



North Star News



JUNE 2012

CBC Campaign Wrap-Up

"Every end is a new beginning"

This issue of the "North Star News" marks the conclusion of the "Pennsylvania Campaign for Better Care (PA-CBC). As we look back on our shared efforts there is much to celebrate. From the Campaign's launch in 2009, we grew our efforts to include over twenty-five partnering organizations. From the "Family Caregiver Support Act" to defense of Medicaid and Medicare, we sought to improve public policy by legislative visits, creative advocacy projects, and sharing the power of our personal stories. A special thank you to all of you who shared your stories and in doing so educated many.

Through our very successful "*LIFT UP YOUR VOICE!*" *Advocacy Trainings*, in one year we trained approximately 100 seniors and caregivers. We held trainings in Beaver, Erie, Pittsburgh, Westmoreland, Wellsboro and Williamsport. Many of the graduates of these trainings stayed involved with our Campaign by participating in our monthly calls, assisting in our advocacy efforts, and joining in our workgroups.

This e-newsletter and our monthly PA-CBC Conference Calls provided opportunities to inform and involve persons in both personal and systemic health care reform. Persons were educated on a broad range of topics and became experts on the Affordable Care Act, Medicare and Medicaid, and Accountable Care Homes, and the Coleman Model for successful transitions in health care.

Our *Healthy Hospitals Workgroup* has done amazing work on building upon and educating the consumer voice in terms of reduction of hospital readmissions. As we glean information from the six focus groups, we look forward to sharing those findings and more importantly educating consumers on what they can do to reduce hospital readmissions.

The work of advocacy is never done because the system continually needs to be reformed. For all you have done to make our health care system more patient-centered and more quality-driven, our thanks and appreciation. The work continues.....

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READ MORE about PA CBC at www.consumerhealthcoalition.org



Raising Health: What happens after the Supreme Court decision?

This past May the Supreme Court heard testimony about the constitutionality of the Affordable Care Act (ACA.) A decision is likely to be made the last week in June. The possible scenarios include:


1. Entire law is upheld
2. Just the personal mandate is struck down
3. The personal responsibility mandate is struck down, but so is the requirement that insurance companies cover everyone and not use underwriting or gender rating to charge people in a discriminatory way
4. The entire law is struck down

Then what happens?

How can PA move forward with implementation? If we lose the mandate then we will fight to win them back on the state level. If the whole law is struck down we will still fight to keep existing laws in place. No matter what the outcome is, we need to have a unified voice and a simple explanation of what the ruling means for folks.



Advocacy Toolbox: What can we do after the decision is made?

Pennsylvania Health Access Network (PHAN) will be collecting stories, creating a video, and talking to the press. Visit pahealthaccess.org to share your story and what the ACA means to you. Also use Twitter hash tag - #ACAMeans to share your story! 

On the day of the ruling – PHAN will hold a statewide press call, press conference in Harrisburg at the Capitol Rotunda, and events across the state. To get involved, share your story, or for more information about events in your area, please contact Leslie Bachurski at 412-456-1877.

We ask that our partner organizations prepare email alerts with coordinated messaging to send out after the ruling is made. Tools and templates will be made available. Remember, whether a positive or negative decision is made, it is important that we remain unified and share one voice on the issue to move forward and implement the law at the state level without further delay or to take action at the state level to protect the lost provisions. Thanks in advance to everyone!



Advocates Speak Out: Beverly

Expectations! Great expectations! Health care on a certain level is played out as a series of expectations; expectations delayed, fulfilled, or disheartened.

Beverly is a veteran of diabetes, battling its symptoms for almost 20 years. Recently she had fallen and developed leg and ankle pain so she went to her usual hospital to be checked out. She did not eat and did not take insulin that morning. She expected her leg to be examined and an x-ray, ordered, and she did receive that care. She was told that nothing was broken, but no specific diagnosis was given. She had history of gout, but this did not appear to be gout, perhaps because it was bruised. She was given a pill for pain, was told that it was Tylenol but different from the Tylenol she normally took at home. She expected this hospital to have all her records since she had been coming here for years. Uncertain whether it was due to the comfort of that thought or the effect of the medication, she fell into a deep sleep.



Six hours later, after having gone to the ED to have her leg checked out, Beverly woke up dazed and confused. It felt like someone had turned on the faucet, like buckets of water poured over her head. Sweat kept coming down her face, her neck, and body. She just remembered the emergency room staff running in, and it was not until a nurse with a glass of orange juice urging her to drink and someone yelling blood sugar of 30 that it dawned on her that she had just experienced a hypoglycemic episode. As she recovered from this dreamless nightmare, still amazed that her body could produce so much sweat, she recounted the few prior hypoglycemic events that she had previously experienced, but nothing like this one. Even though she was a known patient at this hospital and her records were available—thick stacks of chart that she was known for and the understanding that “everything is in the computer,” everyone forgot that she was a diabetic. Things do get crazy in the ED, and sometimes patients are left alone for a long time or forgotten. She now wonders if they ever checked her records.

Beverly was admitted overnight for observation, got an IV in her neck for hydration, and was discharged the next day. A home nurse promptly made a house visit, followed by a physical therapist. She was even referred to a dietician and received all the attention for her diabetes that she did not expect—a blessing in disguise. Since discharge, she has learned to increase protein in her diet, and her blood sugars have been in good range. Her ankle has turned more black and blue since the ED visit, so perhaps she did injure it somehow. It is a reminder of the fateful ED visit and hospital where unexpected things often do happen. Patients like Beverly naively expect familiarity, having had meaningful interactions with the system personally, structurally, and virtually (EMR speaking), but the health care system has, on more than one occasion, failed on these 3 levels despite safeguards. To some clinicians, Beverly is an older diabetic woman with particular leg pain; to others, she’s a lady with ankle sprain or one of many faceless patients or statistics admitted through the ED with unexpected outcomes and complications. Beverly prefers the first scenario—an individual with unique circumstances and needs, seeking attention and treatment in an impersonal sterile technological setting that many patients such as she has come to accept as an extension of her medical home.

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Consumer Health Coalition was founded in 1996. We are a non-profit health care advocacy organization with a mission to “inspire a consumer movement to advance health and enhance access to quality, affordable health care.”

We believe that access to quality, affordable health care, and ultimately good health and wellness, are critical to a person's ability to reach his or her potential. We also know that people experience disparate “starting points” or access to resources that are unfortunately correlated with socioeconomic status, racial or ethnic background, and disability status. CHC is dedicated to the eradication of disparities in health access and outcomes, and will continue pushing until every person has the health coverage and care they need.

“To run a successful advocacy campaign, one needs quality resources, constant communication, and a strong network of support. Here in Pennsylvania, we received all this and more through our working partnership with Community Catalyst. The very successful LIFT UP YOUR VOICE Advocacy Trainings were a product of the creative vision of Community Catalyst. Being able to draw on their connections and insight in terms of policy and further education greatly enhanced our efforts in Pennsylvania.”



~ The Pennsylvania Campaign for Better Care



“The LIFT UP YOUR VOICE! Advocacy Training was like a new day for me! The training was wonderful and I left empowered and engaged in the campaign. The training taught me that I can speak up for things that matter in terms of my health, the health of my community, and, yes, the health of the nation.”

~ Sue Eppers, LUYV Graduate, February 2012 Pittsburgh Training