

“Access to Innovation: Ensuring Cancer Care and Services for Immigrants with Breast Cancer”

This conference was held on May 28th, 2008, as part of the Immigrant Cancer Access Network’s (ICAN/Center for Immigrant Health) ongoing effort to share knowledge about resources and opportunities for immigrants living with cancer throughout New York State. Immigrant patients can face enormous barriers in accessing clinical care and other supportive services while undergoing treatment and after exiting the formal care process. This conference was convened to help address these barriers.

The conference is an inaugural event of the NYU Cancer Institute’s CORE (Cancer Outreach, Outcomes and Research for Equity) Center.

I. Keynote Speaker – Peter Slocum, Vice President for Advocacy, American Cancer Society

Mr. Slocum highlighted ‘Access to Care’ as being the focal point for ACS’ advocacy efforts. ACS’ vision is that is that by 2015 everyone will have timely access to the full range of affordable evidenced-base healthcare necessary to optimize health and well-being.

Why focus on ‘Access to Care’?

- 46 million Americans are uninsured
- Nearly 1 in 8 cancer patients in is uninsured, and 1 in 4 cancer patients below 200% of the poverty line is uninsured

The plan:

1. Frame the issue and educate
 - a. Uninsured women are 49% more likely to die than insured women during the 4-7 years following an initial breast cancer diagnosis
 - b. The uninsured have an increased risk of late-stage cancer diagnosis
 - c. Cancer creates financial burdens
 - d. Cancer is perceived as being the most important health problem facing the American public today
2. Strengthen the science
 - There needs to be more data available—which means more research and attention paid on immigrant/minority and uninsured populations.
3. Evaluate and influence policy options
 - The ACS policy options are centered around 4 principles: These are Adequate, Available, Affordable, and Administratively Simple.
4. Expand partnerships and collaborations
 - a. Continue traditional partnerships
 - b. Expand work with AARP, AA, AHA, ADA
 - c. State and local coalition partners
 - d. Unions, Immigrant groups, Business
5. Train and mobilize grassroots organizations
6. Continue current work
 - a. Patient Navigator program – National Breast and Cervical Cancer Early Detection Program, Colorectal Cancer Early Detection, Prevention and Treatment Act
 - b. State funded screening programs
 - c. Medicaid expansion, ‘Emergency’ Medicaid

II. ‘Emergency Medicaid’ – Jenny Rejeske, New York Immigration Coalition and Francesca Gany, MD, MS, Center for Immigrant Health

Jenny Rejeske and Dr. Francesca Gany discussed general issues that arise in obtaining Medicaid for the treatment of an emergency condition.

-Basics of 'Emergency' Medicaid

-'Emergency' Medicaid is available to those who meet all Medicaid eligibility requirements (including state residency) except immigration status (undocumented immigrants and persons who entered the US under limited visas).

-Covers only the care and services necessary to treat an 'emergency' medical condition,' which is defined as a condition that, after sudden onset, has acute severe symptoms (including severe pain, labor and delivery) which, if left untreated could place the applicant's health in jeopardy, cause serious impairment to bodily function, or cause serious dysfunction of any bodily organ or part.

-Treatment of an emergency medical condition does not include care and services related to an organ transplant procedure.

-'Emergency' Medicaid does not cover nursing facility care or home care services

-Applications for 'Emergency' Medicaid must include a physician form certifying the emergency medical condition.

-'Emergency' Medicaid can cover radiation therapy and chemotherapy.

-Is it possible for an individual to be eligible for both Medicaid and 'Emergency' Medicaid?

-To be eligible for Medicaid coverage, an individual must be a Citizen, National, Native American or be an immigrant in 'satisfactory' immigration status.

-Documents required for applicants/Application Process

-Immigrants applying for the treatment of an emergency medical condition must meet all of the documentation rules for the Medicaid program with the exception of documenting immigration status or providing a Social Security number.

-A completed MAP-2151 (NYC) or LDSS-3955 (upstate) 'Certification of Treatment of an Emergency Medical Condition' must be completed by the attending physician.

-The Local Department of Social Services has up to 45 days to process an application for most applicant/recipients. If a disability review has to be conducted to determine if the immigrant is certified disabled, LDSS staff has up to 90 days to process the application.

-Duration of Coverage

-Coverage is available from the time that the individual is first given treatment for an emergency medical condition until such time as the medical condition is no longer an emergency.

-The maximum total coverage period is 90 days. This coverage period is a combination of retroactive, current, and prospective coverage and cannot exceed a total of 90 days, with no more than 60 of the 90 days representing prospective coverage from the date of application.

Advocates inquired about denials and the formal process for addressing and disputing them. The New York Immigration Coalition and the Center for Immigrant Health are interested in following up with such issues and requested that advocates keep these organizations informed of such encounters in order that proper follow up is maintained.

III. Linguistic Access – Francesca Gany, MD, MS, Center for Immigrant Health

Dr. Gany's presentation highlighted many of the difficulties that limited English inadequately addressed interpretation needs can strain doctor-patient relations, limit trust, and hamper effective care.

She discussed the goals for services to provide high quality interpretation with minimal errors. Because providers and patients often cite time as being a limiting factor with interpreting, there is technology available to speed up the process of interpretation while improving quality. Remote simultaneous medical interpretation (RSMI) enables patients and providers to communicate without the pauses and interjections that are commonly associated with proximal interpreting programs. Instead, interpretation occurs simultaneous with the speech of both doctors and patients.

Health literacy is also a compelling issue in cancer disparities, magnified when there is a language barrier. The Center for Immigrant Health has developed an online visual and audio training program, with funding from Susan G. Komen for the Cure Greater New York City, for patients and providers to address issues of literacy and language in enrolling patients into cancer clinical trials.

IV. Cancer Advocacy Project Services – Laura Mosiello

Laura Mosiello presented on the services that the City Bar Justice Center provides for cancer patients and survivors.

Employment Law: Through legal consultations, volunteer attorneys who are experts in the field address issues about basic employment rights, potential discriminatory practices and practical alternatives to address the immediate concerns of cancer patients and survivors in the workplace.

Health Law: The Cancer Advocacy Project's Health law component provides clients with no-cost legal guidance with health insurance difficulties involving medical denials, outstanding bills and navigating the appeals process.

Wills: The Cancer Advocacy Project, in conjunction with the law firm Stroock & Stroock & Lavan LLP, offers free preparation of basic wills to people undergoing cancer treatment and to survivors.

Social Work: The holistic approach of legal/social work intervention provides clients with more comprehensive social, psychological and legal assessments of their cancer related concerns, with relevant guidance and direction provided.

V. Housing Options for Immigrants with Breast Cancer—Iman Siyam, American Cancer Society and Susan Cohen, Manhattan Legal Services

Both presenters acknowledged the lack of resources available to immigrant cancer patients for housing; however, they attempted to highlight what options do exist and how to access such assistance.

Iman Siyam discussed the American Cancer Society's Hope Lodge (http://www.cancer.org/docroot/COM/content/div_Eastern/COM_5_1x_Hope_Lodge_New_York_City.asp), located on 132 W 32nd Street, which is a free temporary residence for adult cancer patients undergoing treatment in New York City who do not have a residence in the City. In addition to providing a healthy living environment, the facility offers counseling, nutrition classes, and other supportive services to its residents. To gain access to housing at Hope Lodge, patients are referred through the social workers at their treatment facilities. Immigration status is irrelevant and average stay is about three weeks.

Susan Cohen addressed how cancer patients can access repairs for their apartments. Because there are few public housing options available, one of the few ways to address poor living conditions is by making sure that patients are aware of all laws aimed at protecting patients.

She cited several reasons why it is difficult to improve the conditions of immigrants who live in sub-standard housing:

- Language and immigrants' lack of access to sensitive services and literature detailing rights
- Landlords do not want to spend money improving housing
- Blacklisting—many immigrants have been blacklisted because of their financial situations and have been unable to attain housing from other landlords

She gave specific ways in which patients can utilize legal resources to force landlords to make housing repairs. These are the five ways that a tenant may address their landlord and the state of their apartment:

- (1) Asking the Landlord in Writing by Yourself

-In a letter, the tenant lists the repairs needed and a deadline for the landlord to complete them. The tenant writes that if the repairs are not completed by that deadline, the tenant will be forced to use legal means to get those repairs. A good time to send this letter is when making a rent payment, which will prevent the landlord from denying knowledge of the repairs.

(2) Getting Together with Other Tenants in Buildings

-When there are other tenants in the building, a master list of building and apartment repairs can be drawn up. The more tenants that get involved, the more pressure that can be brought against the landlord. Similar to the first type of action, the group of tenants can state that if the repairs are not made by the deadline set, the groups will be forced to take some type of legal action against the landlord.

(3) Making Complaints to Government Agencies

-Through this form of action, tenants may ask government agencies to determine whether the landlord has broken the law by not making the repairs identified or they may ask the agency to penalize the landlord for not completing the required repairs. Each type of agency responds differently. The City agencies may make inspections, write up the violations, and charge monetary fines against the landlord for not making certain repairs. The State housing agency has more effective ways to penalize the landlord. The following are several agencies that can get involved:

- New York State Division of Housing and Community Renewal (DHCR)
- New York City Department of Housing Preservation and Development (HPD)
- New York City Department of Buildings (DOB)
- New York City Department of Health (DOH)
- New York City Department of Environmental Protection (DEP)

(4) Taking a Landlord to Court

-Through this form of action, a tenant or a group of tenants can take their landlord to housing court. HPD does an inspection prior to the first Court date to see if the repairs are serious enough to violate the law.

(5) Forcing the Landlord to Take the Tenant to Court

-In this method, the tenant withholds rent so that the landlord sues them for nonpayment. When the tenant answers the landlord's Court papers, he/she states his/her defenses, which include lack of repairs, and asks for an abatement for the time that she/he was forced to live without repairs. When this is done, tenants must make sure to put aside the full amount of rent in case the Court asks for them to pay rent to the landlord.

There is no correct way to approach this situation. Whichever way a tenant chooses to make his/her move in addressing concerns, she/he must keep written records of all that has been done. All letter and Court papers should be copied! In addition, photos can be taken and included to strengthen any argument for repairs and to emphasize the poor condition of the apartment.

Many tenants worry that their rent will increase because of the repairs made. However, in theory, your rent can only go up based on improvements, not repairs. The line between these two is sometimes not very clear. The only way a tenant's rent can increase is if:

- (1) the landlord makes building-wide improvements and DHCR later grants a rent increase
- (2) the landlord provides a major change or increase in dwelling space, new equipment, improvements, or furnishings in the tenants' apartment and the tenant agrees to pay more in rent for this

All actions need to be made with full consideration of the tenant's legal and health considerations.

VI. Small Group Sessions – There were 8 small group sessions dedicated to the following topics: Innovation, Housing, Language Access, Psychosocial Support, Insurance/Financial Issues, Legal Issues, Hospice-End of Life Care, Survivorship, and Patient Navigation. These groups will form the basis for ongoing ICAN subcommittees.

1. Innovation – This group primarily addressed the difficulties that patients and providers face in enrolling into clinical trials. They noted that barriers exist educationally, systemically, and culturally. Health literacy is a concern. This is often compounded by the fact that many patients have limited English proficiency and require an interpreter. Consent forms pose a huge problem, as translated versions may not be available. Even if they are available, patients with low literacy may be unable to understand their contents. Patient navigation can be helpful in explaining the many layers of regulation and documentation that exist in the clinical trials process.

Participants noted that the ethical issues associated with clinical studies are often difficult to communicate with immigrant patients. Patients may perceive clinical trials as experiments and do not want to be 'guinea pigs.' Their concerns about participation may be furthered by the fact that immigrant patients are often concerned about their immigration status and may worry that their involvement might compromise their security. In addition, age, socioeconomic level and time in the US all can contribute to patient barriers in accessing clinical trials.

2. Housing – This group discussed the pressing need for improving housing conditions for immigrant patients. The group noted the need for a greater supply of affordable and healthy housing. Many people are diagnosed with cancer and then lose their job because of treatment, after which they are unable to pay rent. Because they have no current income and may be unable to find employment after treatment, they do not qualify for rent assistance programs (which operate on future ability to pay). The group felt a need for a program to deal with this situation specifically. It raised the idea of the model similar to that of HIV supportive housing, which has been successful in extending support to all patients regardless of income and immigration status.

3. Language Access – This group discussed the barriers to providing qualified interpretation, which the group noted occurred because of limited time (emergency situations), and because of the use of children and family members as interpreters. Participants identified hospital facilities as needing much improvement in providing better services for all limited English proficient patients. In addition to hospital facilities, smaller clinics need to improve their services because interpreters are not as accessible in such places. The group recommended that patients requiring interpreters should be identified by providers prior to their appointment, when possible. In addition, all staff should be trained on the provision of culturally/linguistically sensitive services.

4. Psychosocial Support – This group identified the different types of support/resources available to patients (listed below), including screening for depression at various facilities. They discussed how there is often resistance from doctors to make referrals to psychiatrists. There is a need for providers to distinguish between coping issues and mental illness issues. Participants also discussed the limited resources available for patients who want to return to their home country at the end of life and the need for providers to respect patients' right to return to their home country.

Examples of Resources for Psychosocial Support:

-Case Managers

-Sharing and Caring

For Depression Screening:

-PsychOne at Lincoln Hospital

For patients to return to their home country

- 'Compassionate Care'

5. Insurance/Financial Issues- This group discussed the need for hospital staff to provide greater assistance to patients with insurance and financial issues. Specifically, small group members discussed making information about public insurance options readily available, mandating by law patient access to Medicaid coverage, and making the paperwork easier to fill out and renew, enabling

more patients to benefit from programs such as Medicaid for the treatment of an emergency condition. Patients are often unaware of financial assistance policies—making it imperative that hospitals post such information in different languages and make it readily accessible to patients. Participants identified Cancer Services Partnership as being a critical resource for enrolling patients into ‘Emergency’ Medicaid, while also recognizing its drawbacks, particularly in the outer counties, where paperwork has to be completed more frequently.

Examples of Resources for Financial Assistance:

Cancer Services Programs

Cancer Care

ACS

CBOs

6. Survivorship- This group addressed issues of isolation that patients feel once they have undergone treatment and the fears of recurrence after treatment has ended. For some, there is a stigma associated with cancer survivorship, for which patients should be prepared. Participants agreed that this can be remedied through follow up calls/letters/resources, support groups, chat rooms, and matching programs. These programs could be best implemented in a “one-stop shopping approach”, so that patients do not have to go to many different places to access services. In addition, long term issues due to treatment can cause stress, so financial support, treatment coverage (which is especially important if there is a recurrence), and psychosocial support should also be made available to survivors.

7. Legal Issues – This group addressed the many legal roadblocks that exist for immigrants with cancer, particularly in the areas of housing, benefits, and immigration. If an immigrant is undocumented, he or she can be daunted by Emergency Medicaid and issues at public facilities. Also, people who wish to get treated for cancer in the US must come here on a tourist visa, which can complicate their ability to stay in the US for long periods of time to receive treatment. While visa extensions are available in some cases for patients receiving treatment, patients often do not know how to apply for such programs, with which an attorney can help.

8. Hospice/End of Life Care – This small group discussed the resources that currently are available to assist patients at the end of life (detailed below). Because undocumented immigrants are often ineligible for hospice care programs, other organizations/programs must be utilized. In addition, participants shared information about cultural issues that may affect end of life attitudes, which include stigmas and an unwillingness to talk about death.

Examples of Resources for End of Life:

-Faith based churches

-Extended families

-St.Rose

-Coler Goldwater

-Hospice of New York

-Visiting Nurse Service

-Lincoln Hospital

9.Patient Navigation – This group discussed patient navigation programs at various facilities. They attributed the success of such programs to collaborations with CBOs. These programs should be models for more facilities, particularly with respect to their psychosocial support mechanisms. In addition, the group identified the primary options that patients have in receiving reimbursement for transportation. They found transportation to be one of the biggest areas of concern in terms of

supportive services, as there are few options for patients who are unable to receive full Medicaid coverage. Listed below are specific resources that the group found to be useful in their work:

Examples of Resources for Transportation:

- CIH Portal
- Cancer CARE -Access a
- Ride
- Medicaid -Private
- Philanthropy

Examples of Resources for Patient Navigation:*

- St. Luke's Hospital -NYU Cancer Institute
- *Partnerships with American Cancer Society and SHARE

VII. Employment Considerations for Breast Cancer Survivors – Julie Brandfield, New York Legal Assistance Group

Julie Brandfield introduced many of the legal barriers that breast cancer patients may face in the workplace. She gave several case examples of patients who have had difficulties and have been appropriately referred/assisted. She introduced several laws and programs that exist to help patients in such situations.

-Need for Time Off

FMLA: Family Medical Leave Act protects the job of an employee who needs to take time off from work to care for him/herself or a qualified family member

- Applies to employers with 50 or more employees
- Employees must have worked at least 12 months and for 1250 hours during the last year
- Can use accrued paid days off (sick or vacation days)
- Can be used for intermittent leave
- Applies to an individual who is sick, but also to qualified family members
- Employer may require a medical certification, but not medical records
- Employees seeking to use FMLA time should review their employee manual or speak to the HR director about taking FMLA time

-Need for Workplace Accommodation

Americans with Disability Act

- Under the Americans With Disability Act, employers with 15 or more employees must provide reasonable accommodation to an employee with a disability so that an employee can perform the essential functions of the job as long as the accommodation does not impose an undue hardship (usually a financial hardship)
- A person has a disability if he/she has a physical or mental impairment that substantially limits one or more major life activities (e.g., performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working). ADA does not list specific diseases or conditions.

Physician's Role as Advocate in Obtaining Reasonable Accommodation:

- A statement from a physician is advisable when an employee seeks a reasonable accommodation

- Employers may require that the employee provide medical documentation to establish that the employee has an ADA disability and needs the requested accommodation when the disability is not otherwise obvious
- Some employers have an actual medical inquiry form, other employers may simply accept a letter

-Discrimination

American's with Disabilities Act

- Applies to all employers with 15 or more employees
- Employer cannot discriminate against an employee or prospective employee because of a disability or perceived disability
- A person has a disability if he/she has a physical or mental impairment that substantially limits one or more major life activities (e.g., performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working). ADA does not list specific diseases or conditions.

New York State Human Rights Law

- Applies to all employers with 4 or more employees
- Same protection as Americans with Disabilities Act
- A person has a disability if he/she has a physical or mental impairment—the impairment does not have to substantially limit a major life functioning activity

-Continued Health Insurance/ Benefits

Short term disability – New York State requires employers to offer a minimum level of short-term disability protection

- Non-governmental employers
- 50% of weekly income up to \$170/week for 26 weeks
- Physician must complete form DB-450 (employed) or DB-300 (unemployed) available on <http://www.legalhealth.org/partnerMatters/forms/db450.pdf>
- Must have worked for employer for four weeks prior to disability
- If terminated, may still be eligible for STD

Long term disability

- Long term disability insurance is not required in New York State—it is a benefit offered by some employers
- Must review the policy for terms of payment
- May be subjected to medical examination by insurance carrier's physicians
- Policies may permit frequent review of condition by carrier

Social Security Disability

- Must be disabled for up to 12 months
- Must have 40 quarters of work history in specified time, if inadequate work history, may be eligible for SSI
- Terminally ill, may qualify for TERI status which can speed up application or appeal
- Can apply on-line (www.ssa.gov), by phone or at local Social Security Office
- Physician will be sent disability questionnaire to complete

COBRA

- An employer must offer COBRA to terminated employees who had group health insurance within 30 days of their termination

- An individual has 60 days to elect COBRA
- Any future insurance carrier, can't exclude coverage as a pre-existing condition (such as cancer) if individual has had continuous coverage (63 day rule)
- COBRA coverage can last for 18 months with an additional 11 month extension for individuals who are disabled and receiving SSD

VIII. Wrap-Up and Evaluation – Conference attendees expressed their deep appreciation for this conference, which brought people together to discuss and explore, in an in-depth manner, a variety of issues that tremendously affect immigrant communities with cancer. The working groups will continue to convene as part of ICAN to ensure that the groundwork laid by the conference will form a foundation for improving access to care.

Our sincerest thanks to the following Advisory Committee members for their help in developing and organizing the conference agenda:

Claudia Ayash, NYU Cancer Institute
Anita Macfarlane, Cancer Information Service
Joelle Vasquez, American Cancer Society
Mari Carlesimo, American Cancer Society
Iman Siyam, American Cancer Society
Laura Mosiello, Cancer Advocacy Project
Jessy Lau, American Cancer Society Asian Initiatives
Marina Mazina, SHARE
Ivis Sampayo, SHARE
Liliana Vaamonde, New York Legal Assistance Group

In addition, we would like to thank the following programs/organizations for their support in hosting this conference:

Susan G. Komen for the Cure Greater New York City
New York Community Trust
NYU CORE Center/NYU Cancer Institute
New York State Department of Health Cancer Services Program
Center for Immigrant Health/NYU School of Medicine