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# Resilient Sisterhood Project: Black Women's Reproductive Health

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by

*Lilly Marcelin and Charlene Galarneau\**

In 2022 the Resilient Sisterhood Project (RSP) will celebrate its 10th year anniversary in Boston, Massachusetts, USA. This New England city – infamous for its anti-Black racism, renowned for its world-class health care and educational institutions, and home to both the Combahee River Collective as well as the Boston Women's Health Book Collective – is the fertile ground from which RSP has flourished. Today, as in the past, RSP envisions “transforming communities to find solutions for diseases of the reproductive system that disproportionately affect Black women”<sup>1</sup>. Why and how RSP came to be with its particular understanding of Black Women's reproductive health justice is the story we tell here.

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Charlene Galarneau is Senior Lecturer at Harvard Medical School, Department of Global Health and Social Medicine, and Center for Bioethics; Emerita Faculty at Wellesley College, Women's and Gender Studies; and Affiliate Researcher at Boston University, Center for Antiracist Research. Her teaching and research explore the ethics of health care, public health, and health policy, in particular concepts and practices of justice that take seriously multiple and diverse communities and their intersecting social relations including gender, race, and geography. Research topics include racism in bioethics, USPHS STD experiments in Guatemala, ACA exclusions and exemptions, reproductive justice, and FDA blood donor deferral policies. Galarneau's 2016 book, *Communities of Health Care Justice*, cultivates a concept of community justice that understands communities as critical participants in determining the nature of just health care. Her initial interest in ethics was motivated by her work with rural community/migrant health centers and the communities they serve.

This article is co-authored following a series of interviews of Lilly by Charlene.

### Listening Beyond the Silences

In her decades of work with survivors of gender-based violence, Lilly Marcelin noticed that many of these women were also dealing with reproductive health problems. Considering that these health issues might be impacting many women in the Black community, Lilly wondered about her family members, friends, and peers. Did they too struggle with these health concerns?

Drawing on a rich oral and cultural tradition of wisdom circles, Lilly invited close family members, friends, and colleagues to gather in circles and one-on-one to speak about their experiences. Professional and working class, young and old, they talked and cried around kitchen tables, in public libraries, and on playgrounds in Boston, Mattapan, Hyde Park, Dorchester, and Cambridge. They invited their loved ones and friends, women who too shared their stories about dealing with diseases of the reproductive tract including uterine fibroids, endometriosis, infertility, polycystic ovary syndrome (PCOS), and gynecologic cancers. Early onset puberty of the young girls in their families was also a concern. They disclosed their feelings of confusion, shame, fear, and anxiety as they struggled daily with these health issues. One woman who worked as a hotel housekeeper-standing on her feet all day revealed that out of fear of staining her clothes, she refused to sit on the bus on her way to work and home due to the prolonged and heavy bleeding of her uterine fibroids.

Over time and throughout the many conversations, common themes arose. Women spoke of multiple visits to different doctors in their attempts to figure out what was wrong. They spoke of feeling that their pain and other concerns were minimized or met with indifference by health care providers. Some women with endometriosis explained that it took many years and seeing seven or more gynecologists before they received a proper diagnosis. Another common theme was their experience of health care providers' use of racist stereotypes of Black women as highly sexualized, for example, by assuming that these women's pain was caused by pelvic inflammatory disease (PID), an illness often caused by sexually transmitted infections (STIs).

Many women spoke of leaving their medical appointments with little information about their conditions. They often felt ill-equipped to ask questions in their next visit. Stories of medical contempt and neglect abounded. Meanwhile these women's undiagnosed ailments worsened and they felt overwhelmed in managing these health issues. Indeed, many felt alone. And they wondered aloud, why was there so much silence, secrecy, and inaction about these reproductive health issues?

As Lilly listened, she began to research Black women's reproductive health issues – in the medical and public health literatures and as addressed by reproductive health organizations. What she learned horrified her. Some reproductive health conditions, such as uterine fibroids appeared to disproportionately affect African American women, while other conditions such as endometriosis appeared to be un-

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<sup>1</sup> [Rsphealth.org](https://www.rsphealth.org). “Black women” is understood to mean women of African descent; women means all persons who identify as women.

derdiagnosed among Black women<sup>2</sup>. And there was much that was simply unknown and/or unattended to in the scientific literature<sup>3</sup>. Furthermore, Lilly found that Black women's health issues were not central issues to most reproductive health organizations. Rather they tended to center their work around middle-class White women's priorities. Black women's reproductive health issues were generally limited to abortion, teen pregnancy, and STIs which, like the clinical stereotypes, stigmatize women of African descent as hyper-sexualized.

It was becoming clear to Lilly that the stigma, silence, and inaction discouraged women from seeking and receiving high quality care in a timely manner. She became convinced that overt and subtle, deeply layered and harmful racist and sexist narratives about Black women's reproductive health needed to be addressed. It became apparent that other societal conditions affected health and thus also needed attention: the stress of chronic racism, inequitable incarceration, harsh anti-immigration policies, unequal exposure to environmental toxins, and access to affordable and healthy foods also contributed to adverse reproductive health outcomes.

Given the troubling data and narratives about reproductive health and social conditions, Lilly began to understand that deeper forces were at work in these women's experiences and stories.

Overwhelming though it was, Lilly felt a deep moral responsibility and commitment to do something to address these interlocking systems of injustice.

After three years of listening to women and learning the research, Lilly knew that she had the collective momentum of a village supporting a vision of action. With great audacity and invoking the spirits of her ancestors for strength and vision, Lilly realized that she needed to start an organization to inform and empower Black women on issues regarding their reproductive health. It would be a grassroots organization focused on community-centered education and advocacy for Black women's reproductive health through a social justice framework. The first activities of the organization would be to focus on education that supported rethinking and reframing the dominant negative and limited narratives around Black women's reproductive health. The organization's advocacy work would center on challenging medical/social inequities that are harmful to Black women's reproductive health. Lilly believed that an advocacy platform was necessary to start a transformative movement of well-informed women who could articulate their reproductive health concerns and needs to their medical providers and influenced social and public health policies.

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<sup>2</sup> Jacoby Vanessa L, Fujimoto Victor Y, Giudice Linda C, Kuppermann Miriam, Washington A. Eugene. Racial and ethnic disparities in benign gynecologic conditions and associated surgeries. *Am J Obstet Gynecol.* 2010;202(6): 514-521, <https://tinyurl.com/4w58va22>.

<sup>3</sup> More information has become available in the last decade. See, for example, Eltoukhi Heba M, Modi Monica N, Weston Meredith, Armstrong Alicia Y, Stewart Elizabeth A. The health disparities of uterine fibroid tumors for African American women: a public health issue. *Am J Obstet Gynecol.* 2014;210(3):194-199. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3874080/>; Sophia King, "Rx For Change: Racial Disparities in Cervical Cancer Mortality," National Women's Health Network, Jan 8, 2021, <https://nwhn.org/13810-2/>.

Naming the organization took months. In honor of the resilience so prominent in Black women as they met reproductive health crises and challenges, and in honor of the close relationships formed among Black women as they shared their stories, the new organization was called “The Resilient Sisterhood Project”<sup>4</sup>.

### **The Resilient Sisterhood Project Emerges: The First Five Years (2012-2016)**

In the summer of 2012, Lilly sublet a small office space in the South End of Boston from an organization that runs an English to Speakers of Other Languages (ESOL) school for immigrants. With seed money awarded by the Katherine W. Davis Foundation and two Wellesley College student volunteers, Lilly launched a peer leadership program entitled “Empowering Black Female Adolescents”<sup>5</sup>. This six-week education and training program for teens 14-19 years old had dual goals: to educate them about the reproductive health of Black teens and women, and to train them as peer leaders in reproductive health. The Davis grant enabled RSP to compensate these teens throughout their training, a reflection of RSP’s valuing of their time.

In the fall of 2012, RSP moved into Boston’s historic Harriet Tubman House which would become RSP’s home for the next eight years. With a great sense of determination, many supporters in “the village” helped out with RSP’s first brochure, donation of office furniture, small financial contributions, and so much more -- Lilly’s daughter designed and built the first website. To provide governance and leadership, Lilly strategically convened an Advisory Council to guide the mission and vision of RSP. The demographic characteristics of Council members varied in race, ethnicity, sexual orientation, age, religious, and socioeconomic backgrounds and included women had been personally affected by serious reproductive health concerns.

Having a dedicated office space and community support provided a moral boost and invigorated RSP’s energy and vision. The new location became a space where Black women could come to question social stereotypes, the culture of silence, and the lack of attention to the health impacts of these reproductive diseases. In order to manage the many financial details of a nonprofit and to lend credibility to RSP as it sought grants from foundations and other funding sources, Lilly chose the Black Ministerial Alliance of Greater Boston to serve as their fiscal agent from 2012-2019.

Lilly began to hold educational workshops in schools, churches, and women’s organization spaces. These workshops focused on the specific reproductive health conditions of Black women including, but not limited to, diseases of the reproductive tract, health equity, reproductive rights/justice, health impacts of racial chronic

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<sup>4</sup> Lilly notes that this name: The Resilient Sisterhood Project, is bittersweet as these women should be able to thrive with less resilience, in other words, to thrive without being burdened by unjust racial and social relations.

<sup>5</sup> Davis Projects for Peace, “Empowering Black Female Adolescents” last accessed August 11, 2021 at <https://www.davisprojectsforpeace.org/projects/projects/node/2198>.

stress on women's reproductive health, maternal health, unequal and cumulative exposure to toxic chemicals, environmental racism, gender-based violence, and oppressive cultural and racial norms. These spaces were revelatory for many attendees as they learned, for example, about the connection between their health and their toxic exposures to common household and personal care products. Given that these issues are not frequently discussed in the Black communities, these workshop participants realized that they were not alone in their lack of knowledge about reproductive health matters. Over time RSP became increasingly well-known as a reliable educational resource.

Collaborating with health care providers would be essential to improving health outcomes. Thus RSP worked to expand providers' understandings of these reproductive diseases and the social determinants of health that contributed to them. Specifically RSP attempted to raise awareness about the impact of racism in health care settings including health diagnoses and prevention, comprehensive information regarding health conditions, and clinician-patient interactions based on empathy, respect, and trust.

As Executive Director, Lilly worked to create, renew, and strengthen strategic collaborations with numerous area nonprofit organizations, colleges, and health institutions. For example, the Silent Spring Institute (SSI), a Boston-based science institution, works on research with physicians, scientists, public health and community organizations to identify and break the links between environmental chemicals and, for example, breast cancer. RSP has partnered with SSI as well as Boston Medical Center, Beth Israel Deaconess Medical Center, and a variety of community-based organizations. Working with Families For Justice As Healing, for example, has enabled RSP to highlight the reproductive health challenges of currently and formerly incarcerated Black women.

In these early years, RSP worked diligently to expand its educational and advocacy work with more workshops, conferences, and collaborative research. RSP became well established in Boston and continued to build relationships across public and private sectors. Reflecting on that expansion, RSP engaged in more significant partnerships with environmental justice organizations such as Clean Water Action and with related academic programs at Northeastern University. In collaboration with these entities and the Environmental Protection Agency, RSP cosponsored a major environmental justice conference in 2016 that centered racial and ethnic minority groups, particularly those from low-income neighborhoods that are adversely affected by multiple toxic exposures.

This conference was the first such community-based and academic convening in Boston to focus on the relationship between the health and well-being of women of color and environmental toxins. A conscious decision was made to invite women physicians and scientists of color who were doing notable research linking reproductive health and the environment as the lead conference speakers. Conference attendees, largely women of color, were elated to engage with these brilliant minds and asked RSP to bring them back in other contexts so that they could learn more and engage further. This unexpected conference outcome has catalyzed new RSP strategies for community engagement.

Lilly, her Advisory Council, and the other RSP volunteers trusted that the significance of their work would be recognized and that additional needed funding would come. And it did. In 2015 RSP received a private multi-year gift that leveraged future foundation grants and allowed RSP to pay staff including consultants and interns. Perhaps as importantly, it deeply affirmed their work. Since that time, most of RSP’s funding has come from private foundations and major and individual donors.

### **The Next Five Years (2017-Present)**

At the five year mark, Advisory Council members gathered to create a Vision Statement which continues to guide RSP’s work today: “transforming communities to find solutions for diseases of the reproductive system that disproportionately affect Black women.” Consistent with this vision, RSP reaffirmed its core education, training, and advocacy goals focused on the reproductive health needs of Black women, and added new education and advocacy efforts in support of social science research on Black women’s reproductive health. Moreover RSP aims to raise public awareness of contemporary research and to contextualize it within the history of medical abuse of Black women’s bodies.

In 2018, RSP created the Young Advisory Leadership Council [YALC]. This group of young Black women between the ages of 18 and 45 actively supports RSP efforts to raise awareness regarding reproductive health issues prevalent in their communities. Members of the YALC are bright, dedicated, motivated individuals highly committed to furthering RSP’s mission and strategic plan through hands-on initiatives.

Drawing on the Sankofa principle of looking to the past to understand the present<sup>6</sup>, RSP organized a particularly memorable event in May 2019 at Wellesley College, with the instrumental support and contribution of the Wellesley Centers for Women<sup>7</sup>. Medical experimentation is part of the historical legacy of Black women’s enslavement in the U.S. In 19th century rural Alabama, Dr. J. Marion Sims practiced surgical techniques for fistula repair on enslaved women. We know the names of three of these women: Anarcha, Lucy, and Betsey. While Sims is honored as the “father of gynecology,” Anarcha, Betsey, and Lucy are largely unknown and faceless. Wanting to celebrate and honor these women and to elevate their humanity, RSP commissioned three paintings representing them. In a special Mother’s Day celebration titled “Remembering Our Foremothers in Gynecology: The Hidden Contributions of Anarcha, Betsey, and Lucy,” these paintings were publicly displayed for the first time<sup>8</sup>. Amidst presentations, song, poetry, dance, food, and spoken word performance, this historical truth-telling revealed continuities to con-

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<sup>6</sup> Sankofa is an African word from the Akan tribe in Ghana meaning that the knowledge of the past must never be forgotten.

<sup>7</sup> For information on the Wellesley Centers for Women, see: <https://www.wcwonline.org>.

<sup>8</sup> A Zoom recording of this Mother’s Day Ceremony is available at <https://rsphealth.org/webinars-events/>.

temporary medical abuses such as the forced sterilization of Black and other women including incarcerated women.

Organizationally, RSP took a big step in 2019 and became a tax-exempt charitable organization. More changes took place in early 2020 with the onset of the COVID-19 pandemic. Adapting to on-line modalities, RSP went entirely virtual. Webinars replaced in person gatherings and an active presence on social media led to RSP drawing even more Black women and allies into its circle, women from across and outside the U.S. This broader exposure has meant that RSP is being invited to speak to a wider range of groups on a wider range of topics. As such, RSP is expanding its influence.

### Looking Ahead

Planning is in the works for three new RSP programs with 2022-2023 launch dates. One centers on developing a protocol for health care providers to address the reproductive health needs of formerly incarcerated women. Understanding that women's incarceration is often related to experiences of gender-based violence, racism, and poverty, and that health care in prison is minimal and often dehumanizing, this new protocol will be a collaboration between RSP and national organizations that are currently serving formerly incarcerated women as they reintegrate into their communities. Incarcerated women report that at times they are able to see health care providers only if specific health needs can be proven, and even then, the wait times are long and diagnosis and treatment are often difficult to obtain<sup>9</sup>. Conditions such as fibroids, endometriosis, and gynecological cancers may remain undiagnosed or untreated. This protocol will help assure that these women receive dignified, comprehensive, and appropriate reproductive health care services.

A second upcoming project involves the development of a two-track mentorship program that supports Black adolescents and young adults in becoming the next generation of U.S. health care leaders. RSP believes that more racial-ethnic diversity in the health professions and science fields are an asset not only for communities of color but for the country as a whole.

One track of the project will support young adults aged 15-22 years old who are interested in health and science careers. This project will blend didactic and interactive teachings about the contributions made by Black women doctors and scientists. It will also address historical and contemporary racist policies in medicine and science related to Black women's reproductive health. Participants will be paired with mentors with whom they will explore career directions and optimally, career selection.

A second track of the project will provide mentors for Black women students at various stages of health-related training including medicine, nursing, various therapies, and the environmental sciences. This endeavor will honor the legacy of Dr.

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<sup>9</sup> Rachel Roth. "She Doesn't Deserve to Be Treated Like This": Prisons As Sites of Reproductive Injustice. In *RADICAL REPRODUCTIVE JUSTICE: Foundations, Theory, Practice, Critique*, ed. Loretta J. Ross, Lynn Roberts, Erika Derkas, Whitney Peoples, and Pamela Bridgewater Toure (New York: The Feminist Press, 2017), <https://tinyurl.com/szpun4ut>

Immacula Cantave, one of the first Haitian women admitted to a Haitian medical school. Dr. Cantave became a successful physician in Haiti and in 1968 moved to the US to practice medicine first in Chicago and later in Boston. She mentored many Black medical students in navigating the arduous aspects of medical school as well as their professional careers<sup>10</sup>.

The third program RSP is launching considers how art can be a form of reproductive justice. It extends the visual representation of Anarcha, Betsey, and Lucy to include other foremothers in the movement for Black women’s reproductive health. RSP will commission additional works of, for example, Fannie Lou Hamer, Henrietta Lacks, and Dr. Rebecca Crumpler. Dr. Crumpler was the first African American woman to earn a medical degree in the US and she practiced medicine in Boston among other places<sup>11</sup>. This art will be used by senior health care providers in the education of health care providers in training. An RSP dream is to create a viewing space for art related to Black women’s reproductive health issues.

As RSP approaches its tenth anniversary, it will engage in another reflective visioning process, inclusive of some of the resilient sisters who a decade ago shared their stories. Part of this reflection will be to re-member the past and to honor these courageous women who broke the silence and lit the fire that became the Resilient Sisterhood Project.

Mindful of Lilly’s mother and grandmother who often said, “Let’s see if we can do a little something,” Lilly speaks these Talmudic words at each RSP workshop – and thus we end here: “Do not be daunted by the enormity of the world’s grief. Do justly, now. Love mercy, now. Walk humbly, now. You are not obligated to complete the work, but neither are you free to abandon it”.

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<sup>10</sup> To learn more about Dr. Cantave’s life, see <https://www.davisofboston.com/obituary/DrImmacula-Cantave>.

<sup>11</sup> To learn more about Dr. Crumpler’s life, see <https://rsphealth.org/blog/2021/06/22/acknowledging-dr-rebecca-crumpler/>.