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The Women's Health Activist®

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Surprisingly Painful IUD Insertion Doesn't Match Contraceptive Counseling, Compromising Informed Consent

By Tessa Ruff

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

DIRECTOR'S MESSAGE

An Open Letter to FDA's New Commissioner

By Cynthia Pearson

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

Dear Commissioner,

I wish you well. Honestly, I do. You've got a big job with, well, challenging bosses. But you know what? *We're* your bosses, too. The public pays for more than half of the Food and Drug Administration's (FDA) budget each year, which entitles us to have a say in the agencies' operations. Late last year, we gave your predecessor, Scott Gottlieb, a report card on his first year as Commissioner — he got mixed grades. Here's what you could do to get all As on your report card:

1. Don't let the White House push you around. Commissioner David Kessler threatened to resign when the administration tried to kill the FDA's plan for nutrition labels.[1] He won. Stand up for what's right.
2. Don't let politics override science on reproductive health. Abortion care is health care and medication abortion is a medical product, not a political football. Immediately withdraw the FDA's politically motivated and medically unnecessary mifepristone restrictions.[2]
3. Require companies to include women, older adults, and people of color in clinical trials in numbers proportionate to their experience of the conditions being studied. Trials of heart attack drugs have only 60% as many women as they should.[3] Don't let staff continue using the excuse that women think heart disease is a male disease.
4. Stop accepting industry's excuses for failing to do post-market studies they *promised* to do, and start imposing consequences. Since 2013, two breast implant manufacturers have repeatedly failed to follow up with patients in studies about long-term health effects; yet, FDA staff says merely: "The FDA may take action."[4] Impose some penalties, already!
5. Stop approving drugs for long-term use in healthy people based just on lab tests. The FDA approves drugs to prevent osteoporosis based on X-ray results, not whether the drug prevents clinical fractures that cause symptoms.[5] Require companies to show that drugs for healthy people actually improve health.
6. Don't fall for fake consumer groups. "Even the Score" pretended to be a grassroots advocacy effort committed to improving women's sex lives. In reality, a drug company created the group after being unable to get its product approved through normal channels.[6] Even the Score folded shortly after the company's drug gained approval.
7. Don't weaken FDA's standards for approving new products. Last summer, the FDA used an expedited process to approve a smartphone app that's a 21st-century version of the rhythm method.[7] Your staff accepted the company's word that the Natural Cycles app is as effective as the birth control pill. Guess what happened? Unintended pregnancies, that's what.[8]
8. Value the Offices of Women's Health and Minority Health. Keep the offices' directors in your inner circle and listen to their advice.

"This may be challenging for someone nominated by the Trump-Pence administration, but we, your employers, hope you'll do the right thing."

Acting on these recommendations requires you to prioritize science and public health over special interests, including drug and device manufacturers. This may be challenging for someone nominated by the Trump-Pence administration, but we, your employers, hope you'll do the right thing. Good luck!✤

References are available from *info@nwhn.org.*

Newer isn't Better When it Comes to Osteo Treatment

By Maggie Gorini

Osteoporosis is a condition that causes bones to become fragile and susceptible to breaking. Osteoporosis leads to approximately 1.5 million fractures in the U.S. annually,[1] causing pain and disability, and having significant consequences for women's health and quality of life. However, not every new osteoporosis drug is worth its side effects. This is particularly true for the two-thirds of patients with compression spinal fractures (commonly associated with osteoporosis) who have no symptoms and are unaware they even need medical attention.[2]

In 2018 alone, Amgen made a modest $2 billion on a single popular osteoporosis drug, denosumab (brand name Prolia) and apparently has no desire to leave this lucrative market any time soon.[3] Earlier this year, a Food and Drug Administration (FDA) advisory panel gave the green light to its new first-line osteoporosis drug, romosozumab (brand name Evenity), made in partnership with UCB. The committee voted 18 to 1 to recommend approval of Evenity for post-menopausal women who are at high risk of fracture and have exhausted all other treatments for osteoporosis. The FDA approved Evenity in April, despite the fact that serious questions about its safety remain.[4]

Like Amgen's earlier osteoporosis drug, denosumab (brand name Prolia), Evenity is a monoclonal antibody administered by subcutaneous injection that works by recruiting the body's immune system to increase bone density. Prolia targets the RANKL protein to stop natural bone breakdown while Evenity targets the sclerostin protein to promote new bone growth.[5]

In two pre-approval studies, women experienced a modest improvement in their absolute risk of spinal fracture (1.3%–4%) using Evenity compared to placebo or alendronate (common osteoporosis drug).[6] An increase in major cardiovascular events found in one study raised concerns about the drug's safety, however. The FDA initially rejected Evenity in 2017 over these heart safety red flags and requested further data and analysis from both studies.[7] New research on Evenity could identify whether the drug's cardiovascular risks are valid and of concern. Sadly, the FDA did not require such investigations as part of the drug's approval. It is worth noting that such required post-approval studies are not always completed in a timely fashion, if at all.[8]

The committee reached an informal consensus that women who have had a heart attack or stroke in the past year should be discouraged from taking Evenity. For this reason, when the drug hits pharmacy shelves, it's likely to carry a Black Box warning, indicating the drug has potentially serious side effects.

It's unclear whether Evenity provides either a benefit over existing osteoporosis drugs or at least a benefit equal to its risks. It is clear that Amgen is counting on the new drug to compensate for falling revenue when Prolia loses its patent exclusivity in the coming years and cheaper generics begin to compete for our bones and wallets. With so many unknowns surrounding Evenity, women should talk with their provider about other less risky and cheaper treatments, and forgo the heart health minefield that accompanies Evenity. Visit *NWHN.org* for more information on osteoporosis screening, diagnosis, and treatment options.✤

References are available from *info@nwhn.org.*

Maggie Gorini is the NWHN's health policy intern.

BOARD MEETING

The NWHN Board of Directors will meet next in Washington, DC, on June 8–9, 2019. NWHN members are welcome to join us for parts of the weekend. If you are interested in attending, please contact the office for more information at 202.682.2640.✤

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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.

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Surprisingly Painful IUD Insertion Doesn't Match Contraceptive Counseling, Compromising Informed Consent

By Tessa Ruff

"I was definitely caught off guard by the pain. I did my research and asked a lot of questions before deciding this was right for me, and I thankfully had an understanding and experienced practitioner. However, even this didn't prepare me for what I experienced during placement and recovery. The pain was much more intense and prolonged than I had been led to believe it would be. It interrupted my life for a solid month before I was able to resume a regular schedule free of high ibuprofen doses and heat pad breaks."[a]

Eleanor,[b] 27, got her intrauterine device (IUD) inserted last year. She decided on a non-hormonal copper IUD because she didn't want to go through the process of finding a hormonal method that worked well with her body and, like many people interested in long-acting reversible contraceptive methods (LARCs), Eleanor wanted a method that's highly effective at preventing pregnancy, lasts for a long time, and is low maintenance. (LARCs include IUDs and contraceptive implants.)

a Eleanor, interviewed for this article

b Name has been changed

Because of these qualities, the popularity of LARCs is on the rise.[1] Many doctors view LARCs as the gold standard of contraception. And, in an era when access to reproductive health care feels particularly vulnerable, having a long-term method of birth control is a comfort to many. While IUDs and other LARCs are a good choice for many, the NWHN is concerned[2] about the risk of providers promoting LARCs rather than offering patients the full range of options and comprehensive information — including realistic information regarding the IUD insertion experience.[3]

While common trusted resources for medical information — including the Mayo Clinic,[4] Healthline,[5] and Planned Parenthood[6] — describe the pain as mild and over quickly, this isn't always the case. In fact, there can be a great disparity between patient information about IUD insertion and women's actual reported experiences.[7] Eleanor is one of many people whose IUD insertion experience can be summarized as: "I had no idea what I was getting into when it came to the pain." While clinicians describe the feeling as a "quick pinch," an Internet search results in many accounts of excruciating,[8] even "cosmic" pain.[9] One woman described it as "bad enough that I went back the next day quite sure they'd punctured something."[8]

Providers also downplay the potential for excruciating pain when they counsel patients. At her initial consultation, Maeve's[a] gynecologist recommended she take a few Advil before the procedure, nothing special — which did not prepare her for the actual experience. Maeve, 23, told *Slate* that it was "probably the worst pain I've ever been in. The IUD insertion was on another level. I was seeing stars by the end of it."[9]

So, why are doctors underestimating and misrepresenting IUD insertion pain? One reason may be that they don't want to scare people away from getting an IUD. If true, this is a sinister explanation — because it means that clinicians are knowingly withholding critical information their patients need to make an informed decision, in order to encourage them to select an IUD as their contraceptive method.

In her article for *Revelist,* Melissa Stanger wrote that, while discussing whether or not to get an IUD, her gynecologist described the insertion pain as usually feeling like "really bad period cramps." After Melisa experienced extreme pain during the insertion, however, her doctor admitted apologetically, "I know... it's like giving birth." And yet, this same physician failed to prepare her patient for the actual experience.[10]

"I know... it's like giving birth." And yet, this same physician failed to prepare her patient for the actual experience."[10]

This is *not* informed consent. Providers' logic is clear, but misguided: if women are told that getting an IUD inserted might cause extreme pain, then they are unlikely to choose the option. And, given how much providers prefer IUDs,[11] they definitely don't want their patients to be scared away from the method. They may rationalize the pain as being short-lived compared to the long-term benefits, and much less painful than experiencing an unplanned pregnancy. In addition, Dr. Eve Espey, chair of the American College of Obstetricians and Gynecologists' LARC Work Group, explained, "We know that if you talk to patients about pain, they tend to experience more [pain]."[12] So, doctors may see downplaying the pain itself as a form of pain management.

It is also possible, of course, that providers believe the pain of the IUD insertion to be less severe than it often is. A study of patients and doctors quantified this difference. On a scale of 0 to 100, patients rated their maximum pain during the IUD insertion process as 64.8 out of 100, while providers perceived the patient's pain as 35.3 out of 100. This is an astounding difference — doctors perceived patients to experience pain at almost half the levels than was really reported.[13]

This makes sense, particularly in light of how hard it is to understand someone else's pain and the long history of women's pain being discounted by medical professionals.[14] The title of an article by *The Outline* says it well: "If Men Had to Get IUDS, They'd Get Epidurals and a Hospital Stay."[15] The author goes on to put it into context of pain management for other procedures, stating:

> When one gets one's wisdom teeth out, you are numbed to all hell, and some people even get put under. I recall getting something like 24 shots of novacaine [sic] all around my mouth. People who get simple moles or cataracts removed, or receive biopsies, get local anesthesia, as do people receiving spinal taps. For colonoscopies, a bloodless procedure unless the doctor is taking a tissue sample, patients get either conscious sedation or full general anesthesia. During cystoscopies, a nonsurgical procedure used to check for bladder cancer, patients, particularly men, have the option of local or general anesthesia.

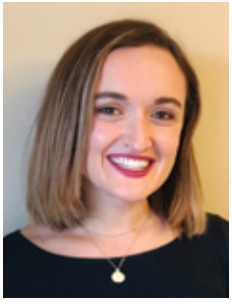
"If Men Had to Get IUDS, They'd Get Epidurals and a Hospital Stay.[15]"

Many studies considered options for pain management during the IUD insertion procedure. Most commonly, providers encourage patients to take over-the-counter pain relievers beforehand, but this has been shown to be ineffective.[16] Cervical relaxers, anti-anxiety medications, and opioids all have also been used, as well. Results have been inclusive in some studies; in others, these pain management techniques have been found to be ineffective, or even to make the pain worse.[17] Right now, the most promising approach appears to be using local anesthesia.[18, 19]

Many professionals are quick to discount "online horror stories" about the insertion process.[20] Even feminist blogs[21] and journalists[20] downplay the pain, trusting interviews with providers over women's experiences. While experiences vary — and patients report everything from feeling just a pinch, to pain that was "horrible but worth it," to pain so bad they "would never do it again" — this is no excuse for downplaying the potential pain outcomes. Despite the lack of scientifically-backed pain management options, and the fact that patients may perceive pain to be more severe when they are expecting it, contraceptive counseling *must* describe the potential pain of IUD insertion. Only then will patients to able to provide fully-informed consent based on all of the information available.

The NWHN thinks that these experiences need to be taken seriously, and that education, counseling, and insertion practices should reflect the potential for severe and debilitating pain. As the old saying goes, prepare for the worst and hope for the best.✤

References are available from *info@nwhn.org.*



Tessa Ruff is the NWHN's Policy Fellow

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NWHN in Action

By Sarah Christopherson

Raising Women's Voices (RWV)

In 2017, congressional Republicans tried and failed to repeal the ACA and gut Medicaid legislatively. In 2018 and 2019, the Trump-Pence administration picked up where Congress left off, unleashing a barrage of regulatory attacks on public health programs. The executive branch has doubled down on earlier efforts to undermine contraceptive coverage through the ACA, sought to take millions of taxpayer dollars from real family planning clinics (including Planned Parenthood) and give the funds to religiously affiliated fake clinics, tried to punish private insurance plans that cover abortion, and attempted to block legal immigrants and their U.S. citizen relatives from accessing public health care. They encouraged red states to overload Medicaid recipients with bureaucratic red tape designed to block coverage, sought to undermine the ability of people with pre-existing conditions to afford comprehensive insurance, and more. While the government's final rules have been issued or are expected soon on all these efforts, it's unclear if the courts will allow them to go into effect.

It can be difficult to mobilize public opinion to fight administrative action, which is less visible and less widely covered than high-drama congressional votes. It can also be disheartening when every day brings a new attack on effective health care programs and policies. But, with the NWHN's assistance, our 30 state and local regional coordinators in 29 states helped the larger movement to generate hundreds of thousands of public comments opposed to Trump's policies, raised media awareness about the attacks, helped make health care a major midterm election theme, and advocated for state-based policy responses.

While stopping this administration from issuing terrible rules is often impossible, we're helping build the strongest possible legal case against them. For example, in response to attempts to gut the Title X family planning program, the NWHN's Executive Director Cindy Pearson and Policy Advocacy Director Sarah Christopherson met with officials from the Office of Management and Budget to highlight the administration's failure under the law to evaluate the proposed rule's real health and economic costs, particularly for women of color. We couldn't stop the rule from being issued, but we can help the courts block it from going into effect.

Challenging Dangerous Drugs and Devices (CDDD)

The NWHN remains one of the few women's health organizations focused on the Food and Drug Administration (FDA) that doesn't accept funding from drug- or device-makers. So, we're free to speak up when the FDA is pressured to loosen its safety and efficacy standards for women's health products. In 2019, the NWHN testified at the FDA on the need to require rigorous testing of vaginal mesh products *before* they're approved, not after. In 2018, we raised concerns about the uterine fibroid drug Esmya and applauded the FDA when it followed our recommendation and refused to approve it.

Our biggest victory was saving the FDA Office of Women's Health (OWH). Coded in deceptively bland language and buried in the 31st paragraph of a long explanation of his plans to re-organize the commissioner's office last year, then-FDA Commissioner Scott Gottlieb tried to (illegally) defund, demote, and prevent the OWH from doing its work. The OWH was created in 1994 in response to women's demands for the FDA to listen and respond to women's concerns, especially about the lack of women in clinical trials of FDA-approved products. It's proven invaluable for responding to consumer concerns and funding critical research. The OWH was codified into law as part of the ACA and can't be downgraded without congressional authorization. Armed with this knowledge, the NWHN helped organize a successful lightning-speed advocacy campaign to save the OWH that included our congressional allies; Gottlieb was forced to back down within a week. Our work saving the OWH was covered by online publication *Rewire* in March following Gottlieb's resignation announcement.

Finally, we parried a pharmaceutical company's efforts to silence our warnings to women about their ineffective, potentially dangerous product. In late 2018, the makers of flibanserin (brand name Addyi) threatened to take legal action against the NWHN unless we removed all of our on-line Addyi-related materials. It seemed that the company believes our "Pass on the Pink Pill — or Pass Out" campaign, initiated in 2015, played a role in the drug's poor sales. We simply wanted women to know that the drug isn't much better than placebo in improving their sex lives and could come with serious side effects.

Securing Sexual and Reproductive Health and Autonomy (SRH)

This spring we rolled out a guide for reproductive health activists responding to state contraceptive policy initiatives — co-written by the NHWN and the National Institute for Reproductive Health. The guide builds on the 2016 *Statement of Principles* we co-led with SisterSong to address coercion in the provision of long-acting reversible contraceptives (*www.tinyurl.com/LARCprinciples*). Along with NIRH and Tennessee-based reproductive justice organization SisterReach, we spoke at the Civil Liberties and Public Policy conference in April about the guide and reproductive coercion more broadly.

We've also been speaking up about the potential risks posed by Natural Cycles, a fertility awareness app the FDA cleared in 2018. The app is promoted as being as "effective as the Pill," but there are reasons to question whether the FDA really agrees or was pressured into fast-tracking its clearance. We're concerned because the Trump-Pence administration has sought to promote religiously acceptable contraceptive methods (like fertility awareness) at the expense of more effective methods in programs (like Title X and teen pregnancy prevention) and in the rule attacking employer contraceptive coverage. (Read more at: *https://nwhn.org/smartphone-contraception/*.)

Finally, we've been active in publicizing medication abortion as a safe and effective way to terminate a pregnancy and defending organizations like Aid Access that help pregnant people self-manage their abortions at home.

Our sexual and reproductive health advocacy work appeared in a range of publications, from the *New York Times* to online-only publications like *Bustle,* geared to young women.✤

Sarah Christopherson is the NWHN's Policy Director

Protecting and Expanding Medicaid Means Confronting Racism Baked into the Program

By Cynthia Pearson

Lyndon Johnson signing Medicare bill, with Harry Truman, 30 July, 1965.

I received innumerable calls in the last few months encouraging me to sign up for Medicare. The callers know one important fact about me: I'm turning 65 soon. With a few exceptions, age is all that counts with Medicare. Turn 65 and you're eligible.

The story was different when my 27-year-old daughter enrolled in Medicaid during a gap between jobs. She faced endless questions: Where had she worked, for how long? How much was she paid? What date was she laid off? Although she and I both live in Maryland, which has relatively generous Medicaid benefits, applying for Medicaid and following its intrusive reporting rules to remain covered was a time-consuming and frustrating experience.

Why is Medicaid so much harder than Medicare? There are lots of superficial answers but, at heart, the answer is "racism." Racism also underlies the current threats to Medicaid, which are worse now than at any time since its creation.

In 2017, Republicans tried to push 15 million people off Medicaid by slashing funding and removing guaranteed eligibility for pregnant people, low-income children, and people with disabilities.[1] When that failed, the Trump-Pence administration invited states to push people off Medicaid by creating extraordinarily difficult requirements to maintain coverage; seven states implemented these policies already and tens of thousands of people lost Medicaid coverage. Yet, while some extreme conservatives discuss cutting Medicare, the program doesn't face any significant attacks like eligibility restrictions, funding cuts, or excluding beneficiaries from the program.

Medicare and Medicaid are so different, it's hard to believe they were created on the same day, in the same piece of legislation. Think of these twin programs as more like Danny DeVito and Arnold Schwarzenegger in *Twins* than Mary-Kate and Ashley Olsen. The programs were born on July 30, 1965, but their story starts back in 1935, when President Franklin Roosevelt proposed a social security program to create a universal safety net. Southern Whites furiously opposed this proposal, because the federal assistance provided to Blacks might upset the racial hierarchy that kept most Southern Blacks economically dependent on Whites. Roosevelt capitulated, and the 1935 Social Security Act excluded domestic workers and agricultural laborers.[2] As a result 60% of Black men and 80% of Black women were not covered.[3]

Warping public assistance programs to exclude Blacks was fully in force by the early 1960s. Welfare (officially, "Aid to Dependent Children") allowed states to provide coverage only to those living in "suitable homes," creating the leeway for states to disproportionately exclude families of color.[4] Southern states often rescinded coverage of Blacks during harvest season.[5] So, in 1964, when President Lyndon Johnson proposed a series of new programs called "The Great Society" — including Medicaid and Medicare — he faced significant Congressional opposition.

The Democratic landslide in the 1964 election gave public health advocates a chance to finally establish a federal health care program. Proponents mobilized around insuring older folks,[6] and Johnson successfully neutralized the opposition of the American Medical Association (AMA) and Wilbur Mills,[7, 8] the House Ways and Means Committee's powerful and racist chair. Medicare passed easily,[9] with equal eligibility across all states and no "worthiness" tests.

While the same Congressional act created Medicaid and Medicare, the former was built out of earlier public assistance programs, with all their racist, distorted, and discriminatory aspects. It expanded health coverage to specific categories of people (i.e., disabled, blind, mothers with dependent children) but imposed means and asset testing and allowed states to determine income eligibility for coverage.[10, 11]

Ceding coverage decisions to the states let the Jim Crow South drag its feet; 32 other states adopted Medicaid before even 1 former Confederate state did[12] and Southern resistance continued for decades. The government mandated that parents of dependent children be covered but, in reality, coverage was almost unobtainable in Southern states, which capped eligibility at income levels as low as 10% of the federal poverty level (FPL).[13] Even when the federal government offered matching funds to encourage states to cover pregnant women, working parents, and certain low-income children, Southern states rejected most of these opportunities.[14]

The Affordable Care Act (ACA) sought to fix this unequal, unjust system by requiring states to participate in Medicaid and equalizing eligibility in all states. Southern states fought back, challenged the ACA in court — and won.[15] A 2012 Supreme Court decision blocked the requirement to expand coverage to low-income adults and most formerly Confederate states continue holding out.[16] Louisiana expanded in 2016, after electing a governor who campaigned on the issue, but pro-coverage candidates in Georgia and Florida lost. Most recent expansion successes are mostly in smaller, rural, predominantly White states outside the South. Nine years after the ACA became law, a disproportionate share of Blacks don't have coverage, in large part because of the Southern CONTINUED ON PAGE 11

YOUNG FEMINIST

Putting the "Med" In Social Media

By Sarah Acs

College was a rough time for me to be on the birth control pill. My schedule was absurdly irregular. I kept my pack by my toothbrush and took my pill before bed, and sometimes that was 11:00 pm and sometimes it was 3:00 am. I traveled regularly for my extracurricular activities and, if I forgot to bring my pack, I'd miss two days. I wanted to study abroad so I had to figure out how to get enough packs to cover the whole time. On top of all of that, I started getting migraines, which can be a side effect of oral contraception.[1] By my senior year, I decided enough was enough — I needed to find a birth control method that worked better for me and my lifestyle.

I started researching different methods of birth control with a checklist in mind. I found the medical recommendations and high success rate of IUDs appealing, but these cold hard facts and statistics felt hard to apply to my own life, so I searched for more personal stories. I was disturbed that the individual accounts I read about IUDs erred on the side of horror stories rather than the average experience. I fell into an Internet rabbit hole of personal blogs that described painful insertions, strange side effects, and the worst outcomes possible. When I searched for "IUD insertion," of course Google provided me with a deluge of absolutely terrifying stories. (See our feature article for more about IUD insertion experiences.) What did I expect, balanced, rational information? The more outlandish the story, the more it stands out on the Internet.

Thankfully, a friend mentioned an intersectional feminist support group she belongs to on Facebook. This group was made by and for Northwestern students and covered a range of topics from experiences with harassment at frat parties to where to find the best ObGyns around town. There was even a whole thread where people shared their experiences with IUDs.

These were women just like me, making the decision to switch their birth control, who were more than happy to share their information and experiences. The people in the group shared their own research, providers' recommendations, and how they personally dealt with insertions and side effects. I was no longer drowning in listicles of IUD disasters! And, while I knew this was not professional medical advice, it was comforting to have a variety of real people to talk to about it. I ended up getting an IUD from my gynecologist back home in Virginia, and during my appointment I actually raised questions I learned to ask from the Facebook group.

These types of on-line support groups exist for a myriad of different conditions. Social media has become an incredible tool to connect people all over the world who have similar experiences. In addition to emotional support, these groups can offer a community of people willing to give practical support as well — such as helping you get to a doctor's appointment.

In some cases, these groups can also help bring about real change in medicine. For example, in 2002 the Food and Drug Administration (FDA) approved a permanent form of birth control called Essure. It became popular because, as opposed to the Pill or IUDs, it was permanent, and less invasive than having a tubal ligation. But, the FDA approval may have been premature. In 2011, Angie Firmalino started a Facebook group called *Essure Problems* to share her story and find other women who'd experienced issues with Essure.[2] The group ballooned to more than 20,000 members; when the group's administrators realized how many people were negatively affected by Essure, they encouraged members to file adverse event reports with the FDA.

Between 2012 and 2014, the FDA saw a jump in adverse event reports from 100 to more than 2,000. In 2015, the FDA held a public advisory committee meeting and members of the Essure Problems group traveled to Washington, DC to provide testimony about their experiences with the method. Essure Problems helped mobilize a large community that encouraged the FDA to listen to their concerns and make real changes. In 2016, the NWHN testified at the FDA, advocating for the use of real-world evidence when making decisions about medical devices, supporting Essure Problems' goals.[3] Later in 2016, the FDA ruled that Essure's label must include a "Black Box" warning, which highlights the drug or device's potential for serious negative side effects. By 2017, the manufacturer, Bayer, had halted international sales; by the end of 2018, it was removed from the American market as well.[4] Essure Problems now has more than 38,000 members and continues to provide women with support and education.

Facebook groups are a great resource, but the platform is not without problems. Privacy is a concern, especially for people who want to share vulnerable information. Targeted ads can also use personal information to prey on vulnerable people from these groups. Since Facebook has come under fire after the 2016 election, for failing to curb the spread of fake news on the site, founder Mark Zuckerburg has made a conscious effort to promote the platform's community-building aspects.[5] The company has recently updated group features and administrator controls, and tried to limit targeted ad marketing within groups.

Facebook has three types of groups: public, closed, and secret.[6] Public groups can be joined by anyone, and everyone can see who is in the group and what is posted. You can search for closed groups on Facebook and anyone can request to join them, but only members can see the member list and group posts. Lastly, you must be invited to join a secret group, since it won't show up in a search, and only members can see the group posts. Closed and secret groups offer a level of privacy for their members that regular Facebook groups may not.

Groups can also have terms and conditions for membership that dictate who that group is for and how to respectfully engage with other members. A group for people with a condition offers different resources than a group for people who are caring for someone with a condition — so it's important to shop around for the appropriate community for you. I found a group that fit my needs; if you are struggling to find a specific community, the great thing about Facebook is that you can build a community yourself.✤

References are available from *info@nwhn.org.*

Sarah Acs was the NWHN's 2018–2019 winter communications intern. She studied sociology at Northwestern University and is looking forward to a career in health communications.

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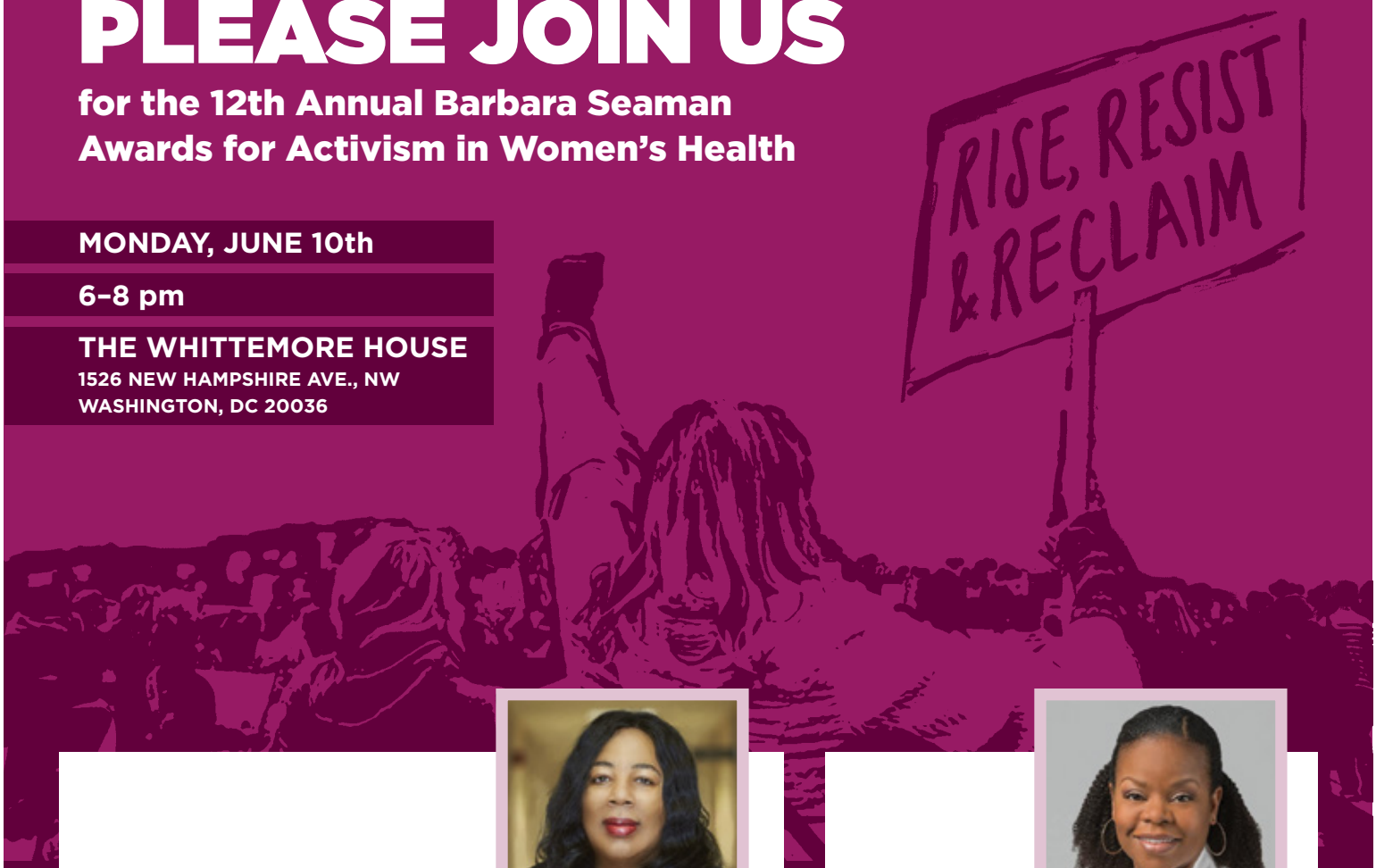

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LIFETIME ACHIEVEMENT AWARDEE

Harriet A. Washington

Harriet A. Washington is the author of numerous books, including *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, winner of the 2007 National Book Critics Circle Award for Nonfiction. The book sheds light on many issues that affected people of color, including the true legacy of James Marion Sims, considered by many to be the "father of gynecology." Harriet details Sims' misdiagnosis of patients during his medical training and his mistreatment of Black enslaved women that led to his medical breakthroughs. In New York, Harriet's work spurred the removal of Sims' statue, whose plaque offered only praise while failing to acknowledge those who suffered and died at his hands.

GUEST SPEAKER

Dr. Jamila Perritt

Dr. Jamila Perritt is a fellowship trained, board-certified obstetrician and gynecologist with a comprehensive background in Family Planning and Reproductive Health. In addition to her clinical work, she develops, organizes, and facilitates health education outreach events to diverse communities, including educating medical practitioners on self managed abortion. She focuses primarily on health equity, reproductive justice, adolescent health, contraception and family planning.

WOMEN RISE UP

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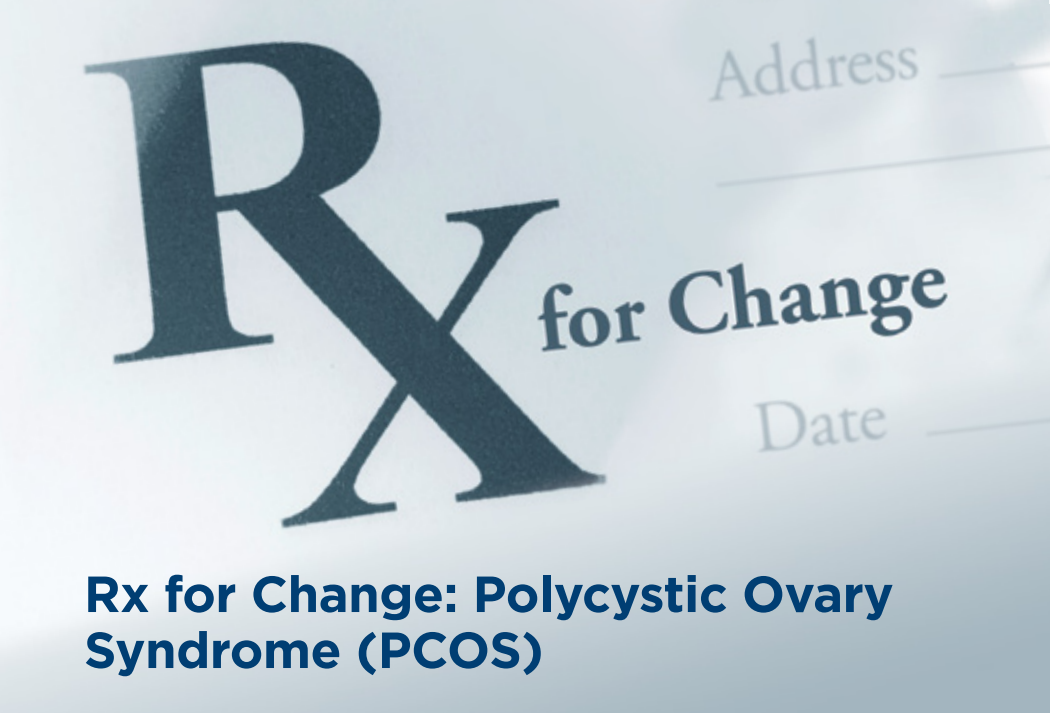

Rx for Change: Polycystic Ovary Syndrome (PCOS)

Adriane Fugh-Berman, MD, is a professor in the Georgetown University Medical Center, and director of PharmedOut, a GUMC project that promotes rational prescribing.

Charlea T. Massion, MD, is a family physician and specialist in hospice and palliative care medicine. She is the Chief Medical Director of Hospice of Santa Cruz County and also teaches physicians about work-life balance and career development.

Polycystic Ovary Syndrome (PCOS). PCOS is another name for "chronic oligoanovulation" — irregular or absent ovulation resulting in irregular or absent menstruation. PCOS may be associated with ovaries that have multiple cysts; hyperandrogenism (increased DHEA and/or testosterone); excessive facial or body hair (hirsuitism); acne; and weight gain. Diabetes, high blood pressure, and uterine cancer are associated with the condition, but it bears noting that obesity is also associated with these conditions even in women without PCOS.

PCOS is a common diagnosis in reproductive-age women, but is far more common in younger women; the prevalence of PCOS signs and symptoms drops drastically after age 25.[1] PCOS may resolve over time, and probably should not be diagnosed in adolescents, since they have irregular periods and their ovaries often appear to be cystic on sonograms.

Several different criteria exist for diagnosing PCOS, none of which actually require ovaries to have cysts (for this reason, some have suggested changing the condition's name). The National Institute of Health (NIH) criteria require anovulation (no ovulation) or oligoovulation (rare ovulation) plus clinical or biochemical signs of hyperandrogenism. The Rotterdam criteria require any two of the following three conditions for diagnosis: anovulation/oligoovulation, hyperandrogenism, and polycystic ovaries revealed by sonogram. The Rotterdam criteria are the standard diagnosis criteria, and have substantially increased the number of women eligible for a PCOS diagnosis.

It doesn't really matter what it's called, though, because different approaches are needed to address different concerns.

Hirsutism associated with excess androgens refers to excess "midline" hair, meaning facial hair (mustache or beard) or hair on the chest or abdomen. This type of hairiness can be treated with oral contraceptives or spironolactone. (Hairiness of the arms and legs is mainly genetic and is not considered part of PCOS.)

Anovulation/oligoovulation can be addressed by weight loss in women who are above a healthy body mass index (BMI). (By the way, being underweight can also cause ovulation to cease.) For women with PCOS who are not overweight, not ovulating, but don't want to get pregnant, hormonal contraception can serve a dual purpose; besides being effective birth control, oral contraceptives, periodic progestin therapy, or a progestin-releasing IUD will reduce the risk of developing uterine cancer. For women who want to get pregnant, ovulation-inducing drugs are available.

Diabetes is another concern, and women with chronic oligoanovulation should be regularly tested for diabetes. Obesity increases insulin resistance, which many women with PCOS have. Metformin, a diabetes drug that sensitizes the body to insulin, may be helpful for women with impaired glucose tolerance, although it is unclear whether the drug fosters health benefits in the long term.

Another PCOS treatment is inositol, a natural sugar-like constituent of the body; as a dietary supplement, inositol is common in foods. Inositol may be helpful for many PCOS signs and symptoms; studies of taking 2,000 mg of inositol twice daily show decreased androgen levels, restoration of ovulation, and weight loss. A meta-analysis of six studies comparing the insulin-sensitizing effects of metformin with myo-inositol found similar effects on insulin levels, testosterone levels, and BMI.[2] One study found that taking 1,500 mg of inositol twice a day was as effective as metformin in insulin sensitization and normalization of the menstrual cycle.[3] It is unclear whether inositol improves the chances of conception among subfertile women with PCOS who are trying to conceive.[4]

Most inositol studies have mainly been done with myo-inositol, which the body transforms into inositol triphosphate, and which regulates insulin and hormones affecting the thyroid and ovaries. Some researchers recommend combining myo-inositol with d-chiro inositol in a 40:1 ratio.[5]

Tessa Copp and other researchers at the University of Sydney point out that, while troublesome symptoms should be treated, giving irregularly ovulating women a disease label may not be helpful.[6] Women diagnosed as having PCOS have higher rates of mood disorders, eating disorders, poor self-esteem, and less satisfying sex lives. While proponents of the diagnosis would attribute these symptoms to the "disease," it may be that the diagnosis itself has negative consequences.❖

References are available from *info@nwhn.org.*

Protecting and Expanding Medicaid

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states' refusal to expand Medicaid.[17]

Worse, some states are now excluding adults by implementing work requirements. The Trump-Pence administration is "empowering states" to determine who's covered. For example, Arkansas' new waiver allows it to implement work requirements, with disastrous results (more than 18,000 people lost Medicaid coverage in just 6 months).[18] It also required Medicaid enrollees to report on-line for months, even though many rural areas, which are disproportionately Black, lack internet access.[19] From our perspective, "empowering states" sounds a lot like "states' rights," many Southern states' excuse for opposing federal civil rights legislation.

As of March, the federal government has approved work requirements in 7 states, with 11 other states applying for such approval.[20] Medicaid is being weakened in states that were outside the Jim Crow South, as well: for example, Michigan's Republican legislators proposed an exemption to the new work requirement designed to apply only to rural, majority White counties.[21]

These attacks threaten a valuable program and reinforce racial discrimination that was baked into Medicaid from the beginning. When it comes to expansion, we've reached the limit of what economics-based rational self-interest arguments can do, because the remaining opposition isn't rational, it's rooted in these deeply held prejudices. What can be done? Our Raising Women's Voices initiative starts at the grassroots, and organizes across race and class. Join us in working to make Medicaid a true safety net for all, so people don't have to wait until they're 65 to get the coverage they need and deserve. Find out more at *http://raisingwomensvoices.net/*.✤

References are available from *info@nwhn.org.*

Cynthia Pearson is the NWHN's Executive Director. She thanks Sarah Christopherson for useful discussions and feedback.

Since You Asked!

Question: I've got a question about estrogen creams. I'm 66 and having trouble with Pap smears (which I get yearly because I am a DES baby who also had a brief bout of HPV a number of years ago). My vaginal opening is atrophying pretty badly. I tried Vagifem suppositories, but those didn't really help. My provider recommended I use Estrace vaginal cream for four months or so before trying to get the Pap again. I wanted to check in about the carcinogenic effects of doing something that.

Answer: After the menopausal transition, vaginal tissues can become thinner,[1] causing dryness and/or itching. As a result, some post-menopausal women experience vaginal pain or discomfort when they have intercourse or a gynecological exam.

Some women find that regular intercourse or other sexual stimulation is enough to keep the vagina supple, while others use vaginal lubricants to prevent discomfort. There are a variety of over-the-counter (OTC) moisturizers and lubricants for vaginal dryness but, in some cases, they do not fully relieve symptoms. For women who don't experience relief from OTC products, low-dose vaginal estrogen is an option. Low-dose vaginal estrogen is available in three forms: creams, tablets, and rings.[2]

The NWHN has warned women about the effects of long-term menopause hormone therapy,[3] including increased rates of cancers and cardiovascular events — but vaginal estrogen is different. Recent studies show that low-dose vaginal estrogen does not have the same increased health risks that are associated with hormone therapy. These studies, based on data from the Women's Health Initiative Observational Study showed that the risk of invasive breast cancer, colorectal cancer, endometrial cancer, stroke, and blood clots was not significantly different between post-menopausal women who used vaginal estrogen and those who did not.[4] The same findings held true for women who had had a hysterectomy. Vaginal estrogen is a local treatment that's administered on the exact place it's treating, so far less estrogen enters the bloodstream than with hormone therapy, which typically uses a pill or patch.[5]

Most studies examining vaginal estrogen's impact are observational studies, meaning that they do not control for all risk factors. Clinical trials are necessary to determine the treatment's exact safety risks. The North American Menopause Society 2017 statement on hormone therapy notes that: "low-dose vaginal estrogen preparations are effective and generally safe for the treatment of VVA [vulvovaginal atrophy], with minimal systemic absorption, and preferred over systemic therapies when ET [estrogen therapy] is considered only for GSM [genitourinary syndrome of menopause]."[6] The NWHN believes that, based on current research, vaginal estrogen is a safe and effective treatment for vaginal discomfort due to menopause.[7, 8]

If you or a family member have a history of cancer, blood clots, and/or heart problems, it's important to talk with your provider when considering vaginal estrogen treatments.[9] It's also important to get checked out if you experience vaginal bleeding while using estrogen cream, since it can be caused by an overgrowth of the uterine lining (the endometrium).✤

The NWHN believes that, based on current research, vaginal estrogen is a safe and effective treatment for vaginal discomfort due to menopause.

References are available from *info@nwhn.org.*

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

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SNAP SHOTS

Donald Trump ran for president on an overtly anti-choice agenda that included promises to roll back the Affordable Care Act (ACA), including coverage of contraception with no extra fees. **News outlets reported that many women sought long-acting reversible contraception (LARCs), such as an IUD, after the 2016 election,** to ensure they had coverage if Trump enacted these promises. A new study examined whether these reports were merely anecdotal or not. Researchers studied LARC utilization in the 30 days before and after the 2016 election, and during the same time period in 2015. The analysis used medical records data for more than three million privately insured women aged 18–45, and accounted for secular and seasonal trends. **The rate of LARC insertions increased by 21.6% from 2015 to the 2016 time periods.** It's not surprising that women value contraceptive coverage and the threat to access affected their choices about protecting their rights and bodies.

JAMA Internal Medicine, February 2019

Gastrointestinal (GI) issues are common among people with Autism Spectrum Disorder (ASD). **Researchers analyzed four types of studies and found that gut microbiota play an important role in mediating ASD symptoms.** The first set of studies found that germ-free mice and rats — bred to have no bacteria living on or in them — displayed less sociability; introducing a healthy gut microbiome corrected many of the rodents' abnormal behaviors. The second set of studies, which assessed fecal matter, showed that people with ASD have different gut bacteria than their peers without ASD. The third set of studies found that people with ASD have higher rates of intestinal symptoms like constipation, diarrhea, and stomach pain. The final set of studies found a link between gut bacteria's effects on the immune system and abnormal immune function in people with ASD. We don't know the exact mechanisms behind gut bacteria's effects on ASD, but **these studies suggest a new direction for future research and treatment possibilities.**

Biological Psychiatry, August 2016

Medication abortion (MA) is safe and effective but, currently, women in the U.S. must obtain the medication from a medical facility, like a physician's office. A new study assessed women's opinions about potential other ways to access MA, using an on-line survey completed by 3,511 women aged 18–49 in representative sample. The survey asked about support for three methods of accessing MA: in advance from a doctor for future use; over-the-counter (OTC) from a drugstore; and on-line without a prescription. Nearly half (49%) of the respondents supported at least one of these ways to access MA: 44% supported advanced prescription; 37% supported OTC access; and 29% supported on-line access. Women liked that these methods were private, convenient, and facilitated ending an unwanted pregnancy as early as possible. **It is well-established that women are capable of accurately dating a pregnancy and of safely using MA outside a medical facility. It's time to expand access to this safe and effective health care service.**

Contraception, October 2018