, and optimize health maintenance, doctor-patient communication and quality of life for ethnically diverse older adults, and the frail elderly.

THREE-YEAR PLAN OF ACTION

HSS Prevention Agenda Priority Two/Chronic Disease

VOICES 60+ Senior Advocacy Program

HSS will implement VOICES 60+ Senior Advocacy Program using its broad network of existing partners and new collaborators, leveraging experience of working with ethnically diverse, older New Yorkers—with special attention to Spanish-speaking seniors—that will reduce the experience of health care disparities among this population. The expanded program will be accomplished through presenting educational workshops with community partners to address two main concerns which impact on medical adherence and health outcomes for older adults: enhancing doctor-patient communication and falls prevention. Depending on the target audience needs, these presentations will be in either English or Spanish.

Specific program goals include:

- Educating and raising awareness of ethnically diverse older adults on issues related to communication with their health care providers about arthritis and their related needs, including a focus on falls prevention by collaborating with community service providers.
- Increasing patient safety and support at home and in their social environment, by linking older adults with community partners that will provide language and culturally appropriate services.

The VOICES 60+ Senior Advocacy Program Three-Year Plan in brief follows.

Three–Year Plan: Priority Area Number Two/Chronic Disease
VOICES 60+ Senior Advocacy Program, Primary and Secondary Prevention

HSS aligns with Prevention Agenda Goals:
- Address health care disparities
- Reduce age-related, cultural, and language barriers to health care related to the impact of arthritis.

VOICES 60+ Senior Advocacy Program will:
- Develop educational workshops on enhancing doctor-patient communication and falls prevention for a culturally diverse community of older adults with arthritis.
- Expand community partnerships in targeted neighborhoods with a focus on the Upper East Side and East Harlem, to increase our patient's safety and support at home through linking to these language and culturally appropriate programs

Program Design:
- Meet with leaders of older adult community service providers
- Identify mutual program needs and goals to serve this ethnically diverse older adult population
- Develop curriculum to present to our community partners (in Spanish, where appropriate)
- Create evaluations tools to measure presentation impact and satisfaction
- Develop specific feedback and referral mechanisms with the community agencies that provide home services to HSS patients
- Collaborate with HSS's Greenberg Academy to prioritize and strategize to meet the needs of target populations

Program Implementation:
- Workshops take place at community partner agencies
- Patient's are referred to relevant homecare services
- Relevant outcome measures are utilized to assess impact

Expanding Supportive Community Partnerships:
- ESCOTA (East Side Council on the Aging) and the East Harlem InterAgency Council on Aging - two consortiums for expanding community service network.
- Greenberg Academy for Successful Aging
- Senior Health Partners
- Senior Companions, Henry Street Settlement
- RAICES, Spanish Speaking Elderly Council
- New York Foundation for Senior Citizens
- Burden Center on Aging and Lenox Hill Neighborhood Association

Measuring Outcomes and Benchmarks:

Year 1
- Build on VOICES 60+ current initiatives
- Identify internal and external community partners and health care service providers
- Pilot referrals to identified service providers
- Define common goals
- Determine number of workshops with partners; review feasibility, resources and number of people who will benefit
- Pilot workshop implementations

Year 2
- Make interim changes and incorporate participant feedback
- Continue workshop implementation
- Develop specific metrics to assess participant satisfaction, demographics and reach, community partner feedback and overall impact
- Prepare program evaluations to determine user satisfaction with services provided and impact of safety and support at home as a result of community partner referral
- Apply agreed-on outcomes measures to targeted populations and communities, adapt if necessary
- Collect, organize and analyze data, including patient demographics, reach, satisfaction, intended behavioral change
- Share impact and results with community partners

Year 3
- Continue to implement initiatives
- Reinforce partners' network
- Continue collecting and conduct analysis of qualitative and quantitative data changes
- Discuss findings with community partners and incorporate any necessary

Reducing Health Disparities for Culturally Diverse Women Living with Lupus

Lupus (systemic lupus erythematosus-SLE) is a chronic and potentially life-threatening autoimmune disease that can cause profound fatigue, joint pain, and organ failure, disproportionately affecting women of color. The illness presents complex challenges to diagnosis and treatment. Currently, the cause and cure for lupus are unknown, but early diagnosis and treatment can help prevent illness progression and improve health outcomes. HSS is a major center for pioneering lupus clinical care and research.

Data Confirms Women of Color Face Disproportionate Risk

- Nine times out of ten lupus strikes women, who usually develop the disease between the ages of 15 and 45 (child-bearing age) and Asian Americans, African Americans, Latina, and Native American women are two-to-four times more likely to have lupus than Caucasian women.
- Studies demonstrate that minority women experience more severe manifestations of lupus than do Caucasian women, such as renal involvement and higher mortality rates. Compounding these ethnic disparities, factors such as low income, educational level and access to health care also disproportionately affect these populations.[11,12]
- Since 1994, the LUMINA (*Lupus in Minorities: Nature vs. Nurture*) research team studying a multi-ethnic U.S. cohort of African Americans, Latinas, and Caucasians) reported that over time, African Americans and Latinas have more severe disease.[13]
- The NIH reports that Latina and African American women have a higher frequency of neurological problems such as hemorrhage, seizures and stroke.
- According to the CDC, Latina and African Americans women have three time higher death rates than whites.
- Among children, girls are 4.5 times more like to be affected by lupus than are boys.

Culturally Sensitive Lupus Support and Education Programs Address Health Care Disparities

With more lupus support and education programs than any other hospital in the country, HSS leads in the development of culturally specific models to reach the women, adolescents and families who may benefit. HSS is the only hospital serving as a community partner for the

[11] Alarcón GS, et al. Systemic lupus erythematosus in three ethnic groups: III. A comparison of characteristics early in the natural history of the LUMINA cohort. Lupus in minority populations: Nature vs. Nurture. *Lupus*; 1999 (3): 197-209.
[12] Alarcón GS, et al. Systemic lupus erythematosus in three ethnic groups: II. Features predictive of disease activity early in its course. *Arthritis and Rheumatism* 1988; (41): 1173-1180.
[13] Bertoli, M. A, et al. (2008). Systemic Lupus erythaematosus in a multiethnic US cohort (LUMINA) LIII: disease expression and outcome in acute onset lupus. *Annals of the Rheumatic Diseases* 67:500-504.

Department of Health and Human Resources' Office of Women's Health National Lupus Awareness Campaign, launched in March 2009, which lists HSS lupus programs in English and Spanish on the campaign's Web site, www.couldihavelupus.gov The goal of this federal initiative, in partnership with the Ad Council, is to increase early diagnosis and treatment, with a focus on traditionally underserved women of color.

LupusLine®, begun in 1988, is the only national telephone peer support program offering one-to-one emotional support and education to people with lupus in the New York tri-state region, across the country and internationally; the program links people who need the service with trained volunteers who have lupus, providing over 20,000 client contacts.

The success of the LupusLine program, measured through published program evaluation, provided a framework to launch more culturally specific national initiatives targeting Latino and Asian American women affected by lupus; Charla de Lupus/Lupus Chat® and LANtern® Programs.

Prevention Agenda Priority Two Program

Charla de Lupus (Lupus Chat)®

Support for Spanish Speakers with Lupus

Charla de Lupus/Lupus Chat® is a unique national program offering people with lupus and their families peer health support and education in both English and Spanish. Based on extensive community needs assessments, this program specifically seeks to reach Hispanics with lupus and their families, particularly women. According to the 2006 New York City Community Health Profiles:

- New York is home to a large, growing population of Hispanics who currently represent 16% of the State's total population.

- HSS focuses services on neighborhoods with a high proportion of Hispanic residents, such as Inwood and Washington Heights in Manhattan where 71% of the people are Hispanic, and the Hunts Point or Mott Haven communities in the Bronx where nearly all 122,000 residents are either African American (24%) or Hispanic (71%). (In comparison, the percentage of Hispanics in New York City is 27%.)

- One-in-five residents in Inwood and Washington Heights is obese, the percentage of people living in poverty is higher than in New York City as a whole, and the birth rate of teenage mothers is higher than in the rest of the City.

Since its inception in 1994, through its varied programs Charla de Lupus has had a total number of approximately 30,000 client contacts and reaches people beyond New York's borders and internationally. Specially trained peer health educators provide culturally relevant education and support helping empower participants and enhancing the quality of life for adults, teens, and children with lupus, and their family members. The initiative also targets Spanish media—radio and print—to raise awareness of available services.

The program consists of:

Charla Line: Offers one-to-one contact through the program's national support and education to adults, teens, and children living with lupus—as well as to family members—through its toll free number.

On-site outreach at community clinics: One-to-one contact is available on site at various rheumatology clinics in NYC. In addition to working at HSS, its home base, the program also operates on-site at Mount Sinai Medical Center (since 1996), and NY Presbyterian—Columbia Campus (since 1999), where it provides peer education to underserved Latino and African American adults, teens, and children.

Charla Teen and Parent Lupus Chat Groups: Monthly community-based groups conducted in English and Spanish—the only service of this kind offered in the metropolitan area—which for the last seven years have been providing support to young people and their families. Meetings, facilitated by Special Surgery's Charla Peer Associates, are offered at Morgan Stanley Children's Hospital of New York-Presbyterian, and give teens and young adults with lupus—who often feel isolated and alone because of their illness—the opportunity to meet and support each other.

Community and Professional Outreach: Information presented at community, educational and faith-based organizations, health fairs and public events, as well as medical schools and health clinics.

Award-Winning Teen Booklet (available in English, Spanish and Chinese): Provides information written by a young woman diagnosed with lupus as a teen, as well resources geared for young people. The booklet, *For Inquiring Teens with Lupus: Our Thoughts, Issues & Concerns*, is available free of charge in English, Spanish, and Chinese.

Advancing the understanding, early diagnosis, treatment, and support of lupus patients and their families, the HSS Charla de Lupus/Lupus Chat ® programs contribute to the Prevention Agenda goals related to chronic disease, and reducing health disparities. The Three-Year Program Plan will leverage relationships with current partners and expand the programs' reach with new partners. Among current partners and services that enable those most at risk to learn more about and access Special Surgery's targeted lupus support and education programs are:

- Morgan Stanley Children's Hospital of NewYork Presbyterian—Pediatric Lupus Clinic in Washington Heights; NewYork Presbyterian's Audubon Family Planning Practice (Young Adult Clinic); Mt. Sinai Adult Lupus Clinic Service; HSS Rheumatology Division; ; S.L.E Lupus Foundation and its Lupus Cooperatives; the Arthritis Foundation; Lupus Alliance (Long Island Chapter) and additional voluntary service organizations and community colleges.

- The program will benefit from a new collaboration with the HSS Education Division Department of Patient and Public Education's SNEAKER© program, which offers hands-on activities to teach young people and their families the importance of good nutrition and has many complementary community affiliations.

Charla de Lupus/Lupus Chat® Program Goal: Sharpen Focus on Adolescents with Lupus

The Charla de Lupus/Lupus Chat teen and parent support group that serves predominantly Latino teens (81% female), plans to target two specific areas for risk reduction among this population: reproductive health and nutrition. HSS is *planning to pilot two new community service interventions* designed expressly for this population's needs, consistent with both primary and secondary health prevention.

As in the rest of the US, adolescents in NYC are at risk for engaging in unsafe sexual practices among other high risk behaviors. Young adults aged 15 to 24 in NYC have the most diagnosed Chlamydia cases; compared to girls in the US as a whole teenage girls in NYC have a higher pregnancy rate. Adolescents have physical, mental, and reproductive health care needs that often go unmet for many reasons; including fear that confidential information will be shared with parents, limited awareness of available health services, and financial barriers. This is particularly true among adolescents from low income backgrounds and minority groups who are more likely to be uninsured than other adolescents.[14]

Low income Hispanic teens with lupus may face increased adverse outcomes related to participating in risky behaviors such as unsafe sexual practices. Due to the changes that lupus and its treatment can have on the body such as weight gain, rashes, and hair loss, teens with lupus sometimes experience low self esteem, which can impact negatively on sexual behaviors.

The program's communities will include Inwood and Washington Heights, which have an average teenage mother birth rate that is 40% higher than NYC overall. This population experiences higher rates of poverty and fewer graduations from high school than the City's average. About one-quarter of mothers in Inwood and Washington Heights receive late or no prenatal care; and poor pregnant teens are more likely to have low birth weight babies, who tend to have more health problems than others.

The health of babies depends on the health of mothers. Lupus usually affects women during their reproductive years and pregnancy can affect both mother and baby, so it is especially important for women with lupus to be monitored by a doctor when planning to have a child. Unplanned pregnancies can put lupus patients at risk for adverse effects. Twenty-five percent of S.L.E. pregnancies are complicated by issues that can be handled, such as blood pressure problems, or modest prematurity. About 25% experience serious maternal or fetal problems, including miscarriage.

To minimize high risk sexual behaviors that can result in STDs or unplanned complicated pregnancies for low income lupus patients, the first objective of the Charla program is to increase routine reproductive health care visits among Latina teenage women with lupus.

As earlier delineated in HSS' Prevention Agenda for the Education Division's SNEAKER© Program, Latino children and adolescents are adversely affected by poor nutrition and lack of exercise which can lead to obesity. Statistics show that nearly 1 in 3 Hispanic children are obese.

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[14] Eliscu A. Vooperman D, Michener J, Nucci-Sack A, Kiaz A. Promoting healthy behaviors in adolescents. City Health Information. 2009;28(2):9-20.

These risks are magnified for the pediatric lupus population because of the effects of their chronic illness and impact of treatment.

Lupus treatment relies heavily on corticosteroid hormones. These potent drugs bring long-term side effects that can include weakened or damaged bones, high blood pressure, high blood sugar (diabetes), weight gain, infections, cataracts and profound fatigue. To mitigate these harmful effects, a diet rich in calcium along with supplemental calcium and vitamin D, is advised.

In addition to the increased risk for the Hispanic population related to nutritional status, it is especially important to address exercise and nutrition in this population because of the compounded risk factors of both the disease and its treatment with corticosteroids (as described above) which further increase risk for weight gain, diabetes, and osteoporosis. In addition, lupus frequently causes profound fatigue, impacting on a regular exercise regimen for lupus patients.

In an effort to begin addressing issues of obesity in this population, the Charla program's second objective in partnership with the HSS Education Division's SNEAKER© program is to promote awareness of healthier food choices among teenage Latino lupus clients and their parents through culturally sensitive nutrition education.

THREE-YEAR PLAN OF ACTION

HSS Prevention Agenda Priority Two: Chronic Disease
Charla de Lupus (Lupus Chat)®

HSS plans to pilot two new community service interventions in the predominantly Hispanic and African American neighborhoods of Inwood and Washington Heights—which have a 40% higher teen pregnancy rate than the rest of NYC— designed to improve routine reproductive health care and nutrition responding to both primary and secondary health prevention needs. HSS operates the program in collaboration with and onsite at the Morgan Stanley Children's Hospital of New York-Presbyterian, Pediatric Rheumatology Service. All program activities are coordinated and facilitated by Special Surgery's Charla staff. It is anticipated that these interventions will help to enhance teen-family-health communication and improve teen ability to manage lupus and its multiple impacts.

Specific program goals include:

- Increasing routine health care, including gynecological visits, among predominately Latina teenage women with lupus
- Promoting awareness of improved nutrition, through culturally relevant educational interventions

The Charla de Lupus Three-Year Plan in brief follows.

Three–Year Plan: Priority Area Number Two/Chronic Disease
Charla de Lupus (Lupus Chat)® : Supporting at Risk Hispanic Teens
Primary and Secondary Prevention

HSS aligns with Prevention Agenda Goals:

- Address health care disparities
- Reduce age-related, cultural, socioeconomic and language barriers to health care
- Emphasize reproductive health and nutrition

Charla de Lupus (Lupus Chat)® Program will:

- Pilot two new community service interventions in predominantly Hispanic medically underserved neighborhoods
- Develop programs tailored to Hispanic teens coping with lupus to improve reproductive health and nutrition, incorporate family needs
- Deepen community partnerships and health care provider collaborations
- Enhance teen-family-health communication and improve teen ability to manage lupus and its multiple impacts

Program Design:

- Build on Charla Chat group participant base for feedback to shape program
- Gather and analyze input from community partners and program participants
- Consult with HSS SNEAKER® program on nutrition component

Program Implementation:

- Roll out intervention through clinic setting and Charla monthly group meetings that reach targeted Hispanic teens with lupus and their families
- Medical teams and peer health educators provide supportive information on medical and psychosocial issues in English and Spanish
- Partner with Columbia Presbyterian's Pediatric Lupus Clinic –Audubon Practice and others to promote teen reproductive health/gynecological care

Strengthen Partnerships:

- Columbia Presbyterian Medical Center—Audubon Practice
- Morgan Stanley Columbia Presbyterian Hospital—Pediatric and Adult Lupus Service
- HSS SNEAKER© program

Measuring Program Outcomes and Benchmarks

Year 1

- Solidify external community partnerships and internal supports and resources
- Define the problem, common goals, and roles
- Identify gaps and finalize collaboration framework
- Undertake needs assessment through targeted outreach with lupus teens—that would best inform the specific needs of the population

Year 2

- Develop specific bilingual outcomes measurements, reflect participant satisfaction, knowledge and behavior change
- Tailor SNEAKER© bilingual information and assets/tools as needed
- Implement interventions - apply agreed-on outcomes measures, adapt if necessary
- Prepare program evaluations
- Collect and analyze data
- Discuss with community/obtain feedback

Year 3

- Implement programs
- Continue collecting and applying outcomes measurements
- Continue collecting quantitative data
- Analyze and present collected data
- Discuss with partners
- Share findings with community

Reducing Health Disparities for Culturally Diverse Women Living with Lupus/Focus on Asian Americans

Lupus continues to be under recognized in the Asian American community, denying women at risk the early diagnosis and appropriate treatment that is so important. Early identification, diagnosis and treatment can influence the disease's progression, severity and psychosocial impact. HSS leveraged its deep clinical expertise and public outreach experience, creating LANtern ® (Lupus Asian Network), an innovative national program for Asian Americans, specifically targeting the Chinese American community.

Data Confirms Asian American at Risk

- While there are fewer studies involving Asian Americans with lupus than of other ethnic groups, national organizations specializing in rheumatic diseases consistently indicate that Asian Americans develop lupus at a rate two-to-three times higher than whites.

- Studies in peer reviewed journals have reported an earlier onset of the disease, greater renal damage, and increased mortality in the Chinese community.[15,16,17,18,19,20]

Communities Face Barriers to Care

- In New York City, Asians comprise just over 12% of the population, with more than 57% immigrating since 1990.

- According to the Community Health Profiles, the Lower East Side, including Chinatown and the East Village, has the highest proportion of Asian residents (27%) of any neighborhood in Manhattan or in the five-boroughs.

- Asian New Yorkers confront numerous barriers: more than 50% have limited English proficiency, one-in-four lives below the poverty level, and many lack health insurance and live in over crowded conditions.

- Thirty-three percent of Chinese adults do not have a high school diploma, compared to the overall City rate of 21%.

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[15] JohnsonSR, UrowitzMB, IbanezD, GladmanDD. Ethnic variation in disease patterns and health outcomes in systemic lupus erythematosus. J Rheumatol. 2006 Oct; 33(10):1990-5. 2006.

[16] Peschken CA, Katz SJ, Silverman E., et al. The 1000 Canadian faces of lupus: determinants of disease outcome in a large multiethnic cohort. J Rheumatol. 2009 Jun; 36(6): 1200-8.

[17] Mok CC, To CH, Ho LY, Yu LL. Incidence and mortality of systemic lupus erythematosus in a sourthern Chinese population, 2000-2006. J. Rheumato. 2008 Oct; 35(10). 1978-82.

[18] Mok CC, Lau CS Lupus in Hong Kong Chinese. Lupus. 2003; 12(9):717-22.

[19] Ward MM. Arthritis Rheum. 2004 Aug 15; 51(4): 616-24.

[20] Koh Wh, Thumboo J., Boey ML. Pulmonary hemorrhage in Oriental patients with systemic lupus erythematosus. Lupus. 1997; 6(9): 713-16.

- When compared with the other 41 New York City Department of Health and Mental Hygiene's neighborhood community health profiles, the Lower East Side ranks below average on half the health indicators tracked.

Prevention Agenda Priority Two Program

LANtern ®

Support for Asian Americans with Lupus

LANtern® is the only national telephone peer support and education program designed specifically for Asian Americans with lupus. The program, led by a trilingual professional social work manager, specifically reaches out to the Chinese community, the largest ethnic subgroup in New York City, through its telephone SupportLine. Health care barriers for Asian Americans have been well documented, and include low socioeconomic status, lack of insurance, immigration status, and linguistic and cultural barriers. LANtern's specially trained volunteers—who have lupus themselves—are bilingual in English and either Cantonese or Mandarin. Through professionally directed and peer assisted interventions, health beliefs and understanding of the illness and treatment are clarified, barriers identified, and access to needed community resources are secured.

LANtern's influence extends from New York's Chinatown to national audiences. From 2003 to 2008, the total number of program contacts with individuals and their families, as well as participation in more than 40 conferences and community events, reached 4,707. In addition, the program responded to requests for more than 6,000 bilingual Chinese publications developed specifically by LANtern to convey its cultural relevance. This Chinese language information, which finds a national and international audience, contributes substantively to the powerful impact of the program, and includes: *Lupus Myths & Facts and Talking About Lupus; What Chinese-Americans and Their Families Should Know About Lupus; For Inquiring Teens with Lupus: Our Thoughts, Issues & Concerns. Publications are available both in print and as PDFs on www.hss.edu/LANtern.*

LANtern reaches the Asian American community through a nexus of connections that includes a multi-stake holder Community Advisory Board, which includes the Charles B. Wang Community Health Center, NYU Langone's Center for the Study of Asian American Health, The SLE Lupus Foundation, the New York Downtown Hospital's Chinese Community Partnership for Health, and NYU Hospital for Joint Diseases.

Among its current collaborations with community partners, in addition to its Advisory Board, are the following:

- The Asian Health and Social Services Council—a coalition of social services and health care agencies of more than 30 service programs. LANtern is a member, a participant, and presenter at its meetings—which bring new audiences.

- LANtern is also a member of the Women's Health Community Advisory Council of the Charles B. Wang Community Health Center, a leader in providing culturally relevant

health care and education. LANtern also serves as a co-sponsor of its annual Asian Women's Health Symposium.

- NYU Langone's Center for the Study of Asian American Health is the first Center to conduct research, training and community partnerships to identify and help reduce Asian American health disparities. LANtern has been a participant in its leadership training program, and is a co-sponsor of its annual conference.

- LANtern also represents HSS, along with LupusLine and Charla de Lupus, to Department of Health and Human Resources' Office of Women's Health for their National Lupus Awareness Campaign aimed at reaching minority women for earlier diagnosis and treatment (described earlier).

LANtern's® Capacity Building Expands the Network and Increases Awareness

Health care providers and hospitals, multi-service agencies, and professional and advocacy groups can play a key role in raising public awareness of lupus among the population and care givers. An expanded LANtern program, focusing on building capacity and increasing awareness, will not only benefit New York's Asian American communities, but the program will also work with national organizations to establish mutual priorities to identify and leverage resources among these constituencies.

Potential new collaborators are:

- The Chinese American Medical Society – a medical society for practicing Chinese American physicians in the NY-NJ areas

- The Asian American Federation of New York – an umbrella advocacy and philanthropy organization

- The Chinese-American Planning Council – a multi-social services agency serving the ethnic Chinese population citywide

- University Settlement, situated in the heart of Lower East Side, the oldest settlement house whose primary service constituents are now composed of ethnic Chinese

- Asian and Pacific Islander American Health Forum, a national health policy and advocacy organization with a mission to promote Asian American health

- Chinese Consolidated Benevolent Association of New York – the oldest service organization for Chinese Americans living in the Greater NY Metropolitan Area.

THREE YEAR PLAN OF ACTION

HSS Prevention Agenda Priority Two: Chronic Disease LANtern's® Capacity Building to Enhance Awareness of Lupus as an Asian American Health Concern

Since it began in 2003, LANtern tapped an unmet community demand in New York's Asian American neighborhoods, and led the way toward devising culturally attuned outreach, information and effective strategies to reach this diverse community as a national and international model. HSS intends to further expand and strengthen the extensive LANtern-connected community-based and national network by forging partnerships with between five and seven community based, professional, advocacy, and multi-service organizations.

Specific program goals include:

- Increase awareness of lupus as an important Asian American health concern through identifying and building capacity with targeted health care organizations, multi-service agencies, and professional and advocacy groups at the local, regional and national levels.
- Develop and implement an informational strategy so that there is an ongoing communication vehicle to promote and sustain this awareness, to enhance opportunities to promote the need for early identification, diagnosis and treatment of this illness among Asian Americans.

LANtern's Capacity Building Three-Year Plan in brief follows.

Three–Year Plan: Priority Area Number Two/Chronic Disease
LANtern's Capacity Building to Enhance Awareness of Lupus as an Asian American Health Concern

HSS aligns with Prevention Agenda Goals:

- Address health care disparities
- Reduce cultural, socioeconomic and language barriers to health care
- Enhance earlier diagnosis and treatment

LANtern ® will:

- Expand its community and national network by forging partnerships with 5 - 7 organizations
- Build capacity of network to carry out culturally appropriate public awareness outreach regarding lupus
- Develop communications strategy to promote best practices and vehicles
- Leverage existing resources through strategic partnerships
- Target collaboration opportunities to increase awareness of lupus as an Asian American health concern

Program Design:

- Build on LANtern experience and participant base to shape program
- Identify service, information gaps and needs
- Undertake partnership process—outreach to organizations for their comparative advantage, aligned goals, and added value
- Develop a cooperation framework and common communication strategy
- Review information needs and accessibility—encourage ongoing networking via e-news and other tools
- Determine with partners program entry points, vehicles and settings

Program Implementation:

- LANtern network rolls out cooperation plan, goals and objectives
- Map member's focus area, reach, expertise and links
- Structure capacity building supports aligned with mapping exercise
- Network/key informants review/assess LANtern intervention
- Develop work plan, timetable, substantive tools and information

Strengthen and Expand Partnerships

- Chinese American Medical Society
- Asian Health and Social Services Council
- Charles B. Wang Community Health Center
- US DHHS's Office of Women's Health –
- American Public Health Association's Asian Pacific Islander Caucus
- NYU Langone's Center for the Study of Asian American Health
- NY Downtown Hospital's Chinese Community Partnership to Health
- S.L.E. Lupus Foundation
- Chinese American Planning Council
- University Settlement
- Chinese Consolidated Benevolent Association of New York
- Lupus Alliance of Queens/Long Island
- Asian and Pacific Islander American Health Forum

Measuring Program Outcomes and Benchmarks

Year 1

- Identify and initiate partnerships with 5 - 7 strategically selected organizations
- Solidify external community partnerships and internal supports and resources
- Develop, with partners, a mapping/tracking tool for planning and evaluating partnership results and impact
- Define common goals, outcomes and roles; identify gaps and finalize collaboration framework
- Disseminate program information

Year 2

- Develop communications strategy to promote best practices and vehicles
- Design, test and issue first LANtern Network e-news letter or related tool
- Implement a collaborative LANtern activity, e.g. lupus wellness event,
- Apply agreed-on tracking and evaluation tool
- Collect and analyze data
- Discuss with partners and community

Year 3

- Issue second LANtern e-news letter or related tool
- Plan results-based collaborative activities
- Continue applying tracking and evaluation tool and collect data
- Assess network results
- Present findings.

6. FINANCIAL AID PROGRAM

Hospital for Special Surgery is very proud of its commitment to provide Financial Assistance to qualifying patients and to ensure that the program is well known to patients and communicated in the preferred languages of our patients.

One of the major successes of the HSS Financial Aid program is its visibility to patients. This is accomplished through extensive Hospital-wide signage posted in two languages in more than 50 locations throughout the facility. All patient bills—initial through final external collection notices—contain a notice alerting patients to the existence of the program. This prominent visibility informs patients and their families of the program's availability at any point—prior to treatment, during treatment, or post treatment. Keenly aware of patient cultural diversity, HSS has produced a financial aid summary in six languages for dissemination at all patient registration areas. Information about the program is also featured on the Hospital's Web site at www.HSS.edu

The creation of a dedicated team to work exclusively with patients has been a key to the program's effectiveness. The three-person team is comprised of a manager and two associates, qualified to understand the complexities and options for each situation. This allows for a quick turnaround when making determinations regarding a patient's eligibility for Financial Assistance. Equally important, the team has created and operationalized a unique database application that enables HSS to track and assess the Hospital's compliance with it Financial Aid program

HSS extended its program beyond the state mandated levels of 300% of the federal poverty level to patients whose income is at or below 500% of the federal poverty level. Hospital policy is to also consider a patient's insurance co-pay, deductible, and co-insurance potentially eligible for discount.

A major challenge faced is that despite the visibility of the program, many patients are reluctant to apply. As noted above, HSS continues to make clear the availability of the program and encourages clinical staff to refer patients who might be eligible to apply. A related program, VOICES Medicaid Managed Care Education, assists patients in navigating the complexities of public insurance programs. The education and advocacy provided through this program allow patients to obtain, and maintain access to our specialty care. In addition, the program provides information, referral and advocacy regarding other options for the patients' broader health care needs.

7. CHANGES IMPACTING COMMUNITY HEALTH/PROVISION OF CHARITY CARE/ACCESS TO SERVICES

Given the current economic situation, during the fall of 2008, Hospital for Special Surgery expanded its Financial Assistance program from at or below 400% of federal poverty level to patients whose income is at or below 500% the federal poverty level. This is important due to the rising uninsured population; current statistics indicate that one out of three New Yorkers under the age of 65 are uninsured. In addition, the expansion of the Hospital's financial assistance program is potentially beneficial to the insured population due to the rising out-of-pocket costs for medical services, including deductibles and other forms of cost sharing such as co-payments and co-insurance.

8. DISSEMINATION OF THE REPORT TO THE PUBLIC

To increase knowledge and promote healthier lifestyles, HSS is dedicated to designing, implementing, and evaluating state-of-the-art programs and community services, and to communicating these programs to diverse audiences as widely as possible. Toward that end, Special Surgery will distribute the Community Service Plan to its community partners, affiliated institutions, and to the offices of the Hospital's local elected officials. In addition, HSS will produce an easy-to-read summary for the public that will be posted on the Hospital's web site, www.hss.edu, which averages 300,000 unique visitors monthly. The summary will include information about the availability of financial assistance.