

The Women's Health Activist.®

FEATURE STORY: PAGE 4
Access to Health Care for Women Living with HIV: A Reproductive Justice Issue

By Ariel Tazkargy, Esq.



IN THIS ISSUE

Director's Message 2

Women and Alzheimer's Disease: A Global Epidemic 6

Young Feminist 8

The Network in Action..... 7

RX for Change..... 10

Snapshots 12

TODAY, NEARLY $\frac{2}{3}$ of AMERICANS LIVING WITH ALZHEIMER'S are WOMEN 6



NATIONAL WOMEN'S HEALTH NETWORK

A Voice for Women, a Network for Change

DIRECTOR'S MESSAGE

When Informed Consent Becomes State-Mandated Lies

By Cynthia Pearson



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

“Abortions aren’t reversible, as anyone who’s had basic sex education knows. But, anti-abortionists have created this term as way to limit the growing use of medication to induce an abortion.”

I think I was sitting on the subway when I first read the phrase “reversible abortion.” Wherever I was, I did a double-take to make sure I’d read it correctly. Yep, that’s what it said! Apparently, politicians have created a *completely* non-existent medical condition — “reversible abortion” — and, what’s worse, passed laws mandating doctors and advanced practice nurses “inform” women that it’s possible to reverse an abortion.

Abortions aren’t reversible, as anyone who’s had basic sex education knows. But, anti-abortionists have created this term as way to limit the growing use of medication to induce an abortion. Medication abortion has been available in the U.S. for 15 years, and involves using two drugs (mifepristone or methotrexate, plus misoprostol) to induce an abortion. Medication abortion has become more common and now accounts for 23% of all U.S. abortions. In some communities, it’s the most common technique for early abortions. (Non-medication abortions are performed by vacuum aspiration, also known as surgical abortion).

Anti-abortionists haven’t had much luck changing public opinion about abortion. According to Gallup polls, 78% of people in the U.S. believe abortion should be legal in some or all circumstances, a number that hasn’t changed much over the last 40-plus years.

Yet, this widespread and consistent public support for a women’s right to safe and legal abortion hasn’t stopped legislators from trying to restrict access to abortion care. Since 2011, state legislators passed a record-setting 231 new abortion restrictions, with dire effects on women’s health.

The latest trend is to force clinics to close unless they can turn themselves into surgi-centers. Targeted regulation of abortion provider (TRAP) laws go beyond what’s medically necessary and require clinics to widen their hallways, enlarge procedure rooms, and even provide a specified number of parking spaces. According to Bloomberg News, 70 clinics have recently either closed or stopped offering abortion care.

But, such burdensome regulations don’t necessarily stop women from getting medical abortion, which can be safely provided in non-clinic settings (including the privacy of a woman’s home).

Stopping people from providing and getting abortion care is what anti-abortionists are all about. That’s where “reversible abortion” comes in. They now claim women can stop a medical abortion that’s already started by taking progesterone, a hormone present in high levels during early pregnancy. This claim has *no* scientific or medical justification. Progesterone is necessary to sustain a pregnancy, but can’t *reverse* the effects of medications that have already disrupted a growing embryo.

Although all legitimate scientific authorities oppose the claim, legislators in Arizona and Arkansas recently passed legislation requiring abortion care providers to “inform” women they might be able to reverse their abortion this way. The goal is to interfere with women’s decision-making process.

These laws are a perversion of informed consent. Informed consent gives patients an opportunity to make sure they know about the benefits and risks of a procedure, device, or medication. Good informed consent processes help patients know what to expect and recognize signs of problems, and gives them a chance to raise concerns or questions. The Network is justifiably proud of our role in advocating for informed consent as a necessary and routine part of health care services. Mandating lies isn’t informed consent, it’s manipulating women, and it’s got to stop. ❀

Thank you to Our Long-Time Supporters!

When we call our members during our phone-a-thons, they often pour support through the telephone line, and let us know they stand with us. In commemoration of our 40th anniversary, the Network wishes to explicitly express our appreciation for our members' generosity and commitment.

We are especially proud that we have hundreds of members who have supported the Network's vital work since our inception. Our members who have been with us for 25 and 35 years love talking with our staff and interns, and let us know they will always support the Network. We want to acknowledge their dedication and support for a future where the health of all women is a top priority. Whether it's speaking on your behalf at meetings with key Washington decision-makers, rallying before the Supreme Court, or helping women enroll in health coverage — we're always in action.

These advocacy efforts have made a difference in the lives of millions of women. This work, maintained over the last four decades, has only been possible because of your understanding and support for our mission.

Our members encourage us to keep up the good work. They tell us how much they enjoy reading *The Women's Health Activist*, and that they pass it on to their friends and family. We love to hear from women whose lives we have impacted. Have a good story? Let us know! Email us at membership@nwhn.org.

Again, a tremendous Thank You to all of our members and supporters, past and present. Your commitment is the torch that guides us into the future to a more just, prosperous, and healthy future for all women. ❖



Board Meeting

The NWHN board of directors will meet next in Berkeley, CA, on June 27-28, 2015. 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. ❖

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

The Women's Health Voice: 202.682.2646

Facebook: facebook.com/TheNWHN

Instagram: [thenwhn](https://instagram.com/thenwhn)

Twitter: [@theNWHN](https://twitter.com/theNWHN), [@RWV4HealthCare](https://twitter.com/RWV4HealthCare)

Pinterest: pinterest.com/nwhn

YouTube: www.youtube.com/user/TheNWHN

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.

Board of Directors

Dara Mendez, *Chairperson*
Anu Manchikanti Gomez, *Action Vice Chair*
Zipatly Mendoza, *Administrative Vice Chair*
Ninia Baehr, *Treasurer*
Charlea Massion, *Secretary*
Dazon Dixon Diallo
Emma Duer
Shalini Eddens
Andrea Friedman
Kira Jones
Kara Loewentheil
Tiffany Reed
Dipti Singh
Mia Kim Sullivan

NWHN Staff

Cynthia Pearson, *Executive Director*
Pat Antonisse, *Finance Manager*
Cecelia Saenz Becerra, *RWV Field Organizer*
Christina Cherel, *Program Coordinator*
Susan K. Flinn, *Newsletter Editor*
Heidi Gider, *Director of Advancement*
Coco Jervis, *Program Director*
Shaniqua Seth, *Health Communications Manager*
Ariel Tazkargy, *Reproductive Justice Law & Policy Fellow*
Amirah Tyler, *Membership Coordinator*
INTERNS: Zoe Kusinitz, Amanda Lynen, Prisca Maldonado

The Women's Health Activist® is a bimonthly 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.

Volume 40, Issue 3

May/June 2015

ISSN no. 1547-8823

©2015 National Women's Health Network



Access to Health Care for Women Living with HIV: A Reproductive Justice Issue

By Ariel Tazkargy, Esq.

This year, the Affordable Care Act (ACA) celebrated its fifth year of providing millions of people with health insurance. In 2015, 11.7 million Americans — including 6.2 million women — got covered thanks to the health reform law.¹ The ACA has been a *huge* advance for women's health, and has largely met its goals to increase the number of people with insurance, improve the overall quality of health care, and stem the tide of rising costs.

Yet, there have been kinks in implementing the ACA, and the most vulnerable Americans risk falling through the cracks. In particular, people living with HIV (PLHIV) have been hard-hit by problems with the ACA — especially women living with HIV (WLHIV), who need access to reproductive and sexual health care. For example, the ACA does not provide for any social support or case management services structured to meet WLHIV's unique needs and keep them engaged in life-saving care.

In commemoration of *National Women & Girls HIV Awareness Day* (March 10), the National Women's Health Network (NWHN), Positive Women's Network – USA (PWN), and SisterLove, Inc., published a paper about WLHIV's continued challenges in accessing health care. The paper, *Ryan White & the Affordable Care Act: Advocating for Public Healthcare for Women Living with HIV*,² analyzes how well the ACA and other publicly funded health care programs meet WLHIV's need for comprehensive,

high-quality care delivered without stigma or discrimination, regardless of the ability to pay.

We believe that HIV services should be integrated into *all* comprehensive women's health care efforts. Yet, our review finds that WLHIV have been overlooked during the course of ACA implementation. In order for WLHIV to fully realize health care reform's benefits, women's health advocates must advocate for other public benefits programs that fill the gaps in ACA coverage. Until we have a robust health care system that adequately addresses the needs of *all* Americans, other publicly funded programs continue to play an essential role in helping WLHIV meet their sexual and reproductive health care needs.

The ACA & Women Living with HIV: More to Do

Over a quarter million U.S. women (280,000) are living with HIV, but women's infection risks are not uniform.³ There are stark racial disparities among people with new HIV diagnoses. A White woman's likelihood of being diagnosed with HIV in her lifetime is 1 in 526, a Latina's likelihood is 1 in 106, and an African American woman's likelihood skyrockets to 1 in 32.⁴ Latina women make up 16 percent of the U.S. female population and represent 19 percent of WLHIV; African American women, who comprise only 13 percent of the U.S. female population, represent 60 percent of WLHIV.⁵

The ACA has improved WLHIV's access to care. Women who work for most large employers can't be denied private health insurance or charged higher rates due to their HIV status. Insurers can no longer impose lifetime caps on coverage. And, many preventive services are now covered without cost — including well-woman visits, HIV screening and counseling, and screening and counseling for interpersonal and intimate partner violence (IPV).⁶

Yet, WLHIV still face significant barriers getting the full spectrum of health care they need. This is particularly true for women in the 22 states that did not expand Medicaid coverage (7 of these are debating expansion) in the wake of the 2012 Supreme Court decision striking down the ACA's Medicaid expansion requirement.⁷

Currently, an HIV diagnosis is not a "disability" that allows PLHIV to automatically qualify for Medicaid; PLHIV *only* qualify for disability-based Medicaid coverage when HIV progresses to AIDS. If all states expanded Medicaid, as the ACA originally required, PLHIV would have been able to access services based on an HIV (vs. AIDS) diagnosis; this makes good sense medically and helps PLHIV live longer, healthier lives. In states that refuse to expand Medicaid, the result is a devastating gap in coverage for PLHIV, especially for women who need reproductive health care. The problems are particularly acute for WLHIV's access to prescription drugs and affordable coverage.

In terms of prescription drug coverage, although preventive services must be provided without cost-sharing under the ACA, HIV treatment is *very* expensive. Some insurance companies discriminate against PLHIV by charging more for HIV-related prescriptions.⁸ Some have placed all HIV medications (including generics) in their highest cost-sharing tiers. A recent study estimated that a person living with HIV could pay more than \$3,000 out-of-pocket, annually, due to discrimination in HIV medication pricing.⁹

In terms of affordable care, the Supreme Court decision allowing states to not expand Medicaid eligibility pushed many low-income people into "the coverage gap." State Medicaid expansion generally lowers the income requirement levels and makes more people eligible for

Medicaid coverage. The “coverage gap” occurs when a person’s income is too low to qualify for health care subsidies,¹⁰ but too high for state Medicaid.^{11, 12}

Unfortunately, almost half (43 percent) of PLHIV reside in states that didn’t expand Medicaid, like Texas and Georgia.^{13, 14} For example, Masonia Traylor, a 28-year-old WLHIV pharmacy technician, makes less than \$10 per hour (less than \$1,000 per month, and less than \$10,000 annually). Her schedule is capped at 30 hours per week, precluding her from getting employee benefits. At her current income, Masonia and her two children qualify for Medicaid in Georgia, but she’s starting a part-time position as a health advocate. The second job will raise her income above Georgia’s Medicaid qualification cut-off. And, even with her increase in income, she won’t make enough to qualify for a subsidy on the marketplace. Without a subsidy, she can’t afford to pay a private plan’s monthly premiums for herself and her two children, as well as the out-of-pocket costs like deductibles and copays for her HIV treatment. Without health insurance coverage, Masonia’s and her family’s health will be jeopardized due to a marginal shift in income.

Ryan White Program Helps WLHIV: Supplementing Gaps in ACA

Until these problems can be addressed, it is critical that other public programs are supported to meet the identified needs of low-income Americans, including WLHIV. In particular, the Ryan White program is critical to ensure that WLHIV can access the full range of care services and medications needed to stay healthy.

Jacqueline Muther — long-time Atlanta HIV advocate and policy manager of the Grady Infectious Disease Program — notes that many of her clinic’s patients make too much to qualify for Medicaid and cannot afford the costs associated with private plans. Muther comments: “The ACA isn’t working in Georgia. It *will not work* in states that fail to expand Medicaid. That’s the core of the thing.” The clinic — like so many serving PLWHA — is often forced to pick up the tab for their care, which it does largely using Ryan White HIV/AIDS Treatment Extension Act funds.

Ryan White funding is distributed

via complementary “parts,” which together, provide primary care and wrap-around services to ensure that PLWHA receive uninterrupted care. “Part D” funds culturally relevant, family-centered services to help women, children, and youth living with HIV maintain continuous care. Part D services — which include case management, peer support, reproductive and mental health care, health education, and transportation for medical appointments — are indispensable for vulnerable PLHIV.

Without Part D services, people who fall into the “coverage gap” will have no way to get the care they need to stay healthy. This is especially true in states that did not expand Medicaid. These programs are essential to meeting the needs of women and others living with HIV.



Recommendations

There is much to do to fully realize the ACA’s goals and protect Americans’ health. Advocates and policymakers must ensure full access to treatment, without interruptions in care, so that PLHIV can lead long, healthy lives. Our document presents three key recommendations to ensure accessible, consistent, and affordable health care coverage is available for all people living with HIV through the ACA and other public programs:

- **ACA Regulations Must Address Discriminatory Prescription Drug Benefits.** Advocates must ensure that HIV medications stay affordable and accessible as the ACA is implemented. Advocates should act as watch-guards over instances of price and/or medication coverage discrimination and any resulting disruptions to care. Advocacy around discriminatory practices around HIV-related medications should also examine the role of the Ryan White CARE Act to meet WLHIV’s needs.
- **Access to Ryan White Services Must Be Protected.** Since ACA implementation is still in its early stages, and many states failed to expand Medicaid, Ryan White must be supported as a critical tool to meet WLHIV’s needs. Part D standards provide a model for the ACA, and should be preserved and/or expanded.
- **Ryan White Part D Services Must Be Expanded.** Advocates must remain vigilant in ensuring that WLHIV’s needs are met by programs like Ryan White Part D services. Ryan White Part D services should be preserved, expanded, and used as a model for the required care provided through Marketplace insurance plans serving PLHIV.

The NWHN and our allies will continue to fight for truly universal health care for women and their families. With our partners in Raising Women’s Voices (RWV), we will advocate for the remaining states to expand Medicaid as part of their ACA implementation. We will oppose high premiums, imbalanced pricing structures for HIV medications, and threats to vital social and medical services that provide care to WLHIV. We will keep working until the U.S. health care system finally meets the needs of all people, including those living with HIV.✿

References are available online or from editor@nwhn.org.

Ariel Tazkargy is the NWHN’s Law Students for Reproductive Justice (LSRJ) Reproductive Justice Law & Policy Fellow. She co-authored the policy paper and article with Melanie Medalle, LSRJ Fellow at SisterLove, Inc. and Nerissa Irizarry, LSRJ Fellow at Positive Women’s Network – USA.



Women and Alzheimer's Disease: A Global Epidemic

By The Alzheimer's Association®

Worldwide, at least 44 million people are living with Alzheimer's disease and other dementias, with at least 5 million in the United States alone. The number of Americans who have Alzheimer's and other dementias will escalate rapidly in coming years as the Baby Boom generation ages. By 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple, from 5 million to as many as 16 million, barring the development of medical breakthroughs to prevent, slow or stop the disease.

Alzheimer's is the 6th leading cause of death in the United States; however, it may cause even more deaths than official sources recognize. The disease kills more people than prostate cancer and breast cancer combined. Alzheimer's disease is the only cause of death among the top 10 in the nation that cannot be prevented, cured, or even slowed.

Women are at the epicenter of the Alzheimer's epidemic

According to the Alzheimer's Association 2014 Alzheimer's Disease Facts and Figures report, women account for almost two-thirds of Americans with Alzheimer's disease. A woman's estimated lifetime risk of developing Alzheimer's at age 65 is

1 in 6, compared with nearly 1 in 11 for a man. As real a concern as breast cancer is to women's health, women in their 60s are about twice as likely to develop Alzheimer's over the rest of their lives as they are to develop breast cancer.

Not only are women more likely to have Alzheimer's, they are also more likely to be caregivers of those with the disease. More than 3 in 5 unpaid Alzheimer's caregivers are women — and there are 2.5 times as many women than men who provide intensive "on-duty" care 24 hours a day for someone living with the disease.

Because of caregiving duties, women are likely to experience adverse consequences in the workplace. Among caregivers who have been employed while they were also caregiving:

- 20% of women vs. 3% of men went from working full-time to working part-time while acting as a caregiver.
- 18% of women vs. 11% of men took a leave of absence.
- 11% of women vs. 5% of men gave up work entirely.
- 10% of women vs. 5% of men lost job benefits as a result of their caregiving duties.

Women's brains matter

Women are leaders and influencers in family, community, business and philanthropy. Realizing the impact Alzheimer's has on women — and the impact women can have when they work together — the Alzheimer's Association has launched a national

"My husband has younger-onset Alzheimer's disease. When my children look back, I want them to know that I did everything in my power to release our family from this tragedy. I am a fighter. I am someone that wants to make a difference."

— KAREN GARNER, CARE PARTNER, WORKING MOTHER, PASSIONATE ALZHEIMER'S ADVOCATE

initiative highlighting the power of women in the fight against this disease. The Alzheimer's Association *My Brain Movement* calls on 1 million women to use their amazing brains to help wipe out Alzheimer's disease — one of the greatest threats to women's health.

We believe women have the passion and the strength to make real change. By using our collective brainpower and voices, we can create awareness of the impact Alzheimer's has on our health, our families, and our nation. We can use our voices on Capitol Hill to increase funding for research and care. And, we can make an impact by donating, volunteering, and getting involved in this issue.

We need our collective brainpower to fight Alzheimer's

The *My Brain Movement* is a united commitment to take action and make change for future generations. Be one of the 1 million women using their brains to wipe out Alzheimer's. The time is now. Join the movement. Learn how you can change the numbers for future generations at alz.org/mybrain. ❀

The Alzheimer's Association® is the world's leading voluntary health organization in Alzheimer's care, support and research.

References are available online or from editor@nwhn.org.



The Network In Action



Raising Women's Voices for the Health Care We Need

On March 4th, Network staff braved the cold and rain to rally in front of the U.S. Supreme Court and voice their support for health insurance subsidies. That was the day the Court heard oral arguments in *King v. Burwell*, a critically important threat to the Affordable Care Act (ACA). At issue is whether the ACA's premium subsidies are *only* allowed on the State Exchanges, or can also help people who use the Federal Exchange to get their insurance. The health and well-being of millions of women and their families depend on these subsidies, regardless of where they get their coverage. Without subsidies provided through the Federal exchange, insurance premiums will be too expensive for a huge number of low- and middle-income Americans. (In 2014, more than 9 million women were eligible for subsidies that reduced their health insurance premiums.)

Ahead of the March 4th oral arguments, the Network mobilized the Raising Women's Voices' (RWV) regional coordinators to build

awareness and respond proactively to the media storm surrounding *King v. Burwell*. The Network organized a community conference call to discuss women-centered messages, sent out press releases, and collected stories about the ACA's impact through our new ShareYourStory@nwhn.org email. These materials highlighted the positive impact that affordable health coverage has had on the lives of women and their families. In the coming months, we'll continue these efforts and mobilize in preparation for the Court's momentous decision, which is expected this summer. Keep up with the latest from RWV by visiting: www.raisingwomensvoices.net.

We submitted comments about proposed rules for the *Summary of Benefits and Coverage and Uniform Glossary (SBC)*. This critical tool provides consumers with clear and consistent information so they can compare their plan's benefits, cost-requirements (like co-pays), and coverage exclusions with other options. The SBC should be a "nutrition label" for insurance plans, but we need the Federal government to weigh in for these summaries to be useful. Right now, the SBC contains several misleading and/or confusing elements that would hamper a woman's ability to accurately determine if the coverage she's buying is affordable and meets her specific

needs. Our comments included a number of recommendations to improve the SBC's accuracy, transparency, and clarity.

Securing Sexual & Reproductive Health and Autonomy

We were horrified to learn that the U.S. Department of Health and Human Services (HHS) planned to shut the Office on Women's Health's *Quick Health Data Online* system by the end of March — a decision that was made with *no* public notice. This unique resource (<http://www.healthstatus2020.com/owh/index.html>) is the most comprehensive database of women's health statistics in the U.S. and can be used for a variety of powerful analyses.

It is widely used by the public health community, policymakers, researchers, and students. We responded quickly and worked with our allies to send a strongly-worded letter to key HHS leadership that expressed our outrage and displeasure about this happening without any input from the women's health community. After receiving our letter, HHS postponed the data system's discontinuation and is re-evaluating the decision; this is a short-term victory that we'll be working to make sure becomes a long-term one!

In collaboration with our Reproductive Justice allies, the Positive Women's Network and SisterLove, the Network co-authored a policy brief highlighting gaps in health reform efforts that prevent HIV-positive women from fully accessing the comprehensive health care that they need. The brief, which was released on *National Women and Girl's HIV Awareness Day* (March 10th) is the subject of our Feature Article on page 4. This brief will support our **CONTINUED ON PAGE 9**



YOUNG FEMINIST

Nobody Said It Would Be Easy

By Taylor Parnham

The accident happened somewhere between the sweet potato hash I made for dinner and the last song on my Richard Stewart vinyl. It was three months since I decided to take a break from a 12-year stint on the Pill, and I was trying to navigate my new relationship *and* new diaphragm. I know what you're thinking: Why switch from an effective method (over 99%) to an underutilized, old school, less effective method (88-94%)?

Honestly? I wanted a break from the synthetic hormones I'd ingested for over a decade, and to see what my adult body was like in its natural state. I'd also decided not to sleep with anyone with whom I didn't have an emotional connection — so I didn't think I was going to *use* the diaphragm that often. My plan was to love myself, focus on my career, and be happy without a partner. You know, that BS we tell ourselves when there are zero prospects in sight. My plans, not surprisingly, were hijacked by a man I'm now seriously dating. Isn't that how it always happens?

There I was: new man, new birth control, and an accident.

Now, for most people, using even a new form of contraception would assuage any fear of potential pregnancy. Not me. I have what my friends call "pregnancy paranoia," which means I think I'm going to get pregnant every month. Regardless if I use two forms of birth control. Regardless if not a single drop of sperm could've gotten through the barriers. Regardless. I have no intention of becoming a mother anytime soon and the thought of pregnancy scares the shit out of me.

Luckily for me and my sexually active sisters, we live in a world where there's an amazing pill called Emergency Contraception (EC). The morning after the accident, my "pregnancy paranoia" reached stage five, and I found myself walking into CVS at 10:00 am with my head held high, on a quest to purchase the pill that so many people advocated and litigated in order to make available over-the-counter.

To give you some background about my confidence level: I'd just

graduated from a top-level university with my Masters of Public Health and a focus in Maternal-Child Health, so I have expert-level Ninja status when it comes to feminism, reproductive justice, and women's health. I could preach about it all day, so I had NO hesitation seeking EC.

I scanned the aisle of condoms, lube, spermicide, tampons, UTI and yeast pills, and found the placeholder where EC should've been. Instead of being able to pick it up right then and there, I stared at a card reading: "Please see pharmacist for assistance with this medication." Say what? I thought those days were over.

Waiting in the pharmacy line, I scanned the employees working that day. All men. Whomp. It's not that I didn't think a man could be properly sensitive to my needs, but asking for EC from a woman is just easier.

After 10 minutes, it was finally my turn. The dude at the register asked what he could help me with, and I asked (as quietly and discreetly as possible) for Plan-B, please. Well, he didn't hear me, so when I said it a second time, he just HAD to repeat it back as loud as he could. Presumably so the six pairs of ears listening intently behind me in line could silently judge me.

"Plan-B? Oh that's in the Family Planning section. Did you look there?" "Uh, I did. The little card with Plan-B on it says to come and talk to you." I huffed.

Of course, he didn't believe me, and had to check for himself. Returning with a puzzled look, he turned to the two *other* male pharmacists and yelled: "Is there any Plan-B back there? You know, Emergency Contraception? I thought it was over-the-counter, but we're having trouble up here." At that last part, he pointed to me. Seriously, bro? Please shame me a little bit more in front of our audience.

Finally, after what seemed like an eternity (but really was only five seconds), one of the other pharmacists said, as if a light bulb went off in his brain, "Oh we don't carry that back here anymore! It's up at the front, next to the nicotine gum." I booked it to the front of that store so fast you'd have thought I was running away from the one-eyed, one-horned, flying purple people eater.

The clerk at the store's front wasn't much better. Yet another man, who, once again, didn't hear me say Plan-B, or recognize the name. By this point, any embarrassment had turned into



The Network's Summer 2013 interns Claire, Elli, and Rachel with over-the-counter Emergency Contraception

anger; eventually, I had to physically *show* this dude what I was talking about and explain what EC was. As soon as he understood, the look on his face was total horror, and my face had gone from a blush to all-out primrose red.

The point of this awfully embarrassing story is that **access does not equal utilization**. Just because we've fought hard to give every woman, regardless of age, the ability to purchase EC doesn't mean women are confident or educated in getting it. Women (like me) face barriers every day as they try to navigate their own reproductive health. In my case, it was insensitive men and judgey customers who shouldn't have been privy to any conversation about my private medical needs. Can you imagine a teenager trying to navigate this scenario?

What can we do? My gut reaction is to say, establishments that provide access to EC should have some sort of sensitivity training on how to treat women with respect, and ensure they don't feel shamed or judged when seeking EC — but that reaction misses the point. It places the burden for change on companies, and perpetuates outdated social norms about women and sexuality.

Women shouldn't be ashamed to ask for something that helps prevent unwanted pregnancies. Society shouldn't teach us that being sexually active is negative. Accidents sometimes happen and, luckily for us, we have the ability to prevent an unwanted pregnancy before it happens. We *all* should be walking into CVS with our heads held high, and be brave enough to ask for what we need. Nobody said this shift would be easy, but I'm so glad we can now get peace of mind from a tiny little pill. It sure did cure my "pregnancy paranoia." ❀

Taylor Parnham is a bohemian feminist who spends her time doing alcohol and drug policy research at a top-level university, all while trying to change society for the better. She enjoys yoga, snuggling with her cat, Bentley, and advocating for reproductive justice.

The Network In Action

FROM PAGE 7

on-going Congressional advocacy efforts to maintain a strong, long-term commitment to Ryan White funding that works with health reform efforts and meets the treatment, care, and reproductive health care needs of HIV-positive women in the U.S.



Challenging Dangerous Drugs & Devices

A little over a decade ago, the Network publicly supported the Food and Drug Administration's (FDA) approval of Essure — a permanent, non-surgical sterilization implant — as part of our efforts to expand contraceptive choices and make sterilization safer. But, we also expressed concerns about the limited amount of data collected during the clinical trial, the trial's short length, and the small number of women included in the trials. We called on the manufacturer to explain Essure's safety and risks in greater detail, and recommended that women have confirmatory tests three months after Essure's insertion to make sure the device had been placed correctly. In the last few months, we've received a growing number of complaints from Essure users about the debilitating side effects and mysterious ailments they're experiencing. In early 2015, several consumers reached out to the Network and sought our help in encouraging the FDA to investigate these complaints. We're speaking with the affected consumers and investigating the complaints, and anticipate pursuing this issue further with the FDA. We'll keep you informed about the situation.✿

Follow Us

Find out more about what we're working on by signing up for our e-alerts at www.nwhn.org, and following us at:



Facebook, Twitter and
YouTube: TheNWHN



Pinterest: NWHN

The National Women's Health Network 40th Anniversary Celebration

8th Annual Barbara Seaman Awards for Activism in Women's Health

*A History of Accomplishments.
A Force for Change.*

FEATURING
GUEST SPEAKER:
Judy Norsigian
*Our Bodies,
Ourselves*



HONORING



Loretta Ross,
co-founder
SisterSong

Monday, November 16, 2015

6-8 pm

The Whittemore House

1526 New Hampshire Ave., NW

Washington, DC

www.nwhn.org/event2015

For sponsorship and more information contact Heidi Gider,
Director of Advancement at 202.682.2640 or hgider@nwhn.org

Rx for Change

Name _____

Address _____

Date _____

Binge-Eating Disorder: Another Invented Disease Brought to You by Pharma

Ever notice how dinner party hosts estimate portions based on their *own* appetites? Small eaters may leave their guests hungry; large eaters may have plenty of leftovers. Adriane's in the latter category; her guests learn to enjoy her food in generous portions, or risk her wrath. Charlea, on the other hand, considers salad dinner. Somehow, we've managed to remain friends.

Sadly, Adriane's hearty appetite may indicate she has a new disease: *binge-eating disorder*. We learned this through a disease awareness campaign, which publicizes a disease without mentioning specific drugs. These campaigns are often used when there's only *one* drug to treat a disease; the process is simplified when the company invented the disease to begin with!

Drug manufacturer Shire created "binge-eating disorder" to promote several amphetamine drugs, including Adderall (mixed amphetamine salts) and Vyvanse (lisdexanfetamine mesylate). According to *BingeEatingDisorder.com* (which doesn't mention drugs or Shire):

- Symptoms include "regularly eating far more food than most people would in a similar time period under similar circumstances." Check!
- And, "Feeling that one's eating is out of control during a binge. The feeling of not being in control can be either the inability to keep from starting

to eat or the inability [sic] to stop eating once a binge eating episode has begun." Check! (When they say, "the inability to keep from starting to eat..." we wonder, before a meal... when one is hungry?)

- "To qualify as 'regular binge eating,' the instances must take place at least once per week for three months." Check! (Only once a week? How about three meals a day?)
- "The time period during which binge eating instances take place can vary by individual, but is generally considered to be less than two hours and does not have to be in one setting." Check! (We think they mean "one sitting," but most meals last less than two hours anyway.)



Charlea T. Massion, MD, is a NWHN Board member, 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.



Adriane Fugh-Berman, MD, is an associate professor in the Georgetown University Medical Center; a former chair of the NWHN Board of Directors; and director of PharmedOut, which educates prescribers about pharmaceutical marketing techniques.

We hope no one thinks being hungrier than one's friends is a medical condition. As Julie Holland (author of *Moody Bitches*, about how pharmaceutical ads target women) says, "They have ads where they show a woman surrounded by pizza and hamburgers and donuts and it says, 'If you eat more than you want to and feel guilty afterwards, you may have this disorder.' Which is sort of like saying, 'If you're a woman, you have this.'"¹

In fact, binge-eating disorder only became a disease in 2013, when the American Psychiatric Association proclaimed it to be one. The new disease was likely created to extend the patent for Vyvanse (first approved for Attention Deficit and Hyperactivity

Disorder [ADHD]), since approval for a new indication — even an invented one — confers additional years of patent protection.

In 2011, Shire stated that it intended to expand Vyvanse's use for other conditions, including schizophrenia, depression, and binge-eating.² In 2014, Shire agreed to pay \$56.5 million to settle charges it over-promoted Vyvanse and another ADHD drugs (it allegedly said Vyvanse could help prevent car accidents, divorce, arrests, and unemployment).³ The fine is nothing compared to Shire's profits. Vyvanse is a blockbuster drug that makes over \$1 billion a year, and binge-eating disorder sales are expected to add \$200-\$300 million annually.⁴

Let's be clear: binge eating can be a symptom of anxiety, stress, or low-self esteem, but "binge-eating disorder" is not a separate, real disease. Binge eating is also part of bulimia, an eating disorder in which people binge and then purge by vomiting or using laxatives. (But "binge-eating disorder," which is bulimia-minus-vomiting, is not a separate, real disease.) Binge eating is best and most successfully treated with therapy and support groups.⁵

Since binge eating can indicate a propensity for addictive behavior, treating it with an addictive drug is a *bad idea*. Yet, that's just what is happening, because Vyvanse is essentially "speed." Binge-eaters need therapy, and overweight people need diet and exercise. In any case, addicting patients to amphetamines is a *bad idea*.

Sure, speed causes weight loss, but the health risks aren't worth it. Besides addiction, amphetamines like Vyvanse can cause strokes, heart attacks, death, psychotic symptoms, mania, anxiety, and insomnia.⁶ Since Vyvanse was approved in 2007, the FDA has received more than 130 reports linking it with suicide.⁷

It's bad enough that a dangerous drug will be used to treat a widely promoted, made-up disease.⁸ It's worse that this dangerous, addictive drug will be prescribed off-label to treat people who are overweight. Although the FDA expressly stated that Vyvanse was *not* approved for weight loss, clinicians are likely to prescribe it for that purpose.⁹ Since everyone has eaten "far more food than most people would in a similar time period under similar circumstances," clinicians may well decide any overweight person

"We hope no one thinks being hungrier than one's friends is a medical condition."

qualifies for this bogus diagnosis and dangerous treatment.

The FDA really bolloxed its 2015 approval of Vyvanse for binge-eating disorder. It didn't ask for outside review and even gave Vyvanse fast-track regulatory review, which should be reserved for important drugs for real diseases. Medicalizing normal human behavior or common symptoms, and renaming subsets or combinations of symptoms, are common strategies to sell drugs. The FDA needs to step up its game and protect the public from disease-mongering scams. ❖

REFERENCES

1. Kirkland A, "Feeling intense emotions doesn't make you crazy — but that's not what Big Pharma wants you to think," Raw Story, April 1, 2015. Available online at: <http://www.rawstory.com/rs/2015/04/feeling-intense-emotions-doesnt-make-you-crazy-but-thats-not-what-big-pharma-wants-you-to-think>.
2. Whitman E, "Binge-Eating Disorder Drug: Vyvanse, Controversial ADHD Medication, Approved by FDA," *International Business Times*, February 6, 2015. Available online at: <http://www.ibtimes.com/binge-eating-disorder-drug>.

[vyvanse-controversial-adhd-medication-approved-fda-1808100](http://www.nytimes.com/2015/02/25/business/shire-maker-of-binge-eating-drug-vyvanse-first-marketed-the-disease.html?_r=0).

3. Associated Press, "Justice Department says Shire will pay \$56.5 million fine," *The Boston Globe*, September 25, 2014, Available online at: <http://www.bostonglobe.com/business/2014/09/24/justice-department-says-shire-will-pay-fine/k1tY6jueY15CiCCf4ZQabL/story.html#>
4. Thomas K, "Shire, Maker of Binge-Eating Drug Vyvanse, First Marketed the Disease," *New York Times*, February 25, 2015. Available online at: http://www.nytimes.com/2015/02/25/business/shire-maker-of-binge-eating-drug-vyvanse-first-marketed-the-disease.html?_r=0
5. Krysanski VL, Ferraro FR, "Review of Controlled Psychotherapy Treatment Trials for Binge Eating Disorder," *Psychological Reports* 2008; 102:339-368.
6. Food and Drug Administration (FDA), *FDA News Release: FDA expands uses of Vyvanse to treat binge-eating disorder*, Rockville, MD: FDA, January 30, 2015. Available online at: <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm432543.htm>
7. Whitman E, "Binge-Eating Disorder Drug: Vyvanse, Controversial ADHD Medication, Approved by FDA," *International Business Times*, February 6, 2015. Available online at: <http://www.ibtimes.com/binge-eating-disorder-drug-vyvanse-controversial-adhd-medication-approved-fda-1808100>.
8. For example: OpenCME, Module 3: *Binge Eating Disorder in 2014 and Beyond: Current and Emerging Directions in Treatment*, available online at: <http://opencme.org/BED-module3>; the Doctor's Channel, *Binge Eating Disorder: Out of the Closet and Into a New Era of Diagnosis and Treatment*, available online at: <http://www.thedoctorschannel.com/view/binge-eating-disorder-cme-part-4>.
9. Food and Drug Administration (FDA), *FDA News Release: FDA expands uses of Vyvanse to treat binge-eating disorder*, Rockville, MD: FDA, January 30, 2015. Available online at: <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm432543.htm>

In Honor Of & Memorial Donor List

TRIBUTE GIFTS

The National Women's Health Network wishes to thank everyone for their generous donations.

Cherelle Aguigui

In Memory of Kristen Nicole Rush

Evelyn Bishop

In Honor of Gene Bishop

Marie Castaneda

In Memory of Patricia Kelly

Adele E. Clarke

In Honor of Virginia L. Olesen

Maxine Nieder

In Memory of Sharon Nieder

Melinda Nordeng

In Memory of Hildy Baker

Jane Pincus

In Memory of Laura Fisher

Susan Points

In Honor of My Daughters

Irene Rabinor

In Honor of Rebecca Rabinor

Lenore Rodah

In Memory of Pauline Furth

This list reflects gifts received through March 15, 2015. If your name is missing, incorrectly listed, or misspelled, please accept our sincere apology, and contact our Membership Department at 202.682.2640.



NATIONAL WOMEN'S HEALTH NETWORK

A Voice for Women, a Network for Change

Nonprofit Org
U.S. Postage
PAID
Permit #1400
Suburban, MD

1413 K Street NW, Suite 400
Washington, DC 20005-3459

www.nwhn.org

Address Service Requested



Printed on 100% postconsumer waste paper. Minimally bleached and printed using soybean ink.

SNAP SHOTS

Girls who consume a lot of sugar-sweetened beverages (SSB) may menstruate earlier. Researchers conducted a prospective study of 5,583 girls aged 9–14, from 1996 to 2001. None of the girls had started their period when the study began; follow-up questionnaires were collected in 2003 and 2005. On average, girls reported having their first period (menarche) at 13.1 years. Those who consumed more than 1.5 servings of SSBs daily experienced menarche 2.7 months earlier, vs. girls who consumed SSBs 2 or fewer times per week. No association was found between naturally sweetened beverages and early menarche. Body Mass Index, a strong predictor of early menarche, explained 9.2% of the association between SSBs and early menarche. Girls who consume more SSBs may have a different overall diet compared to non-consumers, so other foods and nutrients might also have an influence. **Earlier menarche is a risk factor for breast cancer (a 1-year decrease in age of menarche may lead to a 5% increase in cancer risk); SSB consumption can be controlled, so reducing it might also reduce one's cancer risk.**

Human Reproduction, 2015

A new study suggests menopause may not be entirely responsible **for women's sleep problems.** Researchers followed long-term sleeping patterns of 255 women participating in the Penn Ovarian Aging Study from 1996 to 2012. At enrollment, the women were aged 35 to 48 and pre-menopausal; 28% reported experiencing moderate-to-severe sleep disturbances, 56% reported having no sleep problems. Among women who initially reported they had no sleep problems, 25% reported moderate or severe sleep disturbances during the study. Women with mild sleep issues had a bigger increase in poor sleep as they aged, compared to women who were already experiencing moderate or severe sleep issues when the study began. Women who experienced trouble sleeping in their 30s and 40s were 3 times more likely to have trouble doing so during the menopausal transition, compared to women who slept well when they were younger. While hot flashes are strongly associated with poor sleep patterns, a "large proportion of poor sleep in menopausal women occurred without hot flashes." Among women who experience poor sleep during menopause, other factors (i.e., health problems, anxiety, stress) may complicate getting a good night's rest.

Menopause, 2014

Want to avoid fractures as you get older? In addition to common-sense measures to reduce the risk of falling, women might also want to maintain their weight as they age. According to a study that followed more than 120,000 post-menopausal 50-to-79-year-old women for an average of 11 years, **unintentional weight loss led to higher risk of hip and vertebral fractures.** Women who lose 5% or more of their body weight without trying may have an underlying condition, like diabetes or cancer, and either the disease or treatment can weaken bones, and/or lead to falls. Women who intentionally tried to lose weight didn't increase their hip fracture risk, but showed a higher risk of lower limb fracture. Researchers aren't certain why this connection appeared. **Women who gained weight were less likely to experience a hip fracture, possibly because of extra padding, but had increased risk of fracture in their limbs.** Yet another reason to find a balance between food a activity and maintain a healthy weight!

BMJ, January 2015