

## Save the Dates

Saturday, June 8, 2013 is

### The Silver Lining Summit: There is Life With and After Cancer

The 1st Cancer Survivorship Summit in the Hudson Valley

SUNY Orange, Kaplan Hall

The Cancer Resource Center of the Hudson Valley, founded by SLC HAP Alumna **Casey MacDonald**, class of 2010, is a 501(c) 3, non-profit organization whose mission is to be the new voice of advocacy for cancer patients in the Hudson Valley.



We are redefining cancer advocacy as a collaborative, progressive, innovative initiative whose time has come to be the patient centric model of care it was always meant to be by providing informational and educational resources and support services to improve quality of life through all stages of the cancer journey.

This will be a full day conference for cancer patients, cancer survivors, caregivers and healthcare professionals with keynote speakers, survivorship panels and quality of life breakout workshops for living with or after Cancer. Participants include Matthew Zachary, founder of Stupid Cancer.org, the nation's premier organization for young adults with cancer, Cancer and Careers, the country's top resource for cancer and employment issues and SLC student and author **Elizabeth Bailey**, of the resourceful guide, "The Patient's Checklist." Bob and Linda Carey of "The TuTu Project" will be special guests at the Summit. Bob, a professional photographer, is best known for taking pictures (of himself) outfitted in a pink tutu to help his wife Linda cope with her breast cancer diagnosis.

Continuing education credits from the Leukemia & Lymphoma Society will be available for oncology professionals.

Register online at [www.hudsonvalleycancer.org](http://www.hudsonvalleycancer.org). HAP students who would like to volunteer to help the day of the Summit can contact [Casey@hudsonvalleycancer.org](mailto:Casey@hudsonvalleycancer.org).



Sunday, June 9, 2013 is

### Green Gym Day

**A day to celebrate and be active  
in our public parks all over the world**

HAP student **Ariel Hidalgo** loves to run and she wants to make a difference. She is working with Nancercize founder Nancy Bruning in the USA and FunMeFit founder Kate Hill in the United Kingdom to launch the first global community of park "activityists."

And she wants you to join the movement! You can have a great time in nature as you make a difference in a world-wide health crisis. Across the globe, people are getting too little activity and spending too much time indoors. Being active, especially outdoors in the natural light and among the greenery, is one of the best things you can do. You don't need a gym membership, expensive equipment, or to be a health fanatic to begin improving your health. All you need is to have a day of fun activities in a public park.

So enjoy the pleasures and freedom of better health for yourself while inviting and being a role model for others. Whether you go solo or with family and friends, join the global community of Green Gym Day participants on June 9, 2013! Read all about it at [www.GreenGymday.org](http://www.GreenGymday.org)

# HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

Volume 20 • Number 1 • Spring 2013

## Letter from the Director

By Vicki Breitbart

### Violence Is a Health Issue

The Newtown massacre brought the problem of gun violence to the attention of the American public in a dramatic way. While certainly tragic, this was not an isolated event. There have been seven massive shootings this year and it seems that reports of gun deaths appear in the media almost every day. Gun deaths have become a regular occurrence in our country and the numbers are alarming. There are reportedly over 32,000 firearm deaths in a year, exceeding traffic fatalities in this country. While the massive shootings draw a lot of attention, two-thirds of those who die in shootings are individuals in homes with easy access to guns. States that have high gun ownership rates have two times the suicide rates with guns as states with low ownership.<sup>1</sup>

Often the argument against gun controls comes from those who believe that guns are necessary to protect women and children. In reality, guns in the home are reported to increase youth suicides and accidental deaths. The idea that guns make women safer is blatantly false. A 2011 review from the Harvard Injury Control Research Center reported that "far from making women safer, a gun in the home was a strong risk factor for female homicides and the intimidation of women." Intimate partner homicide accounts for nearly half of the women killed every year and more than half of them are killed with a firearm. The risk of homicide is eight times greater for women in abusive relationships when the perpetrator owns a gun.<sup>2</sup> A study of 46 large urban centers found that laws restricting gun access by people with domestic violence restraining orders reduced murders of women by 19 percent. Yet, even when women get orders of protection against their abusive partners, in many instances the perpetrators are still allowed to own and keep their guns, often with deadly consequences.<sup>3</sup>

There are now active discussions about gun control laws at the state and federal level. These moves towards legislation are all critically important steps, but we need to do much more than this to address the pervasive culture of violence in America. The sug-

gested changes in gun ownership warrant support, but a broader perspective is necessary to make real and lasting change in the acts of violence that permeate our daily lives. Much of my past research was about the pervasiveness of intimate partner violence (IPV)—emotional, sexual and physical abuse between two individuals in a relationship, but not necessarily in a domestic setting. According to the Centers for Disease Control, IPV affects 3 out of 10 women and 1 out of 10 men. We found that many acts of violence in relationships are taken lightly and accepted as the "way things are." A lot of abusive behavior in relationships goes unrecognized as violence. In my work, many women didn't identify what happened to them in their relationships as rape until they realized that the definition included any unwanted or coerced sex. Violence in relationships that is undefined can be more than two times more frequent than perceived partner violence and is associated with at least as many health problems.<sup>4</sup>

Violence in relationships has many health consequences that are often overlooked when discussing the more dramatic statistics of homicides and suicides involving guns. In a report on intimate partner violence, it was noted that survivors of IPV are more likely to have symptoms, ranging from more frequent headaches and difficulty sleeping to chronic pain, activity limitations and generally poor physical and mental health, than those who have not experienced the traumas of violence in their lives.<sup>5</sup> These abusive and violent relationships take a heavy toll on the children involved in these situations. There are estimates of up to 15 million children who witness domestic violence annually. Children who witness violence in the home are more likely to be involved in physical aggression and violent behavior and are more prone to depression. This is a vicious cycle of violence in the home.<sup>6</sup>

*continued on page 2*

<sup>1</sup> Suicide made easier. Editorial. *The New York Times*, Feb. 14, 2013.

<sup>2</sup> Dangerous gun myths. Editorial. *The New York Times*, Feb. 3, 2013.

<sup>3</sup> Luo, M. Ruled a threat to family, but allowed to keep guns. *The New York Times*, March 18, 2013.

<sup>4</sup> Sonega, M, et al. Unperceived intimate partner violence and women's health. *Gac Sanit.* 2013. <http://dx.doi.org/10.1016/j.gaceta.2012.11.009>

<sup>5</sup> The National Intimate Partner and Sexual Violence Survey. 2010 Summary Report. CDC, p. 3

<sup>6</sup> Harris, W.W., Lieberman, A.F., Marana, S. In the best interests of society. *Journal of Child Psychology and Psychiatry* 2007, 48:3-4, 392-411

## Letter from the Editor

By Barbara Robb

The December shootings in Newtown are still fresh in the minds of those in the Health Advocacy Program. Three of the contributors to this issue of the Bulletin have written about issues related to violence. Vicki Breitbart's letter is about violence as a health issue. Elizabeth Klampert writes about advocacy efforts to reduce gun violence and Elizabeth Breier addresses the need for reform in our mental health system.

A new feature appears in this issue: a section on implementation of the Affordable Care Act. It has been three years since passage of the ACA, but much work remains to be done. Linda Ricci writes about education and enrollment campaigns, with emphasis on efforts in New York State.

This issue also includes Toi Scott's description of her work at the Sustainable Food Center in Austin, Margaret Rubick's

### [www.slc.edu/health\\_advocacy](http://www.slc.edu/health_advocacy)

The **Health Advocacy Bulletin** is a publication of the Health Advocacy Program at Sarah Lawrence College, One Mead Way, Bronxville, NY 10708.

Program Director: Vicki Breitbart

Editor: Barbara Robb

Email: [vbreitbart@sarahlawrence.edu](mailto:vbreitbart@sarahlawrence.edu)

All material in the **Health Advocacy Bulletin** is the property of the authors and may not be reprinted without permission. Opinions expressed are not necessarily those of the editor or of the Health Advocacy Program.

path to publishing and Gloria Escobar-Chaparro's interview of Stacy Jacob about her work as Manager of Patient Experience at NYU Langone Hospital for Joint Diseases. Rebecca Johnson writes about Dorothy Roberts' talk on the biopolitics of race and health, relating it to her own recent experiences with our health care system.

---

*Violence Is a Health Issue...continued from page 1*

Violence takes a heavy toll on the health of women, men and children. It will take a multidimensional and multidisciplinary approach to deal with this problem. One way is through legislation. The Violence Against Women Act, stalled in Congress for several years, has finally been passed. Imbedded in the law were protections for victims of sex trafficking, also a way overdue piece of anti-violence legislation. The objections to the law had focused on the inclusion of protections for immigrants, American Indians and gays; its passage was a victory for all of us. This legislation and efforts to control gun ownership are all important steps. As health advocates we can be part of screening, identifying, assessing and preventing violence in its many shapes and forms in our culture. We will need to partner with others to create a comprehensive approach that works for change in education, criminal justice and health care systems to create a more just and less violent society.

## In This Issue

Letter from the Director: Violence Is a Health Issue . . . . .	1
Letter from the Editor . . . . .	2
Reports from the Field . . . . .	3
Organizing for Community Health and Food Justice in Austin, Texas . . . . .	3
Interview with Stacy Jacob: Patient Experience . . . . .	4
Path to Publishing . . . . .	5
Points of View . . . . .	6
Our Mental Health System: In Need of Radical Reform . . . . .	6
Can We End Gun Violence? . . . . .	7
The ACA in Action: Implementing Health Care Reform . . . . .	8
We're Not Done Yet: Significant Hurdles Remain in Covering the Uninsured . . . . .	8
Health Advocacy Program Events . . . . .	9
Margaret Keller Lecture 2012: Dorothy Roberts on The Biopolitics of Race and Health . . . . .	9
EXHALE: Add Your Voice . . . . .	9
Student and Alumni Updates . . . . .	11

*The MA in Health Advocacy Program is supported by: The Fund for Sarah Lawrence*

## REPORTS FROM THE FIELD

# Organizing for Community Health and Food Justice in Austin, Texas

By Toi Scott

It seems obvious that food and health justice go hand in hand. What we eat is a huge determinant of our wellness. And just as there are many barriers to access to quality health care, there are also a plethora of barriers complicating access to healthy food. When we add affordability into the mix, the barriers are multiplied.

For folks who sit at the intersection of marginalized identities (race, class, gender, sexuality, ability, etc.), accessibility becomes even more of a challenge. It is at these intersections that I've found myself doing food justice work. I've co-created and cultivated community gardens, engaged community around food justice issues, and assisted in community kitchens and cooking classes. In HAP I was passionate about health justice. My passion for food justice was planted in New York, bloomed in Oakland and has been harvested in Austin.

I moved here to do a second term as an Americorps VISTA (Volunteer in Service to America), this time with the Sustainable Food Center, since their mission seemed right up my alley:

"The Sustainable Food Center (SFC) cultivates a healthy community by strengthening the local food system and improving access to nutritious, affordable food. SFC envisions a food secure community where all children and adults grow, share and prepare healthy, local food. From seed to table, SFC creates opportunities for individuals to make healthy food choices and to participate in a vibrant local food system. Through organic food gardening, relationships with area farmers, interactive cooking classes and nutrition education, children and adults have increased access to locally grown food and are empowered to improve the long-term health of Central Texans and our environment."

At first glance it seems as if Austin has the local food system under wraps. The movers and shakers of the food movement seem to be on every corner planting wicking beds and promoting urban farms and now, food forests. There are also a fair amount of farmers markets and local "food justice" groups. And "everyone" is a locavore—committed to sustaining our local economy by buying from local farms and businesses.

But this is based on a superficial glance. A deeper look shows it's not all it's cracked up to be. There are many disparities along race and class lines. "Food justice" here is impaired by detrimental assumptions about those who are called the "target population" and their motivations, behaviors and access to resources. These are the same assumptions made by the larger food movement.

As a community health organizer/education coordinator for the Sustainable Food Center, I organize within low-income elementary schools attended predominantly by students of color, where I assist parents and teachers in organizing into wellness teams that promote health through various programs and activities. I help connect elementary schools to SFC's programs such as farm to school

(getting local, organic food into cafeterias), assist schools in starting teaching and community gardens, coordinate free basic organic gardening classes and cooking and nutrition classes for parents/families and faculty, and provide health curriculum for students.

---

*"...just as there are many barriers to access to quality health care, there are also a plethora of barriers complicating access to healthy food."*

---

The schools that we organize within are low-income schools on the East Side of Austin, which used to be communities with black and brown majorities. In the 1920s, I-35 was built when the city and state decided to codify racism by constructing a physical barrier and moving all black and brown citizens east of the highway. The government put pressure on communities of color by pushing schools and businesses of color east and by overtly violent and discriminatory housing policy and other laws. Gentrification is now a threat to these neighborhoods, with a loss of local businesses, housing discrimination, and development and revitalization focused around new community members' wants and interests, while basic needs (such as food and housing) of more established community members go unmet. I tell this very common story of gentrification to show how housing and displacement impact the food system for certain populations. Food justice is also used many times as a tool for gentrification, as many of these areas are considered "food deserts." While many markets move in with the influx of new community members, they usually only cater to that populace and are no better than high-end convenience stores without culturally relevant or affordable foods.

Cultural relevance is something I try to emphasize at our organization, since we provide cooking classes for the community and run four farmers' markets here in Austin. The anti-oppression, microaggression and intersectionality research that Josh Lapps and I did for our capstone, and even the Community-Based Participatory Research methods we learned, are very much at the forefront of the dialogue that I have with our staff around organizing and community engagement.

I consult about community organizing and engagement with Food for Black Thought (FFBT), a grassroots organization designed to create dialogue about race and food—a dialogue that is greatly lacking in the current food movement. FFBT facilitates culturally relevant conversations and shows movies like Byron Hunt's "Soul Food Junkies" and "East Austin Food Stories."

*continued on page 5*

## Interview with Stacy Jacob: Patient Experience

Stacy Jacob, a 2011 graduate of the Health Advocacy Program, has taken on the role of Manager of Patient Experience at NYU Langone Medical Center Hospital for Joint Diseases and graciously agreed to speak with Gloria Escobar-Chaparro about her experiences.

**Gloria:** Your title is Manager of Patient Experience, not Patient Relations or Customer Service?

**Stacy:** As the Manager of Patient Experience, I oversee not only the Patient Relations Department, but also Language Access Services, the Volunteer Department and the Gift Shop.

**Gloria:** It seems that more and more hospitals are moving toward the idea of having staff in charge of “Patient Experience,” rather than having a Manager of Patient Representatives, Patient Relations or Customer Service. Why do you think this is so?

**Stacy:** Many hospitals are now focusing on the whole patient experience. In the past, patient representatives have traditionally focused only on resolving complaints and building relationships, but these are only two components of the larger role. I also believe that more hospitals are beginning to focus on the fundamentals of advocacy. Regardless of what we think patients may have experienced, it is not what we think that matters, it is what they believe they have experienced that is important. Hence, the focus is now on patient experience.

**Gloria:** Federal reimbursement rates are moving away from a strict fee for service model to being based on factors such as patient satisfaction and readmission rates.

**Stacy:** When we talk about patient satisfaction, it refers to all the services that we provide, not only the quality or success of the medical treatments patients receive while in our care. Does the patient have to call for their room to be cleaned? Can they rest comfortably at night or are there loud machines that keep them from sleeping? How well are we communicating with our patients? Are we responsive to the patient that is experiencing an issue and is constantly ringing the call bell? We must constantly strive to not only provide quality care and service but to improve all aspects of the patient experience. Ultimately I think the key to patient satisfaction is improving the interactions and communications between patient and staff. Hospitals have to be concerned about patient satisfaction because it is tied to HCAHPS and Federal government reimbursement rates.

**Gloria:** What is HCAHPS?

**Stacy:** HCAHPS is the Health Consumer Assessment of Health Care Providers and Systems survey. It is a way for CMS, the Centers for Medicaid and Medicare Services, to hold health care institutions accountable for services provided to patients. HCAHPS provides a national standard for measuring this type of information.

**Gloria:** How can communications between physicians and patients be improved?

**Stacy:** As a medical professional, there is an obligation to effectively communicate any and all information with and to our patients. After seeing their patients, medical providers tend to ask “Do you have any questions?” The question they should be asking is “What questions do you have?” This question does not force patients to give a yes or no answer, but rather allows patients to discuss the questions and concerns they have but may be afraid to ask, especially if they do not understand what the doctor has said. This rule should not be limited to physicians, but should extend to all care providers.

**Gloria:** What are some of the most important skills or abilities that Patient Advocates will frequently rely on to be effective in their roles?

**Stacy:** To be an effective patient advocate it is important to become familiar with all the hospital’s policies and procedures, and learn the functions of every unit and department. One must be knowledgeable about medical terminology, and understand to some extent medical procedures and the medications that are typically prescribed or the medical devices used. This assists us with identifying problems that may be risk related versus issues of patient dissatisfaction. It is also important to become knowledgeable about insurance and billing issues, as financial complaints are very common. In respect to skills, I think it is very important for a patient advocate to be able to think critically, analytically and creatively.

**Gloria:** As a result of the Affordable Care Act, it’s estimated that more than 500,000 individuals in New York City alone will gain access to health insurance coverage. What impact might this increase in the number of insured patients who are able to obtain medical care have on hospitals?

**Stacy:** I see a positive impact. It is very good for individuals and families to have access to care, particularly our seniors who will have more health care choices. Being able to have a free yearly wellness visit provides the individual with the opportunity to know what is going well and whether they may need further health care. There are many preventive services now required under the ACA, and from an economic standpoint we know that providing preventive measures is more cost effective than having to treat the diseases that result from a lack of health care.

Organizing for Community Health...continued from page 3

I also do informal food and health justice organizing with a group of radical activists who are devoted to creating community dialogue, sharing food in homes and community spaces as a form of resistance, and engaging community through awareness and education around intersecting social justice issues (the overlap of environmental justice, economic justice and food justice, for instance). We’ve found that sharing our stories around food is very healing. At the kitchen table, all kind of issues are voiced and we

find that we’re not alone. In this way, eating together is a form of resistance—and saves time and money, as well.

My future work with the Sustainable Food Center will entail more anti-oppression work and diversifying our newer East Side farmer’s market by showing films and having community dialogue, potlucks and other events in our new building once it’s completed in May. Outside of the organization, I hope to help be a catalyst and co-creator in building black and brown food cooperatives and buying clubs and a wellness center with holistic healers of color.

Toi Scott is a graduate of the Health Advocacy Program.

## Path to Publishing

By Margaret Rubick

In spring of 2012, I was published for the first time, and then, much to my surprise and delight, I was published a second time in the fall. Who would have thought that in middle age I would see my name on the cover of a literary journal and on the chapter of a book? How did it happen?

In my first semester of the Health Advocacy Program I wrote a research paper for the History of Health Care class. Professor Rebecca Johnson met with me in conference and said more than once, “You’re going to have a great paper.” The encouragement helped me continue to explore. I did not have an outline; I just had an idea. I followed where instinct, research and writing took me. I had never used a primary source before and had never gone into a library’s archives. It was all new and exciting to explore. I remember when Laura Weil entered the second-floor classroom and said, “I understand you have a publishable paper.” My response was, “I haven’t started writing it yet.” The early encouragement from both professor and Director helped me. I love possibilities and what I experienced was that I could allow my research to go wherever it took me. I started with a question, not a theory, and the answers I found were multifaceted.

I suppose it would help to know the question: Why did the American Psychiatric Association remove the definition of homosexuality as mental illness from the Diagnostic and Statistical Manual in 1973? I started looking for answers, met some fascinating people and learned some amazing facts (which I will omit here because they are in my paper and in my articles).

I took my 20 plus-page paper and submitted it to the *Journal of American History*, trying for the 2011 Louis Pelzer Memorial Award. I did not win. I sent the paper to *American Scholar* and *Phi Beta Kappa*. From there I searched for journals that published on gay and lesbian topics.

It was my fourth submission that caught an editor’s interest. My paper was much too long—almost 7,000 words. It would have to be reduced to somewhere between 2000 and 4000 words. I cut and cut and then asked the editor to help me understand what should be saved to be relevant for his readership. There was an advantage to having a one-year gap between completing the paper and editing it for publication. I find that while I am writing something, I am in love with my words. I don’t want to change one reference,

one allusion. One year later, I didn’t mind. I knew that the editor, Richard Schneider, knew his audience and he generously jumped in and did a massive redaction of my writing.

The article, entitled “The Women Who Took on the APA,” came out in the March-April 2012 issue of *The Gay and Lesbian Review Worldwide*. Schneider generously put my name on the front cover of the journal. Within days I heard from another editor, Tracy Baim, Editor of the *Windy City News* in Chicago. She knows my primary source, Kay Lahusen, and quickly gave her a call. Baim was working on a book and wanted coverage of the newsletter *The Ladder*, produced by lesbians on the East Coast. Lahusen referred Baim to me, and the rest is, as they say, history. I wrote chapter four, “Ascending *The Ladder*,” of *Gay News, Gay Power*, which was published in November 2012.

“It was my fourth submission that caught an editor’s interest.”

I like to say that the best things in my life have happened via serendipity. I was looking for information on Kay Lahusen’s partner, Barbara Gittings, when I first called her; she became my primary source. I was researching their roles in the Herstory Museum in Brooklyn when I came across *The Ladder*. Tracy Baim contacted me on Lahusen’s recommendation. Who knows what will happen next?

Now, from a pragmatic point of view, if I were to break what happened into steps, they would be:

1. Write the paper and look for a coach, either a professor or someone else who has published.
2. Check to see the relevance to different readers. Make sure your topic is timely.
3. Do searches on publications you’d like to approach. Most have instructions on how to submit.
4. Submit, and repeat as needed.

As you wait and hope, remember that timing is a big part of the decision as to what is published.

Margaret Rubick is a graduate of the Health Advocacy Program.

## Our Mental Health System: In Need of Radical Reform

By Elizabeth Breier

The tragedy in Newtown once again brought mental health and mental illness to the forefront of public attention. As usual, they quickly faded away into the background. The bubble of media attention, speculation, “expert” opinions and personal testimony made it painfully evident how little society understands these illnesses. There is more than one form of mental illness, and each illness can affect each individual differently, despite common symptoms. For Health Advocates working in behavioral health, tragedies like Newtown always raise the same question: how do we eliminate the stigma of mental illnesses and the discrimination faced by individuals with these illnesses, so that they seek help? This problem is at the core of our country’s mental health dilemma.

---

*“Those who speak openly to advocate from personal experience still do so at great risk, both personally and professionally.”*

---

As a Health Advocate with over thirteen years of behavioral health experience, working in community mental health and both national and local advocacy agencies, and as an individual living with my own mental health issues, I am saddened that the progress our society has made toward accepting mental illnesses in the same way that we accept other conditions has been so slow and laborious. Diabetes and cancer are now viewed with no shame or stigma, and yet we cannot seem to accomplish this with mental illnesses. Those who speak openly to advocate from personal experience still do so at great risk, both personally and professionally. Those who live with these illnesses face enormous obstacles in trying to live the way the rest of “normal” society does. Would more understanding and greater social acceptance of mental health challenges stop tragedies such as Newtown? Maybe, maybe not. However, greater acceptance from society at large would increase the likelihood that individuals and families would seek help—and seek help early.

I don’t pretend to have all the answers, but there are some suggestions that I support, particularly after watching the problems that plague the mental health system remain unresolved, and in fact, worsen:

- Mental health reform that is driven by communities, not government. The token representation of a handful of individuals with mental illnesses trotted out as representation is not enough to effect an inclusive societal shift.
- Greater research on the brain, and on the impact of nutrition and environmental toxins on mental illnesses, rather than just focusing on medication efficacy alone. If what an

individual consumes affects the rest of the body, does it not stand to reason that the brain and major mental illnesses are impacted as well? Why then is research primarily focused on medication effectiveness?

- Creation of successful treatments, not the cycle of sickness and dependency that exists in the mental health system today. Psychiatry needs to be held accountable. It is unacceptable for children and adults to rotate through crises and hospitals, with an ever-changing diagnosis and medication regimen. We need more than a checklist from a diagnostic manual.
- An understanding that intervention and treatment are highly effective when done early in life. As long as stigma and discrimination persist, parents are less likely to seek help when their child starts to exhibit signs of mental illness.
- Complete integration of mental health and primary care. The body functions as a whole system, so why treat the brain separately? The body strives for homeostasis, and medicine should as well.
- An escape from the stranglehold of the pharmaceutical industry, starting with mental health advocacy organizations rejecting pharmaceutical company funding.
- Education of our youth about mental illnesses to normalize them, starting early in school. We can reduce stigma within two generations if we start with our youth now.
- Acceptance of mental illnesses as a societal issue, not as the responsibility of professionals only. It takes a village. Recognition and support does not mean everyone makes diagnoses; it simply means that we can create a strong network of support to help one another.
- Regular use and acceptance of alternative treatments, in addition to or, for some individuals, in place of the standard medical model. A strength-based perspective acknowledges that willingness to seek alternative treatment is still a willingness to seek treatment.

I believe these steps are essential to creating a mental health system that works. If we change the way we think about these illnesses, perhaps those who live with them might be more open to treatment—treatment that actually works. As advocates, we must start by raising awareness and changing language. We cannot claim to use person-first perspectives and still use words like “crazy” and “nuts” in referring to others. These words demean and disempower, and fuel the lack of acceptance and understanding that permeates society. It has to start with us, leading by example. Health advocates can create change that lasts past the societal memory of tragedy.

*Elizabeth Breier is a graduate of the Health Advocacy Program.*

## Can We End Gun Violence?

By Elizabeth Henry Klampert

*A well regulated militia being necessary to the security of a free state, the right of the people to keep and bear arms shall not be infringed. —U.S. CONST. AMEND. II.*

On Mother’s Day, May 14, 2000, I joined thousands of mothers (and others) in Washington, D.C., for the Million Mom March to support sensible gun control laws. Here we are in 2013 and the issue of gun control is not only still alive and well, but still unresolved. Attention has been riveted on this topic again because the December 2012 shooting of 20 small children and six of their teachers in Newtown, Connecticut, has really brought this issue home to many people, including gun owners. While the National Rifle Association (NRA) maintains that any limits to gun ownership pose a threat to the Second Amendment right to bear arms, others maintain that access to guns must be curbed and some cities and states have proposed and passed legislation to that effect. Increasingly, gun access is seen as creating a health hazard and is, therefore, a public health issue.

---

*“On the state and local levels, action is taking place.”*

---

The NRA argues that the Second Amendment is sacrosanct and the government cannot place restrictions on an individual’s right to bear arms. Many may be surprised to learn that the NRA’s view was not widely supported by politicians before the 1980s.<sup>1</sup> However, after a relentless effort by the NRA, the Supreme Court finally ruled, in *District of Columbia v. Heller*, 554 U.S. 570 (2008), that the Second Amendment protects an individual’s right to possess a firearm unconnected with service in a militia and to use that firearm for lawful purposes, such as self-defense within the home.

The Court’s decision in *Heller* allows limitations on the right to possess a firearm, contrary to the NRA’s assertion that any such limitations are the beginning of a “slippery slope” to take guns away from American citizens. In fact, Justice Scalia, the author of the *Heller* opinion, recognized the constitutionality of restrictions on Second Amendment rights, which the NRA conveniently overlooks. He stated, for example, that “nothing in our opinion should be taken to cast doubt on longstanding prohibitions” on felons having guns or “laws forbidding the carrying of firearms in sensitive places such as schools.”<sup>2</sup> In other words, restrictions on guns are possible if our politicians have the political will to impose them.

Efforts to control guns are not new. Among the most well-known organizations supporting these efforts is the Brady Campaign to Prevent Gun Violence (“Brady Campaign”), a successor organization to The Center to Prevent Handgun Violence (CPHV). Jim Brady and his wife Sarah became involved with CPHV after he was shot in 1981. In 1991, Sarah Brady became CPHV’s chair and her advocacy

for gun control laws culminated in the passage of the Brady Law in 1994. CPHV changed its name in 2001 to the Brady Campaign to Prevent Gun Violence<sup>3</sup> and in 2002, the Million Mom March merged into the Brady Campaign.

It has been difficult on the national level to pass effective gun control in the face of the NRA’s ability to cow politicians. On the state and local levels, however, action is taking place. For example, alarmed by the prevalence of gun violence in their cities, mayors like Mayor Bloomberg have formed Mayors Against Illegal Guns and are pressing for sensible gun laws. In New York State, Governor Cuomo has signed into law the New York Secure Ammunition and Firearms Enforcement Act of 2013 (NY SAFE ACT) which, among other provisions, bans high-capacity magazines and assault rifles.<sup>4</sup>

Much focus is now on gun violence as a public health issue. This is particularly true as it pertains to children. As the Children’s Defense Fund website shows, in a figure that changes daily, 3,108 children and teens have been shot by guns since the 113th Congress convened on January 3, 2013.<sup>5</sup> In a January 2013 *New York Times* op-ed piece, an emergency room doctor wrote about his ER experiences with gun violence.<sup>6</sup> In response, two doctors asserted that “firearm violence is a public health problem of major proportions.” Also in January, the Harvard School of Public Health sponsored a forum on “Gun Violence: A Public Health Crisis.” Laurence Tribe, a panelist and well-known constitutional lawyer, argued that the Second Amendment is “actually the friend of those who seek stronger gun laws” and that the “slippery slope” argument used by the NRA does not work in reality because the government cannot possibly disarm everyone. In addition, the costs associated with gun violence are rising, amounting to, as one study found, at least \$12 billion a year in court proceedings, insurance costs and hospitalizations.

While gun violence is unlikely to end soon in the United States, the focus now is on what can be done to place limits on gun possession. The NRA is not going away quietly, but as Mayor Bloomberg and others focus attention on the costs of gun violence and its impact on public health, perhaps the goals of the 2000 Million Mom March will finally be achieved.

*Elizabeth (Betsy) Klampert, Esq., is a graduate of the Health Advocacy Program.*

<sup>3</sup> Brady Campaign history, <http://www.bradiycampaign.org/about/history>.

<sup>4</sup> See, e.g., NY SAFE Act. Available from [www.governor.ny.gov/2013/gun-reforms](http://www.governor.ny.gov/2013/gun-reforms).

<sup>5</sup> See, <http://www.childrensdefense.org>.

<sup>6</sup> Newman, D. H. At the E.R., bearing witness to gun violence. *The New York Times*, Jan. 2, 2013. Available from <http://www.nytimes.com/2013/01/02/opinion/at-the-er-bearing-witness-to-gun-violence.html>.

<sup>7</sup> Boufford, J. I. and Barondess, J. A. Guns: a public health issue. *The New York Times*, Jan. 6, 2013. Available from <http://www.nytimes.com/2013/01/07/opinion/guns-a-public-health-issue.html>.

<sup>8</sup> Gun violence: A public health issue. *Harvard Magazine*, Jan. 9, 2013. Available from <http://harvardmagazine.com/2013/01/gun-violence-and-public-health>.

<sup>9</sup> Kennedy, K. Gun violence has a high cost. *USA Today*, March 5, 2013. Available from <http://www.usatoday.com/story/news/nation/2013/03/04/gunshot-wounds-medicaid-insurance-costs/1956445/>.

<sup>1</sup> See, e.g., Toobin, J. So you think you know the Second Amendment? *The New Yorker*, Daily Comment, Dec. 18, 2012. Available from <http://www.newyorker.com/online/blogs/comment/2012/12/jeffrey-toobin-second-amendment.html>.

<sup>2</sup> *District of Columbia v. Heller*, 554 U.S. 570, 626-627 (2008).

## We're Not Done Yet: Significant Hurdles Remain in Covering the Uninsured

By Linda Ricci

Now that President Obama's health care reform has been enacted and state health exchanges will soon be open for business, you would think that near-universal coverage would kick in as of January 2014. Guess again. The 32 million uninsured individuals who are expected to be covered must first be identified, educated and enrolled.

The uninsured are a particularly hard to reach demographic. Recent national polling shows that they are primarily low literacy: one-quarter have not completed high school and a full 90 percent do not have a college degree. Nationally, 30 percent of the uninsured are Spanish speaking. Here, in the Bronx and Queens, other languages are twice as prevalent as English, and among them, all in significant numbers, are Spanish, Chinese, Hindi and Korean.

But there is something even more fundamental to take into account: the attitudes of the uninsured themselves. Many don't think they can afford health insurance, are skeptical that it will cover what they may need or (especially young adults) don't think they need it at all.

However, focus group findings show those now uninsured can be convinced with information about affordability (financial assistance will be available for 85 percent of the uninsured), comprehensiveness (all plans include doctors' visits, hospital services, maternity care and prescription drugs) and protection against the financial insecurity that serious illness can mean.

A new group, Enroll America, is making plans for an education and enrollment campaign along these lines. This Obama campaign-affiliated organization will likely be concentrating its efforts on about a dozen states, including Texas, Florida and Georgia, where there are many millions of uninsured and where there will be no state outreach component because these states are not forming their own exchanges.

By contrast, New York State—with nearly 2.5 million uninsured—is already putting together a vigorous 40 million-dollar effort to reach a targeted and eligible population of approximately one million. New York City-based health advocates, concerned that even more needs to be done, are mobilizing to expand on the State's outreach by bringing together volunteers to prepare for the campaign's launch in the summer. This will leave just a few months before the New York State exchange's six-month open enrollment period starts on October 1, 2013.

Already, the State has contracted with a public relations firm to do everything from television advertising and securing the participation of celebrities to engaging in social media and enlisting coalition partners, such as African-American churches. The State is also signing up firms and non-profits to run navigator programs. Navigators, a federally-defined role for those who sign up the uninsured, will be professionally trained in financial assistance and the intricacies of the many insurance choices. This is an extremely important function because, even though there will be a new online platform (compared variously to Expedia or Turbo-Tax), polls show that 75 percent of the uninsured want in-person help.

Under the umbrella of Health Care for All New York, a broad range of health advocacy groups are working to enlist volunteers to support the work of the navigators by identifying individuals who are uninsured and explaining the advantages of enrolling. Plans for volunteer activities are under way and members of the Sarah Lawrence community are taking part. If you're interested in playing a role in this important initiative, please contact Linda Ricci at [lricci@gm.slc.edu](mailto:lricci@gm.slc.edu).

*Linda Ricci is a graduate student in the Health Advocacy Program.*

### Health Advocacy Program Alumni Survey

Please respond by June 15th

As valued alumnae, we would greatly appreciate your input on what positions you have found since graduating, what impact HAP has had on your career and what additional ways we can be of assistance.

The questionnaire will take about 5 to 10 minutes to complete. Your responses will be confidential and you will not in any way be identified in the analysis. By completing this survey you can help us better prepare our students to enter this exciting field and to continue to better serve you. If you are alumni of the Health Advocacy Program and did not receive the survey by email, please let us know by emailing [cgreene@sarahlawrence.edu](mailto:cgreene@sarahlawrence.edu).

## Margaret Keller Lecture 2012: Dorothy Roberts on The Biopolitics of Race and Health

By Rebecca O. Johnson

It was time for my regular physical. I had spent a year in my old/new hometown trying to find an African-American female internist or gynecologist who would take my health insurance. I finally gave up and made an appointment at the new Center for Health Equity that a local hospital conglomerate has set up in my old neighborhood. It is one of those new medical homes being innovated through the Accountable Care Organization provisions of the Affordable Care Act. (No, this isn't an article about health care reform.) I went in for my appointment. In the course of the various evaluative procedures that pass for scientific investigation of the health of the body, the attending nurse and the very new physician, both women, comment on how healthy I am and how they don't see many middle-aged African-American women who are active, free of chronic illness and not taking a fistful of prescription drugs. But there was one problem. My blood pressure was high that day.

"We will see how you do in the next few weeks," the young South Asian physician told me, "but you know high blood pressure is genetic for African-Americans. There's nothing you can do about it."

It was this medical canard and other equally disturbing racial ideas and racist practices that Dorothy Roberts addressed as the featured speaker at the Fall 2012 Margaret Keller Lecture. Roberts argues in her latest book, *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century*, that "the myth of the biological concept of race—revived by purportedly

cutting-edge science, race-specific drugs, genetic testing and DNA databases—continues to undermine and promote inequality in a supposedly 'post-racial' era."<sup>1</sup>

Robert's lecture gave an overview of the conundrum of racial disparities in health care and the medical misinterpretation of the greater incidence of diabetes, hypertension, low birth weight and obesity as genetic factors. Take, for example, my recent diagnosis with hypertension. It is based on a theory called the "slavery hypothesis"<sup>2</sup> in which the ancestors of African-Americans are posited to have survived the Middle Passage from Africa because of a genetic predisposition to retain sodium, thus not dying of malnutrition.<sup>3</sup> Unfortunately for this theory, no one has found the elusive gene mutation and Africans and Caribbean residents of African descent, whose ancestors traveled on the same slave ships, do not have the rates of hypertension with which African-Americans present.<sup>4</sup>

In her visit to Sarah Lawrence, Roberts' talk demonstrated that the idea of race is real as a cultural phenomena and a

*continued on page 10*

<sup>1</sup> Dorothy Roberts, *Fatal Invention*, The New Press: 2011. Back cover.

<sup>2</sup> Roberts, 2011, p. 113.

<sup>3</sup> Ibid.

<sup>4</sup> Ibid, p. 114.

## EXHALE: Add Your Voice

EXHALE is a national organization based in Oakland, California that was founded by and for women in 2000. It has been a leader in "changing the culture around abortion from one of stigma and shame to one of support and respect." On February 25th, several EXHALE fellows from around the country came to Sarah Lawrence as part of their national tour. HAP and the Women's History Program cosponsored their appearance at the College. By sharing their own abortion experiences and interacting with students and staff in a workshop format, the fellows aimed to teach the basics for pro-voice communication, present

new ideas and tools to support people who experience abortion and build a "pro-voice" movement that goes beyond the labels of both pro-choice and pro-life. In addition to this national tour, EXHALE provides an after abortion talkline and an on-line community to provide emotional support for anyone who wants to engage in conversation about their abortion experience.

*For further information, visit EXHALE: <https://exhaleprovoice.org/pro-voice>*

## An Alumna's Commitment to HAP

By Jennifer Buckley

While finishing up my senior year in college, I learned that Sarah Lawrence had the only Master's level Health Advocacy Program that offered the education and training that I was seeking. The Health Advocacy Program is actively engaged in training its students in this ever-evolving health care field. I was hired right out of the program and I have worked mostly as a hospital patient representative for many years. I'm currently the Senior Advocacy Officer at Memorial Sloan Kettering Cancer Center (MSKCC). I've also worked for HAP as both a consultant and Fieldwork Coordinator.

I am proud to say I am a Sarah Lawrence Health Advocacy alumna. I contribute financially to demonstrate my commitment and to support HAP's current students and faculty.

*Margaret Keller Lecture 2012...continued from page 9*

"political system" but has no validity as a biological reality. But it is what we do in this country: we see each other through the lens of race.<sup>5</sup>

*"Roberts' talk demonstrated that the idea of race is real as a cultural phenomena...but has no validity as a biological reality."*

Racial disparities in health are today a major focus of public health and health care reform efforts. We forget that black people created one of the first national health campaigns when, in 1915, "the Virginia affiliate of the National Negro Business Association established a health week to call attention to the high morbidity and mortality of black Virginians and to develop programs to attack them."<sup>6</sup> It is interesting to remember that the U. S. Public Health Service, which took over management of National Negro Health Week from Tuskegee Institute in 1930, decided in 1950 that National Negro Week and the Health Education and Welfare (HEW) Office of Negro Health Work were no longer necessary, given "the trend toward integration."<sup>7</sup>

Roberts points out that the health problems of African-Americans continued to be investigated in unscientific and politicized ways despite the proclamations of HEW.<sup>8</sup> Progress in genomic

science has done little to debunk these politicized tendencies within the health care and medical establishments. Rather, it has made them worse. Roberts described in her lecture how scientists could go searching for genetic proof of race and health disparities via specious laboratory research and how pharmaceutical companies could use the trappings of the clinical research process to create drugs such as BiDil to sell to the new "racial markets" of the 21st century medical landscape.

We all recognize, and Dorothy Roberts thoroughly and disturbingly documents, that health disparities are real. The problem is how we go about addressing them. There is an underlying blaming of the victim in the poorly designed and conducted genomic research Roberts described in her lecture, as well as the usual blatant profit motive of the pharmaceutical industry. We must attend to Roberts' contention that these disparities are caused by long-standing economic, political and legal inequities. This suggests that most of the medical establishment, from my newly minted primary care physician to the enormous policy change represented by the Affordable Care Act, are frequently asking the wrong questions, ignoring the more pervasive historical effects of racism in this country.

I know I will be having a conversation with my new doctor, about race, medical stereotyping and how my genes don't even begin to tell the story of chronic illness in the African-American community. It's the least I can do for my sisters who are burdened with that fistful of pharmaceuticals and little insight into the true source of their suffering.

*Rebecca Johnson is a faculty member in the Health Advocacy Program*

<sup>5</sup> Roberts, 2011 p. 3.

<sup>6</sup> Gamble, V. and Stone, D. U.S. policy on health inequities: The interplay of politics and research, *Journal of Health Politics, Policy and Law*, 31:1 p. 100. Duke University Press: 2006. Accessed through JStor.

<sup>7</sup> Gamble and Stone, 2006, p. 102.

<sup>8</sup> Ibid.

## STUDENT AND ALUMNI UPDATES

"The Affordable Care Act's Plan For Consumer Assistance With Insurance Moves States Forward But Remains A Work In Progress" by **Rachel Grob** (HAP 1992), Mark Schlesinger, Sarah Davis, **Joshua Lapps** (HAP 2012) and **Deborah Cohen** (HAP class of 2013) was published in the February 2013 issue of the journal *Health Affairs: At the Intersection of Health, Health Care and Policy*.

**Elizabeth Bailey**, HAP class of 2014, was named as one of five finalists for WEGO Health's Rookie of the Year Award for her work developing tools and educating patients, caregivers and health care providers on how to prepare for and stay safe, and sane, during hospital stays. WEGO Health is a social networking platform created to facilitate the development of relationships and sharing of resources among health advocates.

**Christine Dyer-Ward**, HAP 2002, is currently Senior Clinical Research Manager in renal transplant medicine at Brigham and Women's Hospital in Boston, Massachusetts. In this role, Christine has had the opportunity to coauthor four medical journal articles on topics related to renal transplants.

**Maureen Eisner**, HAP 1993, is now Director of Patient Experience at Saint Clare's Hospital, New Jersey.

**Ashley Fletcher**, HAP 2010, is now a Senior Coordinator of Public Affairs and Advocacy with the American Geriatric Association.

**Megan Fortner**, HAP class of 2014, is a Patient Representative at Stamford Hospital in Connecticut.

**Jessica Hill**, HAP 2012, is now Director of Center Programs for Bronx-Westchester Area Health Education Center, where she has organized year round internships and programs for students interested in pursuing health careers.

**Sylvia Hinds-Wynter**, HAP 2011, is a Patient Care Coordinator at Lenox Hill Hospital in New York City.

**Elizabeth (Betsy) Klampert**, HAP 2012, is currently an attorney in the White Plains, NY office of the Cuddy Law Firm, P.C., which provides comprehensive legal services for families of individuals with disabilities. Her practice focuses on SSI/SSDI appeals, special needs planning and Medicaid appeals.

**Valerie McDermott**, HAP 2008, is Manager of Patient Experience at Lenox Hill Hospital in New York City.

**Jessica K. Miller**, HAP 2007, is currently working as a Patient Representative at Memorial Sloan-Kettering Cancer Center, where she specializes in breast, gynecological and colorectal/gastric mixed tumor cancers.

**Margaret Rubick**, HAP 2010, was a contributing author for the recently published book by Tracy Baim, *Gay Press, Gay Power: The Growth of LGBT Community Newspapers in America* (CreateSpace Independent Publishing Platform, November 24, 2012).

**Brenda Shipley**, HAP 2012, is now Project Director for Bioscience Connecticut's Health Disparities Institute, a university-community partnership to enhance research and the delivery of care to minority and medically underserved populations within the state through four program cores: research, policy, outreach and engagement, and capacity building.

**Susan Titus Glascoff**, HAP 1990, had an online response regarding gun control posted to Ross Douthat's blog in *The New York Times*, The Opinion Page, on December 20, 2012.

### Save the Date Mediation in Health Care Certificate Program

Wednesday, June 19 – Saturday, June 22, 2013

Offered by Sarah Lawrence College's Health Advocacy Graduate Program, Center for Continuing Education, and the Westchester Mediation Center, this four-day 35-hour mediation certificate is designed for health professionals, individuals who wish to enter the health profession and professionals engaged with health care issues on a variety of levels. This program will provide 23.5 credits in Continuing Legal Education transitional/non-transitional skills and 2 credits in Ethics and Professionalism. CLE credits are awarded by Pace Law School.

This program is offered on the Sarah Lawrence College campus in Bronxville, New York. Hours will be 8:30 a.m. – 5:00 p.m. There is a residential option available if commuting is not convenient. Please call Crystal Greene at (914) 395-2602 or e-mail [cgreene@sarahlawrence.edu](mailto:cgreene@sarahlawrence.edu) for more information.