Essex County Cancer Coalition
Meeting Minutes
The Priory Restaurant, St. Joseph's Plaza
Thursday, March 10, 2005, 4:00-6:30 pm


Introductions: All participants introduced themselves and stated what organization(s) they represent.

Presentation #1: Shari Short, MA, Partnership Program Coordinator, NCI Cancer Information Service (CIS), Atlantic Region

Shari conducted a presentation on the NCI's Consumer Health Profiles. She first introduced the Cancer Information Service (CIS) and its services such as: 1-800-4-CANCER, LiveHelp, cancer education materials, and information on clinical trials.

Questions/Discussion of Presentation #1

- Question: What is the process of cancer education materials development at NCI?
  
  Answer: Partially based on what individuals who call 1-800-4-CANCER inquire about. Community-based organizations aid in materials development. There is a rigorous translation process consisting of several rounds of back translating. NCI has a schedule for periodic review and revision of educational materials.

- Question: When people call the 1-800 line, do you ask them where they're from?
  
  Answer: The NCI relies on a randomized process of asking callers some demographic questions and what zip code they're calling from. This allows for generation of data by zip code.

- Definition of Consumer Health Profiles (CHPs):
  
  o WHO
    1. Identifying clusters in need of education/outreach
  
  o WHERE
    1. Create maps at state and local levels

  o HOW
    1. Develop outreach strategies and plan screening events based on
      1. demographics
      1. healthcare attitudes and utilization
- media-related habits and activities
- and product & financial preference

CHPs are created with data collected from: Census 2000, PULSE Healthcare Survey, National Health Interview Survey (NHIS), Behavioral Risk Factor Surveillance Survey (BRFSS), PRIZM, and Simmons Market Research Bureau (SMRB).

CHPs provide information on: 1) Demographics--through the Market Matrix Hot Sheet (available in areas from zip codes to state-level) or map and 2) Clusters--lifestyle & demographic information in a map or report format.

CHPs provide information on Census block groups (250-500 households) in the highest level of detail.

Claritas (marketing firm) assigns each block group in the U.S. one of 62 demographically distinct "clusters"--combining demographic data with product, media, and lifestyle preferences. Of the 62 distinct clusters, 31 of them are "medically underserved".

Clusters are defined by residents' social rank, mobility, ethnicity, family life cycle, & housing style. Identical clusters in different geographic areas share similar habits & attitudes.

Other CIS resources/services through partnership with the CIS:
Since CIS regional partnership program staff is available to collaborate with nonprofit, private, and other government agencies at the national, regional, and state levels, they are available to provide assistance on coalition building and evaluation. For example, if the Essex County Cancer Coalition were to create a partnership with the Atlantic Regional CIS Partnership Program, the CIS staff would be able to provide cancer-related expertise in various areas such as: planning cancer education programs and evaluation of success, strengthening the coalition, training assistance (i.e. train-the-trainer programs) and advising strategies to reach target populations.

CIS can assist you with developing public service announcements (PSAs) and print advertisements.

If you would like to send mailings to your target population, the CIS can provide mailing labels for a fee via a company called MedStat. These mailing labels are available at the census tract and block group levels.
There is:

8-10 day turnaround time on producing maps
1-day turnaround time for demographic "hot sheets"

Question: What do the numbers mean—Total women eligible for a mammogram or the number of eligible women who have not received a mammogram?

Answer: The numbers on the maps refer to the total number of eligible women in need of a mammogram (i.e. are not obtaining mammograms).

***For a copy of Shari Short’s slides and handouts, please contact the Coalition Coordinators***

More information about NCI CIS can be found at their national website: http://cis.nci.nih.gov/.

Presentation #2: Mr. Virgil Simons, President & Founder, The Prostate Net

Virgil informed the Coalition of prostate cancer disparities in incidence, mortality, survival rate, and stage of diagnosis in minority men (specifically Blacks and Latinos). Virgil spoke about The Prostate Net’s mission, services, & achievements. He then outlined the Barbershop Initiative--its mission, rationale, objectives, program elements, incentives, publicity, past success, and future vision.

The Prostate Net:

- Offers services in English & Spanish
- Has a call-in center, running 24hrs/day, 365days/year
- Counselors
- Professional education courses

Barbershop Program featured in 2004 issue of Lancet-Oncology.

- Question: How is "Barbershop" being evaluated?

The medical centers participating in Barbershop will be responsible for conducting the evaluation. Evaluation includes:
  1. Number of men receiving information
  2. Number of sessions held (by medical center partner)
  3. Number of men attending sessions
  4. Number of men screened for prostate cancer
  5. Number of positive PSAs and DREs
  6. Type of further diagnostic intervention needed

CEED patients may be referred to Barbershop.

- Question: Is there a need to train healthcare providers in cultural appropriateness?

Answer: Yes. Medical providers receive training on cultural appropriateness.
Medical centers are responsible for contacting the barbers.
Working with the National Association of Barbers
There is a comprehensive training curriculum to train the barbers.
Barbers are given "$250 coupons" to hand out to men interested in obtaining prostate cancer screenings.
The medical centers have agreed to treat any men with abnormal tests or those who are diagnosed with prostate cancer.

In 2004, the Barbershop program was piloted in Essex County through St. Michael's Medical Center.
In 2005, St. Michael's Medical Center and UMDNJ (and others, not yet confirmed) will participate in Barbershop.

Virgil then discussed the "Wired" Barbershop in which computers would be placed in a sample of participating barbershops through which men would be able to access health information.

Question: Is the screening age 40 years or 50 years for prostate cancer?

Men at high risk for prostate cancer can get screened at 40 years to establish a baseline. For normal-risk men, screening generally starts at 50 years.

**Need to Broaden Essex County Hospitals' Participation in Barbershop**
Stan called upon the members to help to broaden the scope of representation of County hospitals involved in Barbershop, especially since key healthcare systems such as Saint Barnabas were not yet signed on.

Virgil had already been working with Ms. Lois Greene, RNC, MBA to implement the Initiative at St. Michael's Medical Center. In addition, Stan and his group at UMDNJ-NJMS had been assisting Virgil with the Initiative at a national level.

Coalition members representing UMDNJ, including Dr. Diana R. DeCosimo (co-PI for the coalition grant) assisted Virgil in the expansion of the Barbershop Initiative to University Hospital (UH) administrators.

**Action Item:** Mike Festa has contacts at St. Barnabas Medical Center, to help gain access for Barbershop. Mike will follow-up with Virgil regarding this matter.

**Outcome:** After the March 10 meeting, Mike, County Health Officer and member of the coalition's Leadership Council, and Mr. Robert Schermer, Essex Coalition member and the coordinator for coalitions in Morris and Passaic counties, assisted Virgil in reaching and meeting with officials at Saint Barnabas Healthcare. As a result of these efforts, Saint Barnabas joined the Barbershop Initiative in May 2005.

***For a copy of Virgil Simons' slides, please contact the Coalition Coordinators.***
***Prostate cancer brochures were also distributed during the meeting.***
More information about Prostate Net can be found at: [www.prostate-online.com](http://www.prostate-online.com).
UPDATES

Chairs/Representatives from the Leadership Council, Advocacy, Development, and Education/Outreach committees updated the Coalition.

LEADERSHIP COUNCIL--Azadeh Tasslimi & Punam Parikh (representatives)

1. A mission statement for the Coalition has been developed (which was distributed to the Coalition members) and approved by the Leadership Council.

2. Dr. Arnie Rosenheck, Dean of the New Jersey Dental School and an oral/oropharyngeal cancer specialist, will be joining the Leadership Council and will be presenting at the June 9th Coalition meeting. **Oral Cancer has been identified as a new cancer priority, since it is 1 of 3 cancers in Essex where the mortality rate is highest in the State.

3. The Coordinators are trying to recruit stakeholders from organizations currently not represented on the Coalition including but not limited to:
   a. the insurance industry,
   b. public office,
   c. faith-based institutions,
   d. and patient navigation programs

4. The Coordinators have developed a presentation outlining the major findings of the Essex County Cancer Capacity & Needs Assessment (C/NA) to be used to recruit additional Coalition members. The coordinators are available to make presentations.

5. The Leadership Council approved the creation of a Clinical Advisory Group that will act as a resource to be called upon for advice/expertise when necessary.

6. The Leadership Council passed a motion for the Coordinators to develop an implementation plan by prioritizing the recommendations of the C/NA. A draft plan will be presented to the Leadership Council at their next meeting on April 7th.

7. The Coordinators are working on increasing access to cancer screenings throughout the county by contacting hospital community health departments and community health clinics regarding free or low-cost screenings and also by creating an ambulatory network to refer patients.

8. The Coordinators will be attending health fairs throughout the county and will be able to disseminate any cancer-related materials on behalf of the Coalition and its members.

ADVOCACY COMMITTEE--Mary Abernathy (Chair)

The Advocacy Committee met to discuss the recommendations in the C/NA and drew up a list of activities to focus on:
1. Focus groups consisting of a cross-section of community members should be conducted to better understand how to reach the inner city population, the importance of cancer screenings, and how to conquer myths.

2. A website with a calendar of free cancer screenings and links to grass-roots organizations should be created and maintained.

3. A program for a curriculum promoting health diets, exercise, and smoking prevention should be pilot tested in New Community Schools.

***Relating this recommendation to statewide efforts being conducted through the NJDHSS-Officer of Cancer Control and Prevention (OCCP), representatives Sue Sanna and Stephanie Hill informed the Coalition that Vinny Smith, Educational Director for the ACS is organizing a "train the trainer" program for 121 school nurses in Newark on August 31st to educate them on cancer prevention and early detection for the seven NJ-CCCP priority cancers.

4. A Speakers' Bureau consisting of medical professionals and survivors should be created to reach out to the community (through churches and social organizations) for education on cancer prevention and treatments.

5. Lobbying for federal healthcare funding for Essex County cancer screenings, education, and outreach for cancer prevention and early detection.
DEVELOPMENT COMMITTEE--Catherine Marcial (Chair)

1. Bill and Catherine have been in contact with Robert Wood Johnson Foundation about potential funding for cancer screening or treatment related efforts. Will provide updates at subsequent meetings.

Member suggested that the Powerpoint presentation of C/NA findings can be used for fundraising efforts as well. (Refer to #4 under "Leadership Council" above.)

Virgil suggested that the Development Committee also look to "non-traditional" partnerships such as local grocery stores, radio stations, unions, movie theaters, etc. Can provide incentives that appeal to the community as well as bring traffic into the local businesses.
Mary reported that Pathmark is open to print 1-800 numbers (ex. CEED program) on their plastic grocery bags.

EDUCATION/OUTREACH COMMITTEE--Marielos Vega (Chair)

1. Funding was secured for a summer medical student to evaluate cancer (lung, oral, cervical, colorectal, breast, and prostate) education materials distributed by health departments in NJ for readability, and cultural sensitivity. Recommendations will be developed based on the results and will be presented to the Coalition at the September meeting.

2. The committee is looking to collaborate with Issac Hopkins from the Newark Campus IRB to incorporate information from the NCI's Clinical Trials Education Series (CTES) CD (in English & Spanish) as well as messages on "general community participatory research" in his presentations to the community. The CD contains information on how to overcome barriers in participation by trial type (prevention vs. diagnostic vs. treatment).

3. In order to combine members' strengths and not to duplicate efforts, an assessment of the Coalition should be conducted to determine which organizations are represented.

4. Infrastructure for a Community Outreach Partnership needs to be established. We can pilot ideas during 2005 to gather pilot data with community involvement and in 2006/2007 can apply for Community Participation in Research PA Number: PAR-05-026. The Education/Outreach Committee will discuss this matter and will report back to the Coalition in June.
Agency/Individual Announcements by Members

Mike Festa announced that he has spoken to the County Hazardous Materials (HazMat) team fire department and has found approximately 20 men who are interested in getting screened for prostate cancer. He inquired whether the screenings could be conducted on-site. He volunteered to draw blood at the screening event.

Stephanie Hill from the Office of Comprehensive Cancer Control & Prevention informed the Coalition that her office is currently developing a formal communications plan, to facilitate communication between County Coalitions & statewide cancer workgroups.

Betty Gallo will be attending the Mayor's Conference to advocate for a "Prostate Cancer Awareness Day" throughout NJ cities.

Akua Agyeman announced that the International Black Women's Congress is sponsoring a breakfast meeting on 4/1/05. They are participating in the ECHO Project where lay community health workers teach other women in the community about breast exams and build awareness of breast cancer.

Dr. Arnie Rosenheck announced that the Oral Cancer Screening Consortium (consisting of 29 agencies in NJ, NY, & PA) is offering FREE oral cancer screenings for those 18+ years on April 7th between 9am-5pm.

In Essex County, the screenings will take place at UMDNJ in the New Jersey Dental School's Oral Health Pavilion on 12th St. between 9am-12pm and 1pm-4pm.

A complete list of screening sites can be obtained by calling 1-877-263-3401 and is also available at: http://www.oral-cancer.org/sites.html. For oral cancer education materials, contact Inez at Dr. Rosenheck's office (973-972-3620).

Screening guidelines include: general population, 1 screening/yr; high-risk individuals: 2 screenings/yr.
Oral cancer cure rate at late stage diagnosis--18%

The Newark Cancer Initiative has chosen to focus their efforts on Prostate Cancer this year.

Evaluation: An evaluation form was distributed at the beginning of the meeting and was completed and returned to the Coordinators.

Next Meeting: Thursday, June 9, 2005 at The Priory Restaurant, 4pm-6:00pm