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The Women's Health Activist®

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Toxic Personal Care Products and Women's Health: A Public Health Crisis

By M. Isabelle Chaudry

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NATIONAL WOMEN'S HEALTH NETWORK
A VOICE FOR WOMEN, A NETWORK FOR CHANGE

DIRECTOR'S MESSAGE

Expanding the Fight for Safety in Women's Health

By Cynthia Pearson

Cynthia Pearson is the Executive Director of the National Women's Health Network.

"We'll need your help, too. Sign up for and watch out for our action alerts, and join us in the fight. Together we can win."

The NWHN has never shied away from big fights. Our founders insisted that women be given written information about their medicines at a time when that was unheard of. We won. In the 1980s, we set out to change the medical and cultural understanding of menopause. We did. In the 2000s, we created a national campaign to fight for universal access to health care. We made huge strides.

Now, we are ready for another big fight. We are determined to get toxic chemicals out of personal care products, and give consumers the right to know what is in the products we put on our hair, face, skin, and vulvas. M. Isabelle Chaudry's article, "Toxic Personal Care Products and Women's Health: A Public Health Crisis," explains just how badly our new campaign is needed. Right now, the Food and Drug Administration (FDA) has no power to require personal care product manufacturers to stop using ingredients that are known to be harmful. In fact, the FDA can't even force a recall of specific products that are known to cause severe injuries.

If we succeed — *when* we succeed — the FDA will have the *power* it needs, and consumers will be able to make more informed choices about which products are safe enough for them to use.

One reason why we're so eager to take on this fight is our deep understanding of exactly how the FDA works, and how industry can twist laws and guidelines to weaken the FDA's power. For example, medical device manufacturers fought hard to create a loophole in the 1976 Medical Device Amendments, passed by Congress in the aftermath of the Dalkon Shield IUD tragedy. That loophole — the official name is the "510(k) process" — lets manufacturers market new devices without any clinical testing if they claim that their new device is substantially similar to an older device.

Using that loophole, manufacturers marketed vaginal mesh without any testing in women, based on the outrageous claim that surgical mesh used in our vaginas is substantially similar to surgical mesh used to repair hernias. Metal-on-metal hip implants, temporomandibular joint (TMJ) implants, and textured breast implants are just a few of the medical devices that caused lasting harm to hundreds of thousands of people, all because industry stacked the deck in its favor.

We won't let that happen this time. We have allies in Congress who are interested in the issue, and we've reached out to a wide network of local, state and national organizations to join us in this fight. We'll need your help, too. Sign up for and watch out for our action alerts, and join us in the fight. Together we can win.

You can sign up for our action alerts on our website (*www.nwhn.org*). If you haven't visited our website recently, you may have missed our in-depth examination of the Trump-Pence administration's recent decision to give a Title X grant to The Obria Group. The Obria Group runs clinics that plan to promote the Femm fertility awareness app as a method of contraception. The Obria Group opposes abortion care and hormonal contraception. The Femm app fits the company's ideological needs, but it doesn't meet women's needs. It hasn't even been cleared by the FDA! As if it weren't bad enough that Trump and Pence want to take Title X money away from real clinics, now they're funding fake birth control, too.✤

Board Members at our Annual Award Reception (L to R):
Dazon Dixon Diallo
Kimberly Robinson
Kentina Washington-Leapheart
Francine Thompson

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Who wouldn't? It's election time again, and the National Women's Health Network (NWHN) is inviting nominations for our Board of Directors. We are seeking candidates who understand the NWHN's mission, support its goals, and are committed to the organization's activist nature. We value diversity in race, class, age, sexual identity, and geographic location. We seek candidates with varied skills and experiences in women's health. All applicants must be NWHN members.

The NWHN has a working Board. Members are expected to attend up to three weekend Board meetings each year and to participate in fundraising and on at least one Board committee. Meetings are held in various locations, including Washington, D.C. and California. For more information on Board responsibilities please email nwhn@nwhn.org or call the office at 202.682.2640.

If you know someone who would make a good Board member, or if you're interested in joining the NWHN Board yourself, please get in touch.

- Nominations will be due in early January 2010.
- Nomination forms will be available on-line in early November.
- All current NWHN members will have the opportunity to vote for the new Board during the Spring 2020 elections.

The NWHN Board of Directors at the June 2018 meeting.

National Women's Health Network
1413 K Street NW, Suite 400
Washington, DC 20005-3459
202.682.2640 phone
202.682.2648 fax
www.nwhn.org
Online women's health column:
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Our Mission
The National Women's Health Network improves the health of all women by developing and promoting a critical analysis of health issues to influence public policy and support consumer decision-making. The Network aspires to a health care system that is guided by social justice and reflects the needs of diverse women.

The Women's Health Activist® is a publication of the National Women's Health Network. We'd like to hear from you. Please email questions or comments to *editor@nwhn.org*. Please send change of address notices to *membership@nwhn.org*.

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Toxic Personal Care Products and Women's Health: A Public Health Crisis

By M. Isabelle Chaudry

UNDER CURRENT FEDERAL LAW, MANUFACTURERS AREN'T REQUIRED TO:

- ☑ use safe ingredients
- ☑ list their ingredients
- ☑ test their products
- ☑ use good manufacturing practices to prevent contamination
- ☑ recall products they know are dangerous

With few exceptions, current federal law does not require makers of cosmetics and other personal care products sold in the United States to get approval from the U.S. Food and Drug Administration (FDA) before their products go on the market. In fact, manufacturers aren't required to list all of their ingredients, test their products, use good manufacturing practices to prevent contamination, or even recall products that they know are dangerous. This means that companies can use almost *any* chemical ingredient in products without first having to prove it is safe for consumers — and many personal care products marketed and sold in the U.S contain toxic chemicals. As then-FDA Commissioner Scott Gottlieb stated in March, "To be clear, there are currently no legal requirements for any cosmetic manufacturer marketing products to American consumers to test their products for safety."[1] As a result of these lax regulations, the cosmetic industry has been mostly self-regulated for more than a century![2]

Toxic ingredients are found in cosmetics and other personal care products that include baby powder, vaginal douches, lotion, body sprays and perfumes, makeup, and hair dyes and straighteners. These toxins have been linked to ovarian cancer,[3] breast cancer,[4] early onset of puberty,[5] fibroids and endometriosis,[6] miscarriage,[7] poor maternal and infant health outcomes,[8] diabetes and obesity,[9] and other health problems.

While unsafe, unregulated products endanger everyone, they pose unique risks to women. Research has revealed that American women spend nearly a quarter of a million dollars on personal care over the course of their lifetimes, far more than men.[10]

For many Black women and other women of color, the risks are even higher and the products are even more toxic.[11] Black women spend four times more than White women on hair care products, in part because they face steep social and professional costs for not conforming to beauty standards based on European characteristics. One study conducted in 2016 found that White respondents rated Black women's natural hair as "less attractive" and "less professional" than when it was straightened.[12] Reports of Black women being fired from their workplace for having natural hair are not uncommon.[13] At the same time, the process of altering naturally curly hair texture to straight hair texture often involves harmful ingredients, such as lye (sodium hydroxide), which "relax" or "perm" the hair.

We know that in many cases, companies actively market dangerous products to Black and Latina women. Earlier this year, for example, a subcommittee of the House Committee on Oversight and Reform heard moving testimony from the family of a Black woman who died from ovarian cancer linked to talcum baby powder.[14] Internal documents from Johnson & Johnson reveal that the company knew for decades that its baby powder posed potential health risks[15] but doubled down on aggressively targeting women of color, distributing free samples in Black churches and advertising on Spanish-language radio.[16]

Toxic ingredients are found in cosmetics and other personal care products that include baby powder, vaginal douches, lotion, body sprays and perfumes, makeup, and hair dyes and straighteners.

In researching toxic cosmetic products for the NWHN, I was shocked by the results of a study conducted by the Breast Cancer Prevention Partners (BCPP). The study found that Just For Me Shampoo, children's shampoo specifically marketed to Black girls, was the most toxic product among those examined for harmful chemicals. I felt awful because I and many of my friends and family grew up using Just For Me products, and I know that many other Black women have as well.

For many Black women and other women of color, the risks are even higher and the products are even more toxic.[11]

The BCPP study found that Just For Me contains 24 harmful

ingredients including 4 carcinogens, 6 developmental toxicants, and 19 hormone-disrupting compounds. What is horrifying about the results is that out of the 32 personal care and cleaning products BCPP analyzed, Just for Me kids' shampoo was even more toxic than the cleaning products![17]

But the problems don't only lie with toxic ingredients. The industry also has few to no legal requirements protecting against toxic contamination. In 2017, an independent investigation found that Just Shine Shimmer Powder (a cosmetic product marketed by retail chain Justice to children and teens), contained high levels of asbestos, a known human carcinogen, as well as toxic heavy metals including lead.[18]

In December 2017, similar problems with contamination were alleged about beauty products sold at Claire's, a makeup and accessories store for girls.[19] Independent testing in 2019 once again found asbestos contamination in certain products sold by Claire's, Justice, and cosmetics maker Beauty Plus Global.[20] The latter two companies immediately implemented recalls of the products. Claire's initially refused to recall the tainted products and, under current law, the FDA does not have the authority to mandate a recall; the company relented in the face of significant public criticism.[21]

These toxic ingredients and contaminated supply chains affect products used by women and girls on the most sensitive parts of their bodies, on a daily basis, for decades; they have all been potentially linked to serious reproductive health problems and even death. It's clear that unregulated personal care products represent a slow-motion public health crisis — one that very few people have ever heard of, in large part because this problem is deeply rooted in issues of gender and race. Those who are the most deeply affected have often had the least power to demand change.

But the tide may be turning. Earlier this summer, the NWHN led 42 national, state, and local organizations in sending a letter to the U.S. House Energy and Commerce Committee (see: *https://bit.ly/31aXR8J*). In the letter, we called on Congress to pass legislation updating the outdated Federal Food, Drug, and Cosmetic Act and to include the strongest possible safeguards to protect women's health.

While several of the letter's signatories have long been active in the fight for safe cosmetics, many others had not previously engaged on this issue. The latter group represents a new and growing groundswell of grassroots activism in response to overwhelming evidence that the current regulatory system is failing women. You can add your voice by calling your members of Congress and urging them to support the strongest possible protections for women in any legislation updating the Cosmetic Act. And, sign up for the NWHN's e-alerts to keep up-to-date on this and other pressing women's health issues, at *www.nwhn.org*.✤

REFERENCES

1. Food and Drug Administration (FDA) Website, *Statement from FDA Commissioner Scott Gottlieb, M.D., and Susan Mayne, Ph.D., director of the Center for Food Safety and Applied Nutrition, on tests confirming a 2017 finding of asbestos contamination in certain cosmetic products and new steps that FDA is pursuing to improve cosmetics safety*, Silver Spring (MD): FDA, March 5, 2019. Online: https://www.fda.gov/news-events/press-announcements/statement-fda-commissioner-scott-gottlieb-md-and-susan-mayne-phd-director-center-food-safety-and.

2. Narayan P, "The cosmetics industry has avoided strict regulation for over a century. Now rising health concerns has FDA inquiring, CNBC Website, August 2, 2018. Online: https://www.cnbc.com/2018/08/01/fda-begins-first-inquiry-of-lightly-regulated-cosmetics-industry.html.

3. Zuckerman D, Shapiro D, *Talcum Powder and Ovarian Cancer,* Washington (DC): National Center for Health Research, 2019. Online: www.center4research.org/talcum-powder-ovarian-cancer/

4. Konduracka E, Krzemieniecki K, Gajos G, "Relationship between everyday use cosmetics and female breast cancer," *Medycyna Praktyczna,* 2014; 124(5): 264-268. Online: www.mp.pl/paim/en/node/2257/pdf

5. Terry MB, Rich-Edwards J, Deierlein A, Senie R, "Brief Communication: Childhood Hair Product Use and Earlier Age at Menarche in a Racially Diverse Study Population: A Pilot Study," *Annals of Epidemiology,* 2011; 21(6):461-465. doi.org/10.1016/j.annepidem.2011.01.009.

6. Hunt PA, Sathyanarayana S, Fowler PA, Trasande L, "Female Reproductive Disorders, Diseases, and Costs of Exposure to Endocrine Disrupting Chemicals in the European Union," *Journal of Clinical Endocrinology & Metabolism,* 2016; 101(4): 1562–1570. DOI: doi.org/10.1210/jc.2015-2873

7. Krieg SA, Shahine LK, Lathi RB, "Environmental exposure to endocrine-disrupting chemicals and miscarriage," *Fertility and Sterility,* 2016; 106(4): 941–947. DOI: doi.org/10.1016/j.fertnstert.2016.06.043

8. Ferguson KK, McElrath TF, Meeker JD, "Environmental Phthalate Exposure and Preterm Birth," *JAMA Pediatrics,* 2014;168(1): 61-67. DOI: doi:10.1001/jamapediatrics.2013.3699

9. De Coster S, van Larebeke L, "Endocrine-Disrupting Chemicals: Associated Disorders and Mechanisms of Action," *Journal of Environmental and Public Health,* 2012; 2012: 713696. DOI: doi: 10.1155/2012/713696

10. SWNS, *Vanity costs American women nearly a quarter of a million dollars,* New York Post Website, July 6, 2017. Online: https://nypost.com/2017/07/06/vanity-costs-american-women-nearly-a-quarter-of-a-million-dollars/.

11. Zota AR, Shamasunder B. "The environmental injustice of beauty: framing chemical exposures from beauty products as a health disparities concern," *Am J Obstet Gynecol,* 2017; 217(4):418.e1–418.e6. doi:10.1016/j.ajog.2017.07.020

12. Johnson AM, Godsil RD, MacFarlane J, et al., *The 'Good Hair' Study: Explicit and Implicit Attitudes Towards Black Women's Hair,* Perception Institute, 2017, pp 1-15. Online: https://perception.org/goodhair/

13. Santi C, "Black News Anchor Fired After Wearing 'Unprofessional' Natural Hair," *Ebony,* January 16, 2019, www.ebony.com/culture/black-news-anchor-fired-unprofessional-natural-hair

14. Salter M, Testimony before the Subcommittee on Economic and Consumer Policy, U.S. House of Representatives Committee on Oversight and Reform, *Examining the Public Risks of Carcinogens in Consumer Products,* March 12, 2019. Online: https://oversight.house.gov/sites/democrats.oversight.house.gov/files/Marvin%20Salter-Testimony.pdf

15. Girion L, "Johnson & Johnson knew for decades that asbestos lurked in its Baby Powder," *Reuters Investigates,* December 14, 2018. Online: www.reuters.com/investigates/special-report/johnsonandjohnson-cancer/

16. Kirkham C, Girion L, "Special Report: As Baby Powder concerns mounted, J&J focused marketing on minority, overweight women," *Reuters,* April 9, 2019. Online: www.reuters.com/article/us-johnson-johnson-marketing-specialrepo/special-report-as-baby-powder-concerns-mounted-jj-focused-marketing-on-minority-overweight-women-idUSKCN1RL1JZ

17. Helm JS, Nishioka M, Brody JG, et al., "Measurement of endocrine disrupting and asthma-associated chemicals in hair products used by Black women," *Environmental Research.* 2018; 165: 448-458. DOI: doi.org/10.1016/j.envres.2018.03.030

18. Tulp S, *Retailer Justice yanks makeup that may contain asbestos,* USA Today Website, July 18, 2017. Online: https://www.usatoday.com/story/money/2017/07/19/retailer-justice-stops-sale-makeup-brand-after-asbestos-report/490456001/.

19. Ducharme J, Claire's Refutes Claims of Asbestos in Kids' Makeup After December Recall, *TIME,* December 28, 2017. Online: https://time.com/5081088/claires-asbestos-recall/.

20. Food and Drug Administration (FDA) Website, *Beauty Plus and Claire's cosmetic products recalled after testing positive for asbestos,* Silver Spring (MD): FDA, June 6, 2019. Online: https://www.fda.gov/cosmetics/cosmetics-recalls-alerts/fda-advises-consumers-stop-using-certain-cosmetic-products.

21. Food and Drug Administration (FDA), *FDA Authority Over Cosmetics: How Cosmetics Are Not FDA-Approved, but Are FDA-Regulated,* Silver Spring (MD): FDA, 2013. Online: https://www.fda.gov/cosmetics/cosmetics-laws-regulations/fda-authority-over-cosmetics-how-cosmetics-are-not-fda-approved-are-fda-regulated.

M. Isabelle Chaudry is the NWHN Senior Policy Manager

Communications intern Julia Kagan and Development Associate Hannah Camp rally in front of the Supreme Court on May 21 to protest abortion bans in Alabama, Georgia, Ohio, and Missouri.

RWV Roundup

By Kalena Murphy

Raising Women's Voices (RWV) has a special mission to engage women who are not often invited into health policy discussions, including women of color; low-income women; immigrant women; young women; women with disabilities; and members of the lesbian, gay, bisexual, transgender, questioning, and intersex (LGBTQI) community. Our 25 Regional Coordinators (RCs) help represent these constituencies' interests.

Week of Solidarity to Defend Abortion

Attacks on abortion are proliferating and have diminished reproductive freedom for thousands. In 2019 alone, abortion bans have passed in nine states: Alabama, Arkansas, Georgia, Kentucky, Louisiana, Mississippi, Missouri, Ohio, and Utah. In response, abortion rights supporters organized two defense efforts in May: a national "Day of Action" and a "Week of Solidarity to Defend Abortion."

The Day of Action was organized by NARAL and other national organizations in collaboration with hundreds of local and state organizations. People gathered in every state to speak out and fight the latest attacks on reproductive rights. "These doors will remain open!" said Kwajelyn Jackson, Executive Director of Feminist Women's Health Center (FWHC) and one of our RCs, at the event at Georgia's state capital. FWHC recently became one of the plaintiffs in a lawsuit challenging the new state new law effectively banning abortion after six weeks. The Week of Solidarity was organized by women-of-color-led organizations, including three RWV RCs: FWHC, WV FREE, and New Voices for Reproductive Justice. All week, we highlighted folks defending abortion in our states and communities.

States Act to Protect Access to Abortion Care

We're thrilled to report real progress by our RCs to guarantee reproductive health care access. Illinois' Reproductive Health Act guarantees that abortion will remain legal even if *Roe* is overturned. Input from advocates, including our RC EverThrive, ensured that contraception, sterilization, and pregnancy and maternity care were included as fundamental rights in the Act. Maine passed The Act to Authorize Certain Health Care Professionals to Perform Abortions, which goes into effect in September. The Act, which permits nurse practitioners and physicians assistants to perform abortion, seeks to addresses the fact millions of U.S. women live more than an hour from the nearest source of abortion care. "The limited number of professionals providing termination services has burdened women in rural areas of Maine," said RC Consumers for Affordable Health Care.

States Make Progress on Postpartum Health Coverage

The U.S. has alarmingly high rates of maternal mortality, particularly among women of color, indicating that our maternity care system is in crisis. Most maternal deaths do not occur in the delivery room. They happen, instead, during the postpartum period, a medically vulnerable time when new mothers face a range of medical conditions, including childbirth complications, chronic conditions, and postpartum depression. The problem is compounded by the fact that the federal government requires pregnancy-related Medicaid

coverage for just 60 days. On day 61, hundreds of thousands of mothers lose coverage; in states that didn't expand Medicaid under the Affordable Care Act (ACA), these women often have no other source of coverage.

In response, during 2019 legislative session, policymakers in Illinois, Texas, New Jersey, and California started to address our national maternal health crisis by supporting postpartum care. Illinois amended the state's public health code to extend pregnant Medicaid beneficiaries' coverage through the first year after delivery. The change was included in the budget implementation plan but lacks dedicated funding, so there is likely to be robust discussion on implementation. RWV RC EverThrive was a key advocate for this legislation.

A proposed bill in Texas would have similarly amended the state's Human Resources Code to require that pregnant Medicaid beneficiaries remain covered for at least 12 months postpartum. The Afiya Center, our Dallas-based RC, was successful in providing language for the bill and pushing the bill forward; Afiya's Policy Director Deneen Robinson testified at the hearing. The bill passed in the House, but didn't make it to a vote in the Senate. Instead, the legislature agreed to a narrower, less expensive two-year initiative to address postpartum depression and substance abuse treatment for some low-income women. We will try again next year!

In New Jersey and California, similar bills have made progress on the legislative floor and are still being reviewed. New Jersey did enact a robust four-bill package to address maternal health, but extended postpartum Medicaid coverage was not included.

RWV Speaks Out While Court Debates ACA

RWV and many of our RCs joined national organizers in a TweetStorm to protest and raise awareness about *Texas v. United States*, the most recent lawsuit that threatens to overturn the ACA. The suit, brought by Attorneys General from Texas and 17 other conservative states, was argued before an Appeals Court in early July. In the TweetStorm, RWV explained that the lawsuit, if successful, could end Medicaid expansion and other ACA provisions, including protections for those with pre-existing conditions and required coverage for maternity care and contraception. RCs in Texas, Maine, Massachusetts, Oregon, New Jersey, New Mexico, Wisconsin, and West Virginia participated in the event. With more than 100 Tweets and retweets, RWV and our RCs helped the hashtags #WhatsAtStake and #TXvUS trend in Washington DC, and #ProtectOurCare trend nationally.

This fight isn't over and the lawsuit is likely to make its way to the Supreme Court. We need to keep influencing the public dialogue, so justices will understand the public sentiment supporting the ACA, and feel more wary about overturning the ACA. Be sure to share your own content that includes stories and highlights using the hashtag, #WhatsAtStake.

Join Us

- Sign up for RWV's weekly newsletter at *http://raisingwomensvoices.net/.*
- You can also get instant updates on our work and our issues via Facebook and Twitter (@RWV4HealthCare).✤

Kalena Murphy is the NWHN's Senior State Advocacy Manager for RWV.

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YOUNG FEMINIST

My Medical Journey Represents a Larger Problem — Gender Bias in Medicine

By Mackenzie Flynn

When I was in 10th grade, I started having seemingly random shooting pain and inflammation in my ankles. This spiraled into burning pain in other joints—my hands, wrists, knees, elbows, etc. This medical mystery turned into countless doctor's appointments and, although I saw several specialists, one individual stood out in particular. I vividly remember my experience with this health care provider, a physician my family had known and trusted for a considerable amount of time. As I sat in his cold and dreary office, I remember being asked to walk on my clearly swollen foot. I retorted that I could not, but was pestered by the physician and quickly submitted to the pressure. I bit my teeth and kept on mentioning how much pain I was in. After analyzing my movement and reviewing my blood work (in which my rheumatoid factor and antinuclear antibodies count were off the charts) for a solid minute or two, I was told that I was a hypochondriac and was perfectly healthy.

Devastated by this encounter, I stopped looking for answers until my symptoms progressed in severity. Now, five years later, I have been diagnosed with Juvenile Rheumatoid Arthritis, Fibromyalgia, and Undifferentiated Connective Tissue Disease (UCTD). These varying diagnoses were given to me from different rheumatologists, but I am still looking for a diagnosis that addresses and reflects *all* of my symptoms — without any luck.

I am not the only woman who has been treated as a "hypochondriac" by a medical professional. Women's medical experiences have long been discounted; as just one example, in the 19th century, "female hysteria" was a common medical diagnosis for women experiencing varying medical symptoms or unorthodox behavior. This misogyny are alive and well to this day. According to Hoffmann and Tarzian, women report more severe levels of pain, more frequent incidences of pain, and pain of a longer duration than men, but are treated less aggressively for their pain.[1] Instead of being addressed appropriately, the National Pain Report notes that women are often told that their pain is "psychosomatic" or is influenced by emotional distress rather than physical causes.[2]

When women do not trust their physicians and feel that their physicians are not taking their concerns seriously, they stop seeking medical assistance. They may hesitate to seek help for medical emergencies — like a heart attack — because they worry they will be seen as "hypochondriacs."[3] When women seek medical care and are taken less seriously than men, it is based on the sexist view that women do not understand their minds or bodies.

When women *do* seek health care, research shows that doctors and nurses prescribe less pain medication to female patients than they do to men after surgery, even though women report more severe pain levels than men.[1] One study found that women waited sixteen minutes longer than men before they received pain medication during an emergency room visit.[4] Statistics on providers' dismissing women's pain are even worse for women of color, as studies show that racial and ethnic disparities in pain perception, assessment, and treatment were found in all settings (i.e., postoperative, emergency room) and across all types of pain.[5]

Even when women overcome all the social and economic obstacles that challenge being able to receive health care, they are still treated unfairly. Something has to change — this is ludicrous.

Women should not have to go through this so consistently in the medical system. I would not wish my medical journey on my worst enemy, and the mountains I've had to conquer in order to get a diagnosis (which still does not fit all my symptoms) have been steep. No one, regardless of gender, should have to go through what I went through. My years of constant doctors' appointments, countless tubes of blood work, crutches, casts, walking boots, bandages, physical therapy, hospital stays, neurology consults, X-Rays, MRIs, and so on have taught me a lot. I know my pain is real. I should not have to prepare to fight for myself every time I walk into a doctor's office. I should not have to question whether my doctor's treatment plan and prognosis is based exclusively on my sex. I should not, under any circumstance, have my validity questioned as a patient based on the fact that I am a female. My health is legitimate and so are my words.

Receiving a diagnosis and treatment for one's pain and discomfort should not be a battle. To make real change, we must continue advocating for women's voices to ensure that women, on a holistic scale, are treated with the respect we deserve and are taken seriously by medical professionals. My experience within the medical realm should be shameful, not normalized. We need more studies on women's experiences and symptoms. We need better sensitivity and interpersonal communication training in medical schools. We need more. We deserve more.✤

REFERENCES

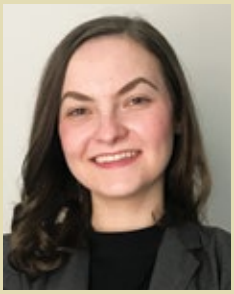
1. Hoffmann D, Tarzian A, "The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain," *Journal of Law, Medicine & Ethics* 2001, 1(29): 13-27.

2. The National Pain Report, *Women in Pain Report Significant Gender Bias,* New York (NY): The National Pain Report, 2014. Online: http://nationalpainreport.com/women-in-pain-report-significant-gender-bias-8824696.html

3. Lichtman J, Leifheit-Limson E, Watanabe E, et al., "Symptom Recognition and Healthcare Experiences of Young Women With Acute Myocardial Infarction," *Circulation: Cardiovascular Quality and Outcomes,* 2015; 8: S31–S38.

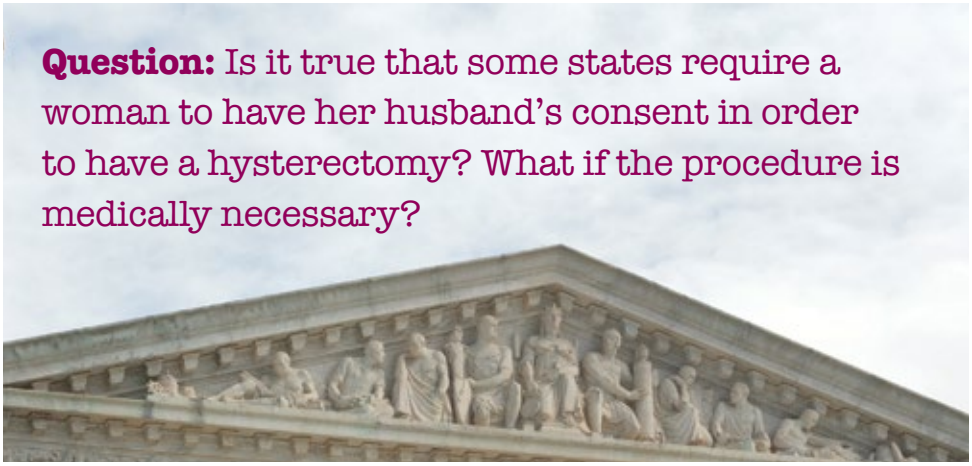
4. Chen E, Shofer F, Dean A et al., "Gender Disparity in Analgesic Treatment of Emergency Department Patients with Acute Abdominal Pain," *Official Journal of the Society of Academic Emergency Medicine,* 2008; 5(15): 414-418.

5. Green C, Anderson K, Baker T, et al., "The Unequal Burden of Pain: Confronting Racial and Ethnic Disparities in Pain," *Pain Medicine,* 2003; 3(4): 277–294



Mackenzie Flynn is a junior at the George Washington University in D.C. studying Political Science with minors in Public Health and Sustainability.

Since You Asked!



Question: Is it true that some states require a woman to have her husband's consent in order to have a hysterectomy? What if the procedure is medically necessary?

Answer:

First, a bit of background. Surgical removal of the uterus is called a "hysterectomy." There are multiple types of hysterectomy, including procedures where the uterus is removed but the cervix isn't (called subtotal, supracervical, or partial hysterectomy), and ones where both the uterus and cervix are removed (a complete hysterectomy).[1]

Hysterectomy is performed for a variety of reasons, including invasive cancer of the uterus, cervix, vagina, fallopian tubes, and or ovaries; polycystic ovary syndrome (PCOS); unmanageable infection or bleeding; and serious complications during childbirth, such as a rupture of the uterus. After hysterectomy, a person cannot become pregnant.

The NWHN believes that hysterectomies are over-performed. While hysterectomy rates are falling in industrialized countries, about one-third of U.S. women will have had the procedure by age 60.[1]

In this time when reproductive health care is under severe attack, it's not surprising that people might be concerned about what services they can access. No state mandates spousal consent for this procedure, and any such proposals would almost certainly be found to be unconstitutional. That's because hysterectomy can be considered to be a sterilization procedure, since pregnancy cannot occur afterwards. Hysterectomy therefore falls under the protections enabling women to obtain sterilization procedures without spousal consent. Numerous state courts as well as federal policy have established this right. (It should be noted that U.S. Supreme Court has not ruled on the question, so it's not 100 percent settled law.)

This is good news in terms of women's autonomy and right to make their own medical decisions. Because of religious refusal policies, however, some private hospitals — particularly religiously affiliated facilities — may require signed consent from both spouses.[2] To find out more about how religiously affiliated hospitals are restricting women's access to reproductive services, see MergerWatch: *www.mergerwatch.org*

The bottom line is that it's very unlikely that a health care provider would refuse to perform a hysterectomy without spousal consent. People who are interested in hysterectomy should discuss the risks with their health care provider privately to make the best decision for their own, unique circumstances. For more information, see the NWHN's Fact Sheet at: *www.nwhn.org/hysterectomy*.✤

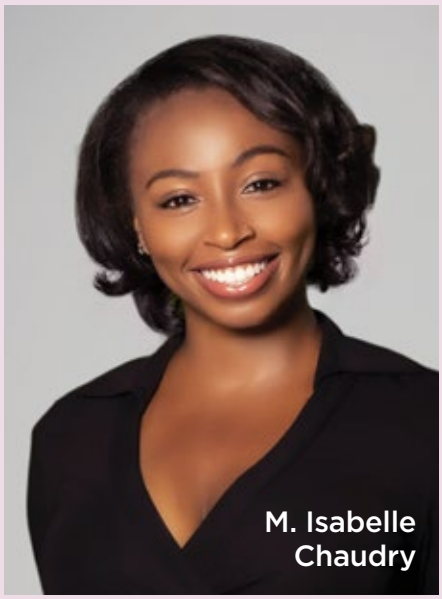
REFERENCES

1. Medicine Plus, *Hysterectomy,* Bethesda (MD): National Institutes of Health, Library of Medicine, 2019. Online at: https://medlineplus.gov/ency/article/002915.htm

2. Guttmacher Institute, *State Laws and Policies: Refusing to Provide Health Services,* New York (NY): Guttmacher Institute, July 1, 2019. Online: https://www.guttmacher.org/state-policy/explore/refusing-provide-health-services

Online women's health column: *www.nwhn.org/since-you-asked*

NWHN Welcomes New Staff



M. Isabelle Chaudry

Marcha (Isabelle) Chaudry is the new Senior Policy Manager, responsible for leading the NWHN's women's health and consumer safety policy efforts. Prior to joining the NWHN, Isabelle served as a law clerk for the Senate Health, Education, Labor, and Pensions (HELP) Oversight Committee, and as an Associate Staff Counsel at the Pennsylvania State Education Association, advocating on behalf of union workers and teachers. Isabelle is passionate about public policy and women's rights, and her legal article on workplace sexual harassment was published in May 2019, in the *Seton Hall Legislative Journal*. She earned a J.D. with distinction in Alternative Dispute Resolution from Howard University School of Law and a Bachelor's of Science degree from Howard University.✤

The Reproductive Justice Movement: A Model for a More Inclusive Movement to Improve End-of-Life Options

By Ninia Beahr

I am a member — and critic — of the right-to-die movement, which seeks to expand access to assisted dying for people facing incurable, unbearable suffering. Much of my background is in abortion activism. In the 1960s and early 1970s, the mainstream pro-choice movement was led by middle-class White women and focused on the single issue of abortion. By the early 1990s, women of color, through the Reproductive Justice (RJ) movement, were pushing mainstream pro-choice groups to understand that "choice" must mean not only the choice to have an abortion but also the choice to conceive, carry and raise children in safe, healthy, culturally-appropriate environments.

Today, the right-to-die movement is led mostly by middle-class White people and focuses primarily on legalizing access to physician aid in dying for terminally ill, mentally competent adults. Applying lessons from the RJ movement to the right-to-die movement might mean understanding that "choice" at the end of life includes not only the choice to hasten death but also the choice to live and die according to one's values and with better medical, social, financial, and environmental supports for the ill or frail elderly and their caregivers.

The RJ movement was created in the U.S. to advance and protect reproductive freedom for diverse women by incorporating a core commitment to human rights and addressing medical, social, economic, and racial and ethnic injustices that limit many U.S. women's reproductive choices. The RJ movement is informed by injustices that include slavery and its legacy, the colonization and even genocide of indigenous people, and the widespread and longstanding adoption of eugenic programs and practices. By developing a movement that insists women should have access to abortion and that the context in which women make the abortion decision should be informed by this history and include better options now, the RJ movement promotes women's ability to self-determine their own lives.

The U.S. right-to-die movement could do the same. It could acknowledge America's historical population control efforts — and it could explicitly prioritize a commitment to guard against population control activities. Similarly, it could address America's unique status among the developed countries where aid in dying is legal in any jurisdiction as the only nation without universal health care, the nation with the highest poverty rate, and the nation with the weakest social safety net. And, it could seek out opportunities to work in coalition with groups acting to improve end-of-life supports for diverse individuals (and their caregivers) whether or not they want assisted dying.

The RJ movement teaches the importance of having a broad, diverse group of people at the table when setting the agenda for a movement. Today's right-to-die movement focuses on legalizing medical aid in dying. I support this agenda but I also see it as limited in some of the same ways the mainstream pro-choice movement was limited before the RJ movement emerged. Could a broad end-of-life movement, informed by the RJ movement, evolve in the U.S?

"Could a broad end-of-life movement, informed by the RJ movement, evolve in the U.S? To explore these issues, I interviewed veteran abortion and RJ activists about their perspectives on the right to die."

To explore these issues, I interviewed veteran abortion and RJ activists about their perspectives on the right to die. Interviewees were in their 60s, 70s, and 80s and lived across the country in urban and rural environments. Half were women of color (African American, Puerto Rican, Native American, Korean American, Native Hawaiian). None of the women I interviewed opposed legalizing aid in dying, provided some safeguards were in place. They did not generally see dying as a "women's issue," but they acknowledged that women's longer life span, higher poverty rate, and cultural role as care givers might make the end of life — whether as the dying person or the caregiver to a dying person — a gendered experience. All interviewees believed that end-of-life issues are important. Some prioritized access to assisted dying as a key concern, while others were more interested in related issues such as increasing the availability of culturally-appropriate assisted living and nursing home facilities or expanding supports for in-home care for elders and their families.

NWHN has a history of being before its time in terms of raising issues that may not, at first, seem to be "women's issues." In 2003, long before the passage of the Affordable Care Act, NWHN prioritized affordable, accessible, quality health care for all as one of its top three goals. "Health care for all" applies not just to women — but to everyone. In 2007, the NWHN partnered with the Black Women's Health Imperative and the MergerWatch Project to create "Raising Women's Voices for the Health Care we Need" (RWV). RWV was, and continues to be, based on the idea that "women are grassroots experts in what is wrong with the current health system and what it takes to fix it because of our roles as arrangers of health care for our families." As Baby Boomers continue to age, either our own potentially gendered experience of dying or our role as caregivers might, to quote RWV, make women "grassroots experts" on what is needed in an inclusive end-of-life movement.✤

Ninia Baehr wrote her Ph.D. dissertation on what the right-to-die movement could learn from the U.S. abortion and RJ movements. She served as a board member for NWHN for 8 years and currently works as a hospice nurse.

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SNAP SHOTS

The menopausal transition brings with it a great deal of physical change — including changes in weight, size, shape, physical symptoms, and sexual function. These can affect how women perceive their bodies and may impact **health-related quality of life (HRQoL).** Researchers examined the potential relationship between middle-aged women's body image, sexuality, and HRQoL, using data gathered from 1,026 Taiwanese women. Using a variety of scales, data were collected on demographic characteristics, sexual function, body image, relationship with partner(s), menopausal symptoms, and HRQoL. The results indicated that **negative self-perceptions about appearance and menopausal symptoms were related to poor HRQoL. A higher frequency of orgasm predicted a better HRQoL physical component summary; sexual satisfaction and relationship satisfaction with a partner** predicted a better HRQoL mental component summary.

Maturitas, August 2019

The term "surprise medical bill" refers to charges when an insured person inadvertently receives a health care service from a provider that is not covered by their insurance plan. **Two-thirds (67%) of Americans are "very" or "somewhat" worried about being able to afford unexpected medical bills.** Emergency Room (ER) visits are particularly likely to result in surprise medical bills, since it can be challenging for patients to ensure they receive care from a covered (i.e., in-network) provider in these situations. A Kaiser Family Foundation poll analyzed 2017 claims data from 19 million individuals enrolled in large employer health plans and **found that almost one-fifth (18%) of ER visits resulted in a surprise medical bill;** 16% of in-network hospital stays resulted in one or more out-of-network charges, placing patients at-risk for surprise medical bills. ER bills were **most likely to include an out-of-network charge in Texas, New Mexico, New York, and California.**

Kaiser Family Foundation, June 2019

A proposed federal regulation would require women with dense breasts (who have higher breast cancer risks) to be given information on supplemental imaging, and for screening mammogram reports to include information on the patient's breast density. But, there's a better way to identify women with increased breast cancer risk who might benefit from supplemental imaging. Researchers analyzed outcomes from 638,856 40-to-74-year-old women who had 1,693,163 digital screening mammograms between 2005-2014. Women with dense breasts accounted for almost half (47%) of the study population, and 60% of advanced cancers within 12 months of screening. Outcomes were examined with respect to women's breast density and their Breast Cancer Surveillance Consortium (BCSC) five-year risk score. Women with dense breasts and a 5-year risk of less than 1.67% had high rates of false-positives (which lead to more tests and, in some cases, unnecessary surgery). Breast density should not be the sole driver of a supplemental screening recommendation. A combination of both breast density and the BCSC 5-year risk scorebetter identifies women at higher risk for advanced cancer who might benefit most from **supplemental imaging.**

JAMA Internal Medicine, July 2019