

PULSE of NY Patient Safety and People Living with HIV/AIDS

August 2015

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www.pulseofny.org

PULSE of NY partnered with two community organizations that provide HIV/AIDS support groups: Options for Community Living and the NS-LIJ Health System Center for AIDS Research and Treatment (CART). PULSE presented one educational workshop to Options for Community Living members, and three focus groups were conducted with CART. The Directors that we worked with from each organization were eager to have PULSE of NY become involved with the support groups. Workshops focused on effective communication skills, medication safety, health literacy and patient's rights. Information about patient safety was provided, and the participants were asked, following the presentation, what are some obstacles they may face in getting safe, quality medical care because they are living with HIV/AIDS. Participants told of their experiences and of the stigma still attached to people living with HIV/AIDS.

The group from CART decided that a brochure dispelling the myths of living with HIV/AIDS that they could distribute, would be helpful to them.

To develop this brochure, we asked the group questions and participants worked in pairs to discuss.

The three questions were:

- What do you want people to understand about you?
- What do you want people to stop saying about you?

After reconvening, many answered with very personal responses. These showed a trend:

- People want to give them advice.
- People think they are sicker than they are.
- People think they are not living a productive life.

The group created a general-purpose pamphlet that can be distributed by people living with HIV / AIDS to help dispel the myths. The pamphlet can be used as a tool in sensitivity training for health care staff, patient advocates and the friends and family of people living with HIV/AIDS.

The brochure explained that many common beliefs about living with HIV/AIDS are not true.

The final meeting with the group was held in July 2015 to share and submit any additional approved comments on the brochure.

To view the brochure, go to www.patientsafetyadvisorycouncil.org. For a copy of the brochures send a note and a self-addressed stamped legal size envelope to: PULSE of NY, PO Box 353, Watagh, NY 11793-0353.

About PULSE of NY: PULSE of NY is a nonprofit organization raising awareness about patient safety through advocacy, education and support services. Founded in 1996.

