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The Women's Health Activist®

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NATIONAL WOMEN'S HEALTH NETWORK
A Voice for Women, a Network for Change

DIRECTOR'S MESSAGE

The Network: Inside & Out

By Cynthia Pearson

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

"A lot has changed since the Network was founded 40 years ago. Women have more power and representation in civic and political life — but not nearly enough."

In 1975, the U.S. Supreme Court ruled that states had to allow women to serve on juries; Connecticut's Ella Grasso became the first woman governor who did not succeed her husband into office; and the Food and Drug Administration (FDA) had recently suspended sales of the Dalkon Shield IUD for causing infections and deaths among women who used it.

A lot has changed since the Network was founded 40 years ago. Women have more power and representation in civic and political life — but not nearly enough. The government and medical establishments pay attention to women's health needs and concerns — but not nearly enough. Too many women still lack access to the full range of information, services, and options. So, the Network continues to advance our vision of a just health system that reflects the needs of all women.

What does it take to keep an organization going — let alone thriving — for 40 years? A focus on important issues, first and foremost. If the cause that motivated an organization's early supporters doesn't continue to be important, neither will the organization. We are happy that women's health remains an important issue for so many (although we wish more politicians would join us in prioritizing evidence and science over anti-women dogma). It also takes support. The Network has chosen to build and nurture a membership base that provides a significant proportion of our financial support. In this way, we resemble many consumer advocacy organizations, and differ from most other patient/disease advocacy organizations.

Many of you have been Network members since the very beginning. We have several hundred members who joined the Network within our first decade as an organization and continue as active members today. We are honored by these members' continued confidence in — and support for — the organization and our work.

In the decades since our founding, both long-term members and those who have joined more recently have turned to the *Women's Health Activist (WHA,* formerly called the *Network News)* for accurate and timely information on important women's health issues. Even in this era where the Internet offers access to fast, free, and easily reached information, the *WHA* remains the place where the NWHN publishes in-depth articles.

This issue is no exception. It contains great articles on topical issues, with information that's hard to find anywhere else. Christina Cherel explains how an industry-funded PR campaign managed to pressure the FDA into approving a drug it had turned down twice before. Adriane Fugh-Berman gives our analysis of recently published results of a menopause hormone therapy study — results that contradict claims made by researchers in charge of the study. Of course, we're also proud of our website — in fact, we've launched a re-design that makes it more interactive and user-friendly. Learn more about the changes in our article on page 6.

In this issue of the *WHA,* we're also sharing information about the other things an organization needs to keep going for 40 years: a strong Board of Directors, and dedicated staff. The Network's Board has been cited as a model for organizations seeking to break out of the "friends elect friends" model of board service. CONTINUED ON PAGE 11

Do YOU Want to Join The NWHN Board of Directors?

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

The NWHN has a working board. Board members are expected to attend three weekend board meetings each year and to participate in fundraising and on at least one board committee. Meetings are held in various locations, including Washington, D.C. and California. For more information on board responsibilities and get a nomination form, please call the office at 202.682.2640 or visit the NWHN's website at *www.nwhn.org/board-nomination-form.* For a copy of candidates' statements from past elections, see *www.nwhn.org/candidate-statements-2014-board-elections.*

If you know someone who would make a good board member, or if you're interested in joining the NWHN board yourself, please send in a nomination!

Forms are accepted by:

- Fax: 202.682.2648
- Email: *nwhn@nwhn.org*
- Mail: NWHN, 1413 K Street NW, Suite 400, Washington, DC 20005

All nominations must be received in the NWHN office by **January 10, 2016**. Nominations received after this date will not be valid. All current NWHN members have the opportunity to vote for the new board during the Spring 2016 elections.

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Our Mission

The National Women's Health Network improves the health of all women by developing and promoting a critical analysis of health issues to influence public policy and support consumer decision-making. The Network aspires to a health care system that is guided by social justice and reflects the needs of diverse women.

The Women's Health Activist® is a 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.*

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KEEPS on Keeping On

By Adriane Fugh-Berman, MD

The myth that menopausal hormone therapy prevents heart attack and dementia should have died a swift death after the definitive results of the Women's Health Initiative (WHI) a dozen years ago. But the concept that hormones might prevent some disease — in some women, somewhere, sometime, somehow — just keeps rising from the grave.

The Kronos Early Estrogen Prevention Study (KEEPS) is the name of an unnecessary trial that was conducted by hormone enthusiasts after the WHI proved that the harms of menopausal hormone therapy (including increased risks of breast cancer, heart attacks, strokes, and dementia) outweighed its only disease prevention benefit — a reduced risk of fractures.

The research question explored in KEEPS was based on the ludicrous "timing hypothesis." This implausible hypothesis posits that, although healthy women given menopausal hormones experienced no disease prevention benefit, a benefit *might* be revealed if hormones were given to women who were close to the menopausal transition rather than to older women who went through menopause many years earlier. This was always a faulty foundation for a study because the average age of menopause is 51 and the WHI had *already* studied more than 5,000 women in their 50s — and found no such benefits. (For background on the claims made by KEEPS researchers, see "Two Years Too Late: Researchers Announce Hoped-For Results, Stall on Revealing Actual Data" at *https://www.nwhn.org/two-years-too-late-researchers-announce-hoped-for-results-stall-on-revealing-actual-data.*)

National Women's Health Network (NWHN) members know that the NWHN has been the most important and effective force for questioning claims for hormone therapy's benefits, and demanding that the right studies be done to assess the impact on women's health. Our efforts helped launch the WHI, a large, long-term, federally-funded, randomized controlled trial that examined the risks and benefits of hormone therapy in more than 26,000 women.

Let's review what the WHI found:

- Starting in 1991, more than 16,000 women took either an estrogen/progestin combination (Prempro) or a placebo. In 2002, this study was stopped early because women taking the combined pills experienced harm, including higher rates of invasive breast cancer and heart attacks.[1]
- Another arm of the WHI study tested an estrogen-only hormone therapy (Premarin) against placebo in more than 10,000 women. All of the women had had hysterectomies, so they did not need a progestin to protect their uterus from estrogen-induced cancers. In 2004, the WHI's estrogen-only arm was stopped because an increased risk of stroke was found among women taking the hormones.[2]

"We've said it before and we'll say it again: The risks of menopause hormone therapy overwhelmingly outweigh benefits for menopausal women."

These findings have been verified by other research. A systematic review of the WHI and 22 other randomized controlled trials of menopausal hormone therapy use, involving a total of 42,830 women, found that estrogen-progestin combinations increased the risk of a cardiac event; blood clot; stroke; breast cancer; gallbladder disease; death from lung cancer; and, in women over 65, dementia.[3]

Although there was little point

in doing a smaller, limited study after the large, comprehensive WHI study showed no benefit, the KEEPS researchers, many of whom had received payments from hormone manufacturers, randomized 727 recently menopausal women (with an average age of 52.6, and 1.4 years past their last menstrual period) to either a placebo or oral or transdermal (skin patch) estrogen with micronized progesterone. Notably, the progestin in this study was different than that used in the WHI — some alternative medicine practitioners have touted micronized progesterone as a better "bioidentical" hormone. These women were followed for four years. Hormone therapy failed to benefit measures of cardiovascular health and — in recent news — failed to have any benefit on cognition in a large substudy that included 693 women.[4]

All of the KEEPS findings are consistent with the results from the WHI and other randomized controlled trials — except that KEEPS found a minor mood-elevating effect in non-depressed women who took oral (but not transdermal) estrogen. There was *no* effect on real depression. (WHI, on the other hand, found no benefit of hormones on symptoms of depression or any other quality-of-life measures.)

When even the most loyal hormone enthusiasts can find no benefit of hormone therapy, it's time to give up searching. The concept that hormones will benefit some woman, somewhere, if we just gave the right dose and mix of at some crucial — but elusive — moment is magical thinking. At this point, anyone who believes that menopause hormone therapy benefits women's hearts or brains believes something that is inconsistent with science.

We've said it before and we'll say it again: The risks of menopause hormone therapy overwhelmingly outweigh benefits for menopausal women — excepting those who have severe hot flashes or vaginal dryness, which estrogen helps.

The KEEPS results should drive the final nail in the coffin of the myth that menopausal hormone therapy has health benefits that outweigh its risks. So, why do we have the lurking sense that someday, the specter of hormone benefit will rise from the dead again to haunt us?✤

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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.

The NWHN at the FDA

From the White House to Capitol Hill, you can count on the NWHN to stand up and make sure women's voices are heard loud and clear. To this end, the NWHN frequently attends meetings at the Food and Drug Administration (FDA) to provide our comments on specific drugs and devices and the agency's guidelines for testing and approval. On **September 24,** NWHN staff testified at the FDA about the Essure device for permanent birth control. We spoke about the importance of informing scientific research with women's real, lived experiences. This wasn't our only recent FDA visit. On **November 4,** we head to the FDA to comment on guidelines for approving osteoporosis drugs; on **November 9,** staff will attend a public meeting and speak about adverse drug interactions with hormonal contraception (like flibanserin's). We work hard to ensure that Federal regulations of drugs and medical devices are attentive to women's needs, not pharmaceutical industry interests. Stay tuned for upcoming articles conveying the results of these meetings — we'll feature an article on Essure in the January newsletter!✤

Alternative Approaches To Address Menopausal Symptoms

The most common complaint among women going through the menopausal transition is about hot flashes and night sweats. Given the risks of menopause hormone therapy, many women seek alternative approaches to controlling these problems. These include:

- Following a low-fat diet, which has been found to help with menopausal symptoms and has the added benefit of reducing the risk of ovarian cancer.
- Losing weight, regardless of what type of diet is used, helps reduce menopausal symptoms.
- Getting enough exercise, which helps with symptom control (especially for very active women). Research indicates that physical activity, including yoga, helps with symptoms including hot flashes and pain. Exercise can also reduce stress and the risk of breast cancer, and improve mental health and bone density.
- Taking anti-depressants, which have been shown to help with hot flashes. It appears that venlafaxine (Effexor) and paroxetine (Paxil) are the most effective anti-depressants for treating hot flashes. Paroxetine is now available in a repackaged formula at a lower dose than used for treating depression.
- Exploring other drug therapies; potential hot flash treatments include the anti-seizure medication gabapentin and the blood pressure drug clonidine.

Lifestyle factors not only work for menopausal symptoms, but also have other health benefits as well. Non-hormonal drug therapies are also an option, but should be approached with caution until more is known about their long-term effects.

Finally, if you're considering using hormone therapy for symptoms, start with the lowest dose possible, and make sure you're familiar with the warning signs of complications, such as blood clots and stroke. While rare, these complications are serious and even life-threatening. For references and more information, see our article from the November 2014 issue of the *WHA,* at *https://www.nwhn.org/non-hormonal-alternatives-for-menopausal-symptoms.*✤

NWHN Launches New Website!

For 40 years, the National Women's Health Network (NWHN) has delivered information and analysis to help women's health activists advocate on behalf of themselves and their families. Our members and supporters know that the NWHN is a reliable source for evidence-based information. We are happy to announce that — in order to make sure women have access to the information they need — we have recently re-designed and re-launched our website.

The site's new look and updated features will allow our members to become more engaged with our work. (The address is the same: *www.nwhn.org.*)

What can you do through the new site?

- **Get the facts.** The website has a wealth of health-related information including Fact Sheets and background information on important issues, as well as articles from the *Women's Health Activist.*
- **Share your story.** Have you faced obstacles accessing quality health care? For the last 40 years, we have made sure that women's voices are heard. Now we want to hear your story and learn about any health care-related issues you may be facing.
- **Become a member.** By joining us, you become an integral part of a trusted organization and will receive a one-year subscription to our bi-monthly newsletter, the *Women's Health Activist.*
- **Subscribe to our email list.** You will always be up-to-date on what we have to say about cutting-edge and critical women's health issues.
- **Share our content.** If you like what you read, leave a comment and share the content with your activist network.
- **Connect with us on social media.** Stay connected with us on Facebook, Twitter, and Pinterest to keep up-to-date on the latest in women's health news.❖

The Network is thankful for the support of its members, and we hope our new website reflects our appreciation!

Loyal *Women's Health Activist* readers, we have a fun challenge for you that involves a few quick clicks around our new website!

The first five individuals who complete the challenge and submit correct answers to the following questions will **receive either a one-year NWHN membership or gift membership** for someone else. Please send your answers to *nwhn@nwhn.org.* If you win, we'll email you!

1. Who are the Network's founders?
2. What are the current advocacy priorities for the Challenging Dangerous Drugs and Devices Campaign?
3. What are two of the many ways you can get involved with the Network?
4. True or False: Female Sexual Dysfunction is one of the Network's advocacy issues?

Flibanserin: The FDA's Approval is Bad Science and Bad Precedent

By Christina Cherel, MPH

This year, the Food and Drug Administration (FDA) made history — for all the wrong reasons. After a five-year battle for approval, on August 18th, the agency succumbed to a relentless and clever public relations campaign and approved flibanserin, the first drug to treat hypoactive sexual desire disorder (HSDD) in women. That means that, as soon as October 17th, flibanserin will be available by prescription for premenopausal women with HSDD under the trade name Addyi. Despite proponents' claims, this approval is not a monumental event for women's sexual rights. The medicalization of sexual desire and sexual behavior should not be celebrated as revolutionary. We understand very little of what is "normal" for women when it comes to sexuality, so why is the FDA approving a drug to treat a disorder that may not be a disorder after all?

Viagra's approval and subsequent rocket sales in the 1990s prompted a race to create a "pink counterpart" for use by women. For more than 15 years, the pharmaceutical industry has been trying to produce a drug to treat women's sexual problems. But, sexual dysfunction drugs for women are critically different than drugs like Viagra for men. Whereas Viagra helps men who *already want* to have sex but are physiologically unable to do so, flibanserin changes brain chemistry to help women want to *want to* have sex. The FDA had good reason to reject these drugs in the past — because they *just don't work.* Very little is known about women's sexuality. We do know that many of women's sexual problems are shaped by interpersonal, psychological, and social factors, which cannot be easily regulated by taking a daily pill.

The FDA rejected flibanserin twice before — in 2010 and 2013 — because it was clear to Federal reviewers that *it simply didn't work.* The drug's sponsor, Sprout Pharmaceuticals, Inc., had to change its own definition of effectiveness to show even modest (at best) improvements in sexual desire outcomes. The FDA's own internal investigation of flibanserin indicated there were many unresolved questions about the seriousness, severity, duration, and frequency of the drug's side effects. Women reported experiencing sudden prolonged unconsciousness, and serious blood pressure declines with dystolic readings in the 40s. These serious adverse reactions were uncommon, but raised troubling questions about the safety of this drug. Also, flibanserin clinical trial data revealed higher dropout rates among women who were randomized to take flibanserin versus a placebo. The discrepancy in dropout rates between the case and control arms of the trial isn't trivial. For the FDA's Advisory Committee and staff, flibanserin's minimal effectiveness did not justify the drug's potentially devastating complications.

Then came a misleading campaign called "Even the Score," which enlisted women's health advocates, organizations, and even Members of Congress to call for "gender parity" in sex drug approval. The campaign claimed that men had 26 drugs to treat sexual dysfunction and women had 0, a gross exaggeration and manipulation of the actual numbers (tactics included counting all generic drugs separately to make the discrepancy look bigger than it is). The campaign implied the FDA's review of flibanserin's application was sexist, and that it held women's sex drugs to a higher approval standard than men's. Requiring sound clinical trials and proof of safety and efficacy isn't sexist — it's good science.

"...in its 25-person study, Sprout was "only able" to recruit two women who consumed moderate amounts of alcohol to test its effect. So, the company conducted an alcohol study conducted primarily in men to assess flibanserin and alcohol's effect in women."

The FDA was right to reject this drug twice before; unfortunately, the marketing campaign swayed the FDA the third time around. (Read more

CONTINUED ON PAGE 11

YOUNG FEMINIST

The Political is Personal: The Impact of the 20-week Abortion Ban

By Zoe Kusinitz

My first job out of college was as a clinical assistant at an abortion clinic. Although not a topic I drop into casual conversation, it is something about which I am fiercely proud. "The personal is political" is a hallmark of the reproductive justice movement — and one that remains unwaveringly true. But, the reality I discovered while working at the clinic is that *the political is personal.*

Law after insultingly cruel law is proposed, and too often passed, restricting access to abortion care. When news of the latest heinous law breaks, many of my comrades in the reproductive justice movement — especially those engaged in national policy work in Washington D.C. — curse the selfish and disconnected politicians who promote them, and struggle to comprehend the impact on the millions of women who are now a little less safe and a little less equal.

Along with the cursing and incomprehension, I see the faces of the women whose lives are impacted by these laws. I see flashes of the young mail-order bride who came to the clinic seeking an abortion so she could distance herself from her abusive spouse. I see the awkward teenager with the eyebrow piercing, who was able to receive treatment for cervical dysplasia because it was detected at the time of her abortion. I remember the hands held, tissues offered, and jokes cracked to break awkward silences. I remember the unshaved legs and manicured toes in purple padded stirrups and the women they belonged to.

And then, my stomach knots, when I remember why I am remembering these women and their stories: some new restrictive law or policy that makes these real human's lives worse.

In May 2015, the House of Representatives passed H.R. 36, the Pain Capable Unborn Child Protection Act.[1] This bill would ban abortion after 20 weeks post-fertilization, based on the scientifically unfounded idea that fetuses at this stage can feel pain.[2] The legislation contains no exception for a woman's health or fetal anomalies, and has mercilessly narrow rape/incest exceptions. This bill, a version of which already exists in 11 states,[3] is egregiously cruel, counter to medical evidence, and arguably unconstitutional. Thankfully, in September, H.R 36 failed in the Senate.

If this bill became law (which happily is unlikely as long as Democrats hold the White House), a woman with a life-threatening condition would be forced to wait — against medical judgment — until she is dying to terminate her pregnancy after 20 weeks, rather than intervene when her condition is less severe and the procedure is safer. This makes a sham of the "life of the mother" exception. Evidently, the preservation of a woman's health does not warrant intervention — only when she's on her deathbed could doctors be allowed to practice lifesaving medicine, say the Republican lawmakers behind this bill.

It would mean that a woman who has an anomaly scan (typically performed between 18–20 weeks of pregnancy)[4] that reveals a fetal anomaly so debilitating it is incompatible with life would be forced to carry that pregnancy to term only to lose her child hours after birth. It would mean that any woman seeking her constitutional right under *Roe vs. Wade* to access abortion before viability (usually deemed to occur at 24 weeks post-fertilization) will be barred from doing so.[5]

The situations described above are hypothetical and, intangible; the real people whose stories are represented by these scenarios remain, too often, unknown to us, and voiceless.

So let me tell you about Sarah.*

Sarah came into the clinic with her husband, devastated but composed. She was devastated because this was the day she would end her wanted pregnancy. She was composed because, with the support of her husband and expertise of her doctor, she had decided that this was the best option for her, her husband, and the child they wanted but would never know.

One week prior to this frigidly cold cloudy morning, Sarah and her husband went to their doctor for an ultrasound. This procedure is used to scan for conditions that indicate chromosomal abnormalities and irregular development that are not detected in earlier diagnostic tests. During Sarah's ultrasound, performed in her 20th week of pregnancy, her doctor detected a previously unnoticeable abnormality — a severe fetal heart defect. This defect guaranteed a short and brutal life for Sarah's baby, a life that would begin and end in the Neonatal Intensive Care Unit (NICU) over a matter of days.

Sarah and her husband only had a few weeks to decide how to proceed before they would not longer have the option to terminate the pregnancy, because Minnesota limits abortion after viability to procedures necessary to preserve the mother's life and health.[6] (This choice would also be prohibited under H.R. 36.)

So, a week after the ultrasound that changed their lives, Sarah and her husband arrived at the clinic, heart-broken but resolved to end the pregnancy with a D&E procedure. I was with Sarah during her two-day procedure. I held her hand while the doctor dilated her cervix to begin the procedure. The next morning, I stroked her hair while the doctor completed the procedure. And I sat with Sarah and her husband as they said a sorrowful goodbye to their baby.

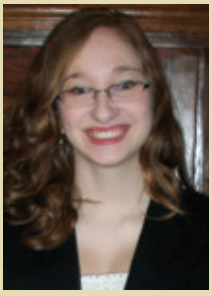
Sarah is just one patient. She is just one story. She is among the *one percent* of women whose abortion occurs after 20 weeks,[7] a number that illustrates this choice springs not from spontaneity or indecision — but from complex and often unforeseen circumstances.

When the House of Representatives passed H.R 36, I saw Sarah's face.

It is because of patients like Sarah that I understand the gravity of the damage caused by callous and calculated politicians and their transparent agendas. These politicians are not protecting women's health — they are forcing women to the brink of death before allowing doctors to intervene. They are not sparing developing fetuses from pain — the scientific evidence doesn't support their fabricated claims. They are simply gearing up to tear down *Roe vs. Wade* and they are willing to sacrifice Sarah's autonomy and safety to do so.✤

**The woman's name has been changed to protect her privacy.*

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



Zoe Kusinitz is a recent graduate of Macalester College with a degree in Psychology and Women & Gender Studies. She is a trained abortion doula and a passionate defender of reproductive justice.

Longtime Network member Meika Loe continuously takes advantage of the matching gift program doubling the value of her contribution to the Network.

Employee Matching Gift Programs

The Network has always said "no" to BigPharma money because we know who we are accountable to — our members. But, for that reason, the growth and sustainability of our advocacy campaigns is dependent upon the support of thousands of individuals. As we challenge dangerous drugs and devices, secure sexual and reproductive health rights, and expand access to health care, it's important that we are able to **make each and every dollar** count.

Did you know that you can help us raise more money when you leverage your donation through matching gift programs?

Find out if your employer offers a matching gift program by checking its website or going to your Human Resources or Payroll Departments. As many as one in ten corporations and educational institutions offer Matching Gift programs for their employees. By taking advantage of this benefit, you can double — or even triple — the value of your contribution to the Network!

If your employer matches donations, you will want to learn the specifics about donation guidelines, eligible charities, and how to sign up for the process. Once you find out how to enroll, simply complete the process by telling your company that you'd like it to match every donation you make to the Network. Your employer will contact us, or instruct you to contact the Network directly, so we can verify that we received your donation. The company then issues a matching gift contribution to the Network. It's just that simple!

Longtime supporter Meika Loe continuously utilizes her employer's matching gift program: "The Network has been a huge help to me both personally and politically. I have utilized Network resources for family members who are having a hard time finding women's health research on topics that are important to them. I have used the newsletter in my college courses on women's health. And as a medical sociologist, I have worked in tandem with the Network on women's health activism, lobbying the Food and Drug Administration to block the rush for the next female Viagra. When my husband and I give to the Network, we want our dollars to really make an impact, so we always ask his employer to match our donation — and they do."

"When my husband and I give to the Network, we want our dollars to really make an impact, so we always ask his employer to match our donation — and they do."

Employee matching gift programs are a great way to maximize your personal contributions to the Network and amplify your gift's impact. We are happy to help with this process. If you have questions, please contact our Membership Department at *membership@nwhn.org* or 202.682.2640.✤

TICKETS ARE STILL AVAILABLE!
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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.

Monday, November 16, 2015
6–8 pm
The Whittemore House
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Washington, DC

GUEST SPEAKER

Judy Norsigian
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HONORING

Loretta Ross
Co-founder SisterSong

Laura Kirkpatrick
Chapter Leader, Class of 2017 Medical Students for Choice chapter organized by students at Georgetown University

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Bending the Old Saw

By Laura Kaplan

There's an old saw that says: The right cares only about individuals and not about people in the aggregate, while the left cares only about people in the aggregate and not about individuals.

Sadly, in my own life, the old saw has all too often been true. When my cousin was diagnosed with pancreatic cancer, the right-wing think tank he worked for (the kind of place that likes to "prove" that class size does not affect student performance) kept him on full-time salary until his death, even though he could not go in to the office. A few years later, when my mother was diagnosed with ovarian cancer, the good guy lefty organization I worked for showed no such care. Ten days before my mother died, and just before Christmas, they told me I would be laid off as of January 1st.

Recently a dear friend in her 60s, who is a lifelong mental health professional, left her State job to work for a not-for-profit mental health agency in a supervisory position. She took a $10,000 pay cut and, on top of that, only gets 2 weeks paid vacation for the next few years.

I could go on with examples in this vein, but my point here is not to flood you with stories. What I'd like is for those of us who run progressive organizations, or sit on their boards, to look critically at the way our employees are treated. We who work for small organizations in the not-for-profit world know all too well that our options for financially compensating staff are severely limited: we just can't raise enough to pay people what they might make in larger organizations or in the for-profit world. Often, we can't even hire enough people to adequately staff our organizations. As a result, we expect the people we hire to put in more than 100 percent, working long hours and taking on many responsibilities.

We don't have any choice. We can only spend what we can raise. But we **do** have a choice about how we structure work and benefits to reflect the value we place on our staff. If non-profit leaders ask people to work for us, on what are essentially *our* projects, we better find ways to let staff know they are not expendable and that their efforts are valued. There are ways to do this that will not upend our budgets.

We want staff members to take ownership of their work, and to create plans to accomplish their goals. Targeted staff meetings or one-on-ones can help people explore their ideas. If we solicit staff input this way, we have to believe that the people who do the work have insights leadership might not have into how to improve, enhance, or enlarge the impact of their work. We also can examine supervision and interpersonal dynamics. Is the person being supervised getting what she needs? Is she being respected? Are office tensions that are unaddressed affecting staff's work?

Making sure staff know that their input and perspectives are respected is not easy. To complicate matters, there are unstated power dynamics at play. Who has the power? Whose position is considered more valuable? Do people feel that their jobs will be jeopardized if they speak honestly?

Generous and creative benefits are another way to recognize the value of our workers. Increasing vacation time is an easy way to do this. Let's not make our decisions about what to offer based on what similar non-profit organizations do, but rather on the needs of people to recharge and rest from what is often hectic, high-pressure work. Personal leave, sick time, family medical leave, and flextime are all benefits that we can expand to enhance the workplace environment.

The NWHN has a benefit that I think is excellent: the organization provides a transit benefit to all its employees. The benefit is a monthly stipend that offsets the cost of transportation for staff. Although this type of thing adds to the budget, it is minimal compared to the good will it generates.

One of my pet peeves is unpaid lunchtime. Many non-profit organizations do not pay for their fulltime employees' lunch breaks. A regular day is considered to be 9:00 am to 5:30 pm, or some version of that. I urge Executive Directors and boards to revisit this. It adds value to people's work experience if we can simply include lunch breaks in their paid time.

These are just a few ideas. I haven't even mentioned retirement accounts, or Flexible Savings Accounts (FSAs) for health care expenses that are not covered by health insurance, or even health insurance. I'm interested in your ideas, as both leaders and staff, about ways to improve the work environment. Contact me and perhaps, in a future newsletter, we can include your innovations in these areas. Let's find new ways to bend, if not break, the old saw.✤

Laura Kaplan is a lifelong women's health activist and the author of The Story of Jane. She is a former NWHN board member.

DIRECTOR'S MESSAGE
The Network: Inside & Out

FROM PAGE 2

Network members play a big role in determining who serves on the Board: you're eligible to submit nominations for Board candidates, and cast your ballot for the candidates you think are best for the organization. This issue includes information about Board nominations: if you're interested in serving on the Board, or know someone who would make a great board candidate, turn to page 3 for more information.

And finally, our dedicated staff. When staff members come or go, we often take a moment to tell you a little bit about them, or thank them for their years of service. But, we rarely talk about what we do internally to support these fantastic individuals. Laura Kaplan presents an interesting commentary about the ways non-profit organizations can support staff beyond paying good salaries. She mentions the Network's transit benefit as an example of a creative way to support staff.

Thank you being our supporters and our partners…and for giving us a chance to share the Network — inside and out.

Flibanserin: The FDA's Approval is Bad Science and Bad Precedent

FROM PAGE 7

about the campaign in the *Women's Health Activist's* March/April 2015 issue.)

Despite the drug's approval, there are lingering concerns. The FDA expressed special concern about flibanserin's ability to drastically reduce blood pressure and the implications for women who consume alcohol while taking it. Based on these concerns, in 2013, the FDA recommended that Sprout provide further evidence of flibanserin's safety, specifically regarding its interaction with alcohol and its effect on driving ability. Flibanserin is taken on a daily basis indefinitely; hence, many women who take it are likely to have a drink at some point — and they absolutely need to know what the side effects will be.

Inexplicably, in its 25-person study, the sponsor was only able to recruit **two** women who consumed moderate amounts of alcohol to test its effect. So, the company conducted an alcohol study conducted primarily *in men* to assess flibanserin and alcohol's effect ***in women***. The FDA required Sprout to conduct post-approval trials testing the safety of using alcohol while taking flibanserin. This is a weak and inadequate measure to ensure the safety of women who use the drug, particularly since, historically, a substantial proportion of post-approval trials are never completed — despite being a condition of approval. There are many unanswered questions about how the drug will interact with hormonal contraception and many other common medications, as well.

Women experiencing distress as a result of unsatisfying sexual lives deserve to have their concerns taken seriously — but at what cost to their health? Some flibanserin proponents argue that fainting isn't a serious side effect and that women should be able to decide if the risks are worth the drug's minimal efficacy. Fainting while you are driving, however, could be fatal and is not simply a matter of inconvenience.

Women must be able to rely on the FDA to ensure that any drugs or devices marketed to, and used by, them are safe and effective. Flibanserin's approval set the dangerous precedent that clever marketing can sway the FDA's evidence-based, decision-making process even when the data reveal minimal efficacy and serious adverse events.

Despite the FDA's approval, women still do not have all the information they need to make informed decisions about flibanserin's safety and effectiveness. Women deserve better research that examines the causes of, and possible treatments for, sexual disorders. And, we need more research on sexuality in general, since we currently do not understand what is "normal" for women and men to experience throughout their sexual lifetimes. Sexual experiences can be a meaningful part of life, and help should be available for those who need it. In the future, it may be possible to develop a drug that's effective for some of women's sexual problems. We're not there yet, however.

Christina Cherel is the NWHN Program Coordinator

In Honor Of & Memorial Donor List

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

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SNAP SHOTS

Trust but verify, indeed. A new study finds a **significant drop in positive clinical trial results in the years since the launch of the Federal *clinicaltrials.gov* registry in 2000.** The registry requires researchers to record their methods and outcome measurements *before* they collect data, and has been hailed as a victory for transparency and accuracy. Researchers can no longer cherry-pick the data they report in order to match and validate a desired result. In a sample of 55 trials testing heart-disease treatments, **57% of trials published before 2000 had positive results, compared to just 8% of those published after 2000.** The authors assert that this registration of clinical studies has led to more "rigorous research." **The finding raises questions about positive clinical trial results published before the registry took effect, including the risk that "at least half of older, published clinical trials could be false positives."**

Nature, August 2015

Chemotherapy may be a thing of the past for some women with early-stage breast cancer. **A new study finds that gene-activity tests can accurately identify women whose cancers are likely to respond positively to hormone-blocking drugs and who, therefore, get no additional benefit from chemo.** The study included 10,253 women with early stage, hormone-positive breast cancer; 16% were classified as "low-risk" for cancer recurrence, 67% as "intermediate risk," and 17% as "high-risk." Among low-risk women, who received drugs instead of chemo, less than 1% had a cancer recurrence and 94% were free of invasive cancer after 5 years. These results were so significant that they were released early. Researchers continue to assess outcomes in the "intermediate risk" group, who were randomized to receive either hormone-blocking drugs only, or both drugs and chemo. **The ability to avoid unnecessary chemotherapy is great news,** since the treatment also has health risks and harmful side-effects.

New England Journal of Medicine, September 2013

We've long known that White women are more likely to be diagnosed with breast cancer, but **Black women are more likely to develop — and die from — aggressive, hard-to-treat breast cancer.** These differences are **not all due to socio-economic factors (like access to care), and show clear genetic patterns.** New research examined information from women diagnosed with cancer between 1988 and 2013; the study examined exome sequencing (exomes are the protein-coding genes) and gene expression data from 663 and 711 White, and 105 and 159 African American women, respectively. The results found that, overall, Black women's tumors were more likely to have a variety of genetic mutations, many of which are linked to more aggressive forms of cancer. These results may pave the way for the development of **targeted treatments for the tumor subtypes that disproportionately affect Black women, and help reduce the racial disparity in breast cancer outcomes.**

Journal of Clinical Oncology, September 2015