



**FAMILY CENTERED**  
**PATIENT ADVOCACY TRAINING**

PULSE of NY ♦ PO Box 353 ♦ Wantagh NY 11793-0353 ♦ (516) 579-4711 [www.pulseofny.org](http://www.pulseofny.org)

**PULSE of NY**  
**Patient Safety Advisory Council**  
Year 3 Report  
August 2012

**Mission**

The mission of the PULSE of NY - Patient Safety Advisory Council (PSAC) is to have a wide-reaching impact on improving patient safety awareness and health literacy in local communities while strengthening ties with health care providers.

**History**

The Council began in 2009 by Ilene Corina, President PULSE of NY, as a project of the Patient Safety Leadership Training program sponsored by the American Hospital Association/National Patient Safety Foundation. For the first year, funding for the project came from Long Island Unitarian Universalist Fund, Nassau Suffolk Hospital Council, and North Shore-LIJ Health System. Since the initial development, the Council has continued with on-going support from North Shore-LIJ Health System.

**Description**

The Long Island Patient Safety Advisory Council (LI PSAC) is an independent group of community leaders representing disease-specific organizations, diverse socio-cultural groups, and adults with low health literacy, brought together to incorporate patient safety into their organizations and programs. The primary objective of the Council is to learn, from the grassroots level, what community leaders and their constituents believe is needed to address quality and patient safety. Additionally, participants are expected to acquire knowledge and tools that can be passed on to their respective organizations and interest groups, in order to fulfill the following goals:

- 1) Prepare patients to advocate for themselves and their family members,
- 2) Improve health literacy and communication between the community and local health systems,
- 3) Increase patient safety through patient centered care in local healthcare settings.

**Year 3 Review**

PULSE of NY representatives engage in the community meeting with leadership and members of organizations and interest groups while provide education on patient safety. Learning happens at pre-established or special meetings and is a convenient way to disseminate information directly to the community.

Beyond the Council participants, year three focused on a six month series of educational seminars. The Council also began to serve three new target groups: (1) families caring for loved ones with Alzheimer's/Dementia, (2) volunteers who work with low literacy adults, and (3) young pregnant mothers - 17 to 23 years-old - who are caring and advocating for their children.

We met with an Alzheimer's/Dementia support group in Merrick, Long Island and did a 45 minute presentation on patient safety. Following that presentation a discussion with about 20 participants lasted two hours. They described what it is like to be an adult child, spouse or friend of a patient with dementia and how they feel the safety or the patient's quality of care may be compromised.

PULSE representatives met with two groups of volunteers at Literacy Nassau. Following a 45 minute presentation the volunteers shared some of the obstacles that adults who cannot read or comprehend English have pertaining to receiving safe, quality health care.

We held three sessions with young, mothers at Momma's Houses in Nassau County and will continue with this group through 2013. (The report of this work is not yet completed but will include a case that includes accompanying an 18-year-old mother with no family support to the emergency room with her 7-month-old child.)

The Council sponsored a six month series of guest speakers in Freeport, NY who helped empower people with important information about the healthcare system. This informal gathering was an open discussion instead of lecture and encouraged participants to bring questions on the following topics.

- Health Insurance/ Medicare (January)
- HIPAA (February)
- Eldercare needs and resources (March)
- Advanced Directives (April)
- Safe lifting and handling of patients (May)
- Safe Injection practices (June)

Additional programs offered in September were on healthcare diversity and disparities. National leader in diversity, Amy Wilson-Stronks, former staff member of The Joint Commission, spoke about the national work being done in diversity. Dr. Terry Ann Parnell, Associate Chief Diversity and Inclusion Officer for the North Shore-LIJ Health System spoke about the work being done island-wide.

Linda Kenny from Medically Induced Trauma Support (MITSS) in Boston, MA was a guest in April to discuss support following a medical injury and the importance and value of empathy needed towards the patient as well as the clinician.

Each session had evaluations and a brief summary available for those who wanted additional information.

This year we had a logo developed by Farmingdale College Senior Advertising class (see above) and the mission/vision of The Council was also finalized.

PULSE of NY is grateful to North Shore-LIJ Health System for continuing to supporting this valuable work for another year. Our primary focus for 2012 and 2013 will be to build a dynamic website as a method to disseminate the information to anyone who is seeking a useful resource including patients and their families seeking information and assistance on safe and quality health care. We will also be seeking additional groups to partner in the future.

To date, we have educated and reported on or have developed tools for:

Pharmacy students ó St. John's School of Medicine  
Hispanic/Latino community ó Central American Refugee Center  
Disabled Adults ó Long Island Center for Independent Living  
End of Life -Advanced Directives ó Hospice Care Network  
Families of intellectually and developmentally delayed children ó Independent parent advocates  
Alcohol and drug dependent persons ó LI Council on Alcohol and Drug Dependency  
Transgender persons ó Trans Solidarity Project  
Alzheimer's / Dementia caregivers ó Merrick Alzheimer's/ Dementia support group  
Low literacy adults ó Literacy Nassau  
Young Mothers ó Momma's House

PULSE of NY has had a continued relationship of support and has gathered valuable information on their current and future needs of these various groups. We look forward to continuing to spread the word about patient safety throughout Long Island communities and continuing to fulfill the mission of the PULSE of NY - Patient Safety Advisory Council.

Submitted by:

Ilene Corina,  
President PULSE of NY,  
Chair, Long Island - PSAC