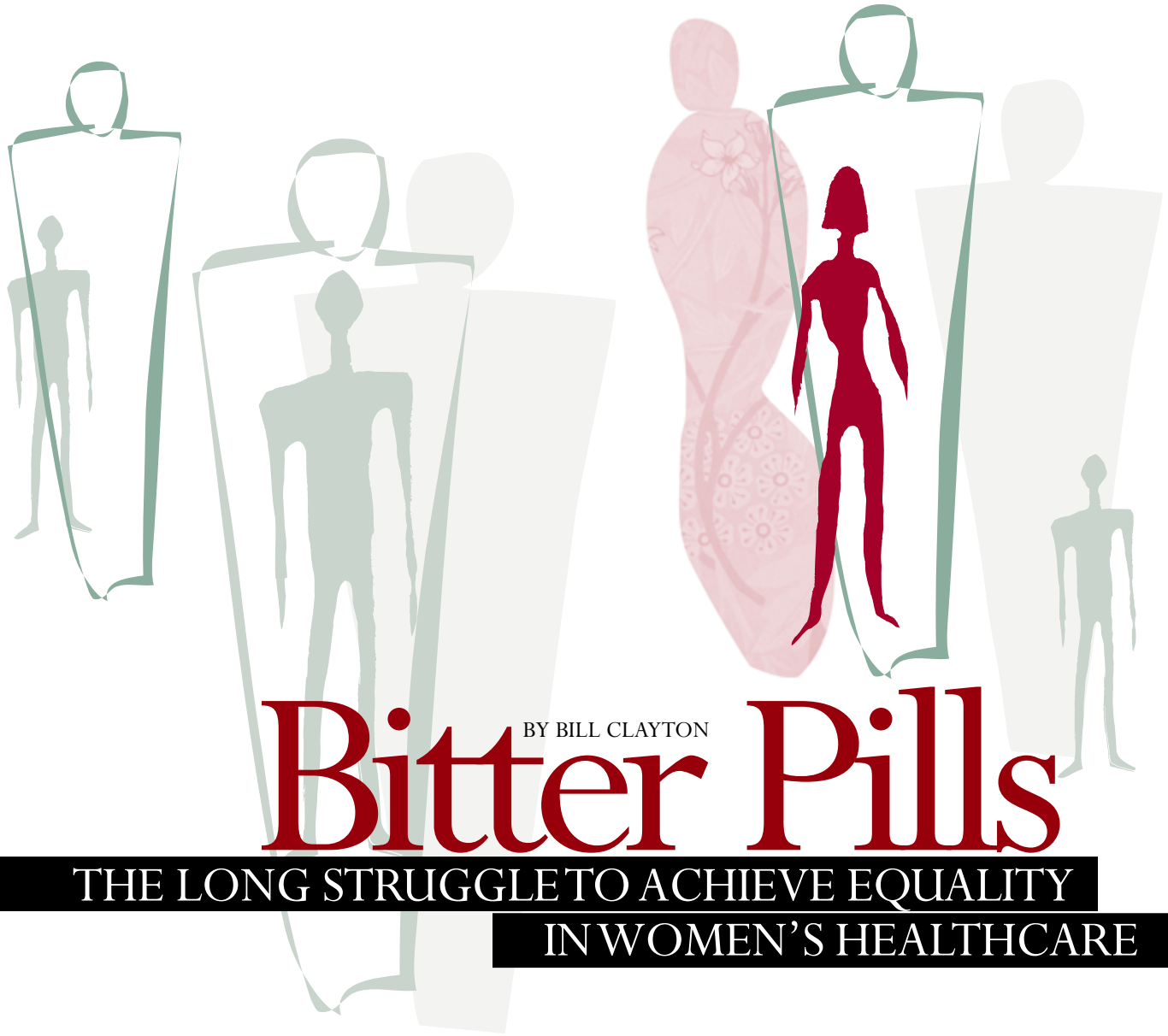

BY BILL CLAYTON

Bitter Pills

THE LONG STRUGGLE TO ACHIEVE EQUALITY IN WOMEN'S HEALTHCARE

Just about the time Madelon Stockwell walked onto the U-M campus to become the University's first female student, a 56-year-old woman by the name of Lydia E. Pinkham was 1,000 miles to the east, throwing herbs and alcohol into a pot on her kitchen stove.

Madelon Stockwell

The year was 1870. For Madelon Stockwell and the University of Michigan, it was the beginning of a new chapter in an awakening women's movement. For Pinkham, a pioneer in the pursuit of women's health and social rights, it was the start of a new phase in women's healthcare, because she was brewing an elixir that would become the most successful patent medicine of the century, and would affect women and women's healthcare in ways no one could imagine — then or now.

In those days, doctors believed that almost all of women's sicknesses arose from their reproductive organs. So, gynecologists removed them to "eliminate a woman's fainting spells, hysteria and sexual desires." They removed healthy ovaries for little or no reason — a practice that had a mortality rate as high as 40 percent. And, as if to demonstrate how embarrassed they were at their own ignorance, doctors conducted basic gynecological exams by reaching up under a woman's skirts as she stood there, fully clothed.

Then Lydia Pinkham burst on to the scene, telling women to stop visiting doctors; exercise; eat fresh fruits, vegetables and grains; and take her herbal formula — "Lydia E. Pinkham's Vegetable Compound."

Ads called the potion "a sure cure for prolapsus uteri, or falling of the womb, and all female weaknesses including leucorrhoea, irregular and painful menstruation, inflammation and ulceration of the womb, flooding…for all weaknesses of the generative organs of either sex, it's second to no remedy that has ever been before the public, and for all diseases of the kidneys it's the greatest remedy in the world."

Pinkham's potion flew off the shelves. Why? Because in its many ads, it promised a woman what doctors couldn't: relief from pain; happiness borne of good health; reproductive assistance; and a way to get healthcare without putting herself in the hands of men, who seemed to control everything, not just medicine.

By the mid-1920s, women had won a number of social and political freedoms, but they still lived in the shadow of men. Feminism had strong undercurrents throughout the next several decades, but didn't flower until the 1960s and 1970s. The Supreme Court included women in the 1964 Civil Rights Act. Not long after, the Court declared that abortion was legal. Women battled for equal pay, federal support for day-care centers, recognition of lesbian rights and protection from rape and the abuse of wives and children. Unfortunately, a lot of those advances existed in name only. What might best summarize the conditions that women still faced was a speech at a 1972 American Psychological Association conference about covert sex discrimination against women as medical patients.

Feminist, author and pro-abortion lawyer Carol Downer stepped up to the microphone. "In what has been described as the 'rape of the pelvis,'" she said, "our uteri and ovaries are removed, often needlessly. Our breasts and all supporting muscular tissue are carved out brutally in radical mastectomy. Abortion and preventive birth control methods are denied us unless we are a certain age or married, or perhaps they are denied us completely. Hospital committees decide whether or not we can have our tubes tied. Unless our uterus has 'done its duty,' we're often denied. We give birth in hospitals run for the convenience of the staff. We're drugged, strapped, cut, ignored, enema-ed, probed, shaved – all in the name of 'superior care.' How can we rescue ourselves from this dilemma that male supremacy has landed us in? The solution is simple. We women must take women's medicine back into our own capable hands."

And they did.

Taking Control

The women's movement slowly brought about many of the changes that it was after — not always with good effects. The newfound independence that today's women enjoy has made them more susceptible to chronic diseases and other health concerns, including cancer, heart disease, stroke, osteoporosis, diabetes, workplace and household injuries, and sexually transmitted diseases.

So, now the movement is challenging doctors, researchers and administrators to reverse these tendencies, and healthcare and medicine are taking on a new look as a result.

Today, medicine is no longer just a man's world. For example, though men still dominate the ob-gyn field — about 64 percent of the doctors practicing obstetrics and gynecology are male — most of the doctors now training in the specialty are ➤

TEN WAYS GENDER DIFFERENCES CAN AFFECT HEALTH

1. **After women and men consume the same amount of alcohol, women's blood-alcohol content is higher than men's — even allowing for size differences.**
2. **In a sample of women and men who smoke the same number of cigarettes, women are 20 to 70 percent more likely to develop lung cancer than men.**
3. **Women come out of anesthesia more quickly than men — it takes women an average of seven minutes to awaken; men, an average of 11 minutes.**
4. **Women get more pain relief than men when taking pain medications known as kappa-opiates.**
5. **Women are more likely than men to suffer a second heart attack within one year of their first heart attack.**
6. **In taking the same drugs — even everyday drugs such as antihistamines and antibiotics — women and men can experience different reactions and side effects.**
7. **Despite the fact that women have stronger immune systems to protect them from disease, women are more susceptible to autoimmune diseases such as rheumatoid arthritis, lupus, scleroderma and multiple sclerosis.**
8. **After unprotected intercourse with an infected partner, women are twice as likely as men to get a sexually transmitted disease, and 10 times more likely to contract HIV.**
9. **Depression in women is two- to three-times more common than in men. This statistic is due, in part, to the fact that women's brains produce less of the hormone serotonin.**
10. **Post-menopausal women lose more bone than men. One result of this is that women constitute 80 percent of the total population of people with osteoporosis.**

Source: Society for Women's Health Research

women. This year, women have filled 70.3 percent of the nation's ob-gyn residencies, compared with slightly less than half 10 years ago. And the shift is increasing.

Allen Lichter, M.D., dean of the Medical School, has been involved in women's health issues for a long time. He spent the early part of his career in radiation oncology, focusing largely on gynecologic cancers, and the second half of his career to-date dealing primarily with breast cancer. He cares deeply about the issues of women's healthcare.

"There's a great deal to say about the important role women have played in influencing the way medicine looks at their healthcare," he says. "I think probably the most striking example is the change in the way breast cancer is managed, moving from mastectomy to lumpectomy and radiation therapy. This was not a treatment that researchers developed in the laboratory and then tried out on mice and then tried out on rabbits and then finally made an announcement that they were ready to try it on people. This was something that our patients dragged the medical profession to, at least in the late '70s and early '80s, over tremendous resistance from classical practitioners. It took tremendous courage for women to say they wanted to be treated in this newer way, when so much of traditional medicine was telling women that, by not being treated with standard mastectomy, they were literally risking their lives. So we owe a tremendous amount of respect and admiration to women who helped show us that we could manage an important illness like breast cancer in a fundamentally different way."

Women's Healthcare at U-M

At the University of Michigan, gender awareness has created an entirely new dynamic in the U-M Health System. Timothy R.B. Johnson, M.D., Bates Professor of the Diseases of Women and Children and chair of the Department of Obstetrics and Gynecology at the U-M Medical Center, says that the University "has a strong reputation for gender studies — Michigan is seen as a leader. Last year our Women's Health Program was ranked among the top 10 in the country, and I think justifiably so."

One pivotal reason for that success has been the Program's interdisciplinary approach to patient care, educational programming, and gender-specific resources and research.

Photo: Martin Vloet

Juliet Rogers

Photo: Bill Wood

Timothy R.B. Johnson

Juliet Rogers, director of the Women's Health Program in the U-M Health System and a Ph.D. candidate in Health Management and Policy at the U-M School of Public Health, says that the Program, established in 1994, "doesn't benefit one single department, but it truly benefits the women who come to us as patients and as community partners. It's unique. Other institutions have tried to set up something multidisciplinary, but haven't been successful. We've tried to set ourselves up so that we're a value-added program."

In fact, when the Women's Health Program helps secure a grant, the grant goes to another department. It's a small program that does big things and affects a lot of people – and does those things on a modest budget that, as Rogers points out, is creatively allocated to projects that matter most.

"In hospital terms, we don't need to become a huge cost center. We have a really small budget, and I think we do a lot with it because what we do doesn't always take money. We foster partnerships, we foster collaboration, and we encourage people to think about women's health in the most basic ways. We work with departments to help them make their areas more efficient, more effective and easier for women to use. We help them to package information in ways that we know women want it. We help them with simple things like figuring out what women are really looking for. We've also become a complaint center — when women have a complaint, they go to the Women's Health Resource Center [the physical presence of the Women's Health Program which acts as a clearinghouse for women's health information], and they feel safe doing that." ➤

The women's movement slowly brought about many of the changes that it was after — not always with good effects. The newfound independence that today's women enjoy has made them more susceptible to chronic diseases and other health concerns, including cancer, heart disease, stroke, osteoporosis, diabetes, workplace and household injuries, and sexually transmitted diseases. Now the movement is challenging doctors, researchers and administrators to reverse these tendencies, and healthcare and medicine are taking on a new look as a result.

The Women's Health Program:

MAKING A DIFFERENCE THROUGH EDUCATION AND INFORMATION

Recognizing the importance of education in the evolving world of healthcare, the Women's Health Program created the Women's Health Resource Center. The Center provides a number of channels through which medical professionals and women looking for answers to healthcare questions can get the latest information.

Deidre Maccannon

Deidre Maccannon, co-director with Timothy Johnson and Juliet Rogers of U-M's National Center of Excellence in Women's Health, explains that the "Women's Health Resource Center can be accessed by coming to the Center, by phoning in, or by dialing in on-line. We get some 2,000 inquiries a month, and a large number of those are on-line.

"A woman can call and ask a question about anything. She might have just seen a provider and was told she had a particular condition and wants to be sure that she's aware of all her treatment options beyond what that practitioner told her. Or maybe she read something in the newspaper and wants to know if she has it. Maybe she'll just want more specific information about a condition. She can ask the professionals and volunteers at the Resource Center any question she has and get specific information."

Women can also attend events such as Women's Health Night Out and the Annual Women's Health Day. In short, the Resource Center is a woman's link to information — and to people who are genuinely concerned about her healthcare.

Gender-specific education for healthcare professionals has also become a concern for the Women's Health Program. To address this, the Program reviewed and revised the Medical School's curricula, and offers opportunities for continuing medical education that focuses on women and women's health issues. For instance, physicians and nurses can attend lunchtime seminars about community resources, screening tools and diagnostic tools. They have access to a manual that the Program created to educate healthcare professionals about working with people who are in potentially dangerous situations.

"One of our jobs," according to Tim Johnson, "is to take people and transform them, then send them out to make a difference. We're training people at this Medical School to make a difference. People see what's going on here. They see this Health System transforming, and they suddenly realize that they can go back where they came from, take what's taken us five or six years to change, and then they can change things much more quickly where they are. Whether it's delivering babies in comfortable rooms, or delivering babies underwater. All of these things are markers for social and cultural change."

"It's an ongoing process," Juliet Rogers adds. "It won't be finished for who-knows-how-long."

A Profound Impact on Women's Health

The Women's Health Program made such a profound impact with its programming and its service to the community, that the U-M Health System named it "1997 Program of the Year." That same year, the Program also received national recognition when the U.S. Department of Health and Human Services named the University a National Center of Excellence in Women's Health. This designation meant that U-M was a model women's health center in five different areas: clinical care, education, academic leadership, women's health research, and community outreach and involvement.

"Certain things we follow all the way through," Rogers says. "Some are goals, some are actual deliverables — from producing original patient-education materials to contributing to setting a national women's research agenda."

Deidre S. Maccannon, M.D., co-director of the National Center of Excellence in Women's Health at the University of Michigan, says that women's healthcare at U-M is different because it's "much more woman-friendly. The linkages are established with professionals who are sensitized to women's specific problems within those specialties and not just to general care. So a woman can move seamlessly through the system, whether it's for reproductive/gynecologic care, primary care or psychiatric/mental health care — the linkages are there."

It's ironic that the success and recognition of the Women's Health Program have also benefited men by creating an environment that produced outreach programs and curricular opportunities designed for young men. This surprising outgrowth was a milestone in gender relations because, when male students started asking why they didn't have something like the Women's Health Program, they were looking at the downside of inequity with which women had been so long familiar.

The problems with male-centric research are obvious. If investigators don't include women in drug trials, for example, the findings won't show — until it's too late — whether or not a drug is safe or effective for women, or if the drug might damage a fetus. So, the reasons that researchers have given for excluding women from clinical trials are the very reasons why they must include them.

The Shortcomings of Male-Centric Research

For the most part, over the years, health researchers have used male subjects in their studies and excluded women. Why? Investigators point out a number of reasons. For one, it was hard to recruit and retain women in clinical trials. Another reason was the potential for a woman's hormonal changes to complicate a study's results. Yet another reason was that researchers not only feared damaging a fetus, they also dreaded the liability they faced if anything *did* happen to a fetus. (Because of the concerns about damaging a fetus, clinical trials excluded women of childbearing age, until very recently.)

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In response to the challenge of finding willing participants who also fit the parameters of the trials, the Women's Health Program came up with a highly creative — and original — solution: the Women's Health Registry (see page 35). In essence, it's a list that links research investigators to women who have medical profiles that best fit each study.

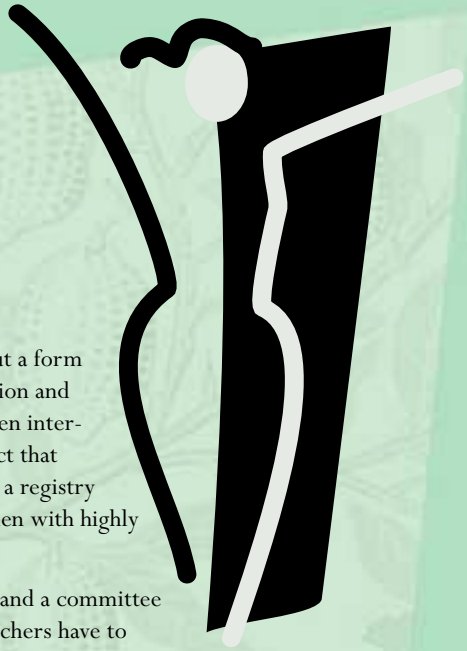
Dean Lichter realizes the vital role that the Registry will play in research: "We have seen so many advances that have been propelled by the willingness of women to enter clinical research trials, knowing that in some of these trials they would not receive a direct benefit. But they do know their sisters and daughters and neighbors behind them will benefit. It's a wonderful testament to the commitment and the courage of women to want to improve their health status and the treatment of diseases of women."

The Women's Health Registry is one more pivotal step that typifies the long struggle women have waged in the movement to achieve equality in healthcare. And although women haven't reached the end of their campaign, they have reached a point where they are, however, not likely to be driven to seek solace from the likes of Lydia E. Pinkham's Vegetable Compound. m

Lydia Pinkham had company in pioneering improvements in women's health.

A New York state physician who had practiced medicine quietly with her father and, after his death, on her own, saw a way of making an enduring impact on women's health. Having never set foot on the U-M campus, Elizabeth Bates, upon her death in 1898, left a bequest to the Medical School to create a professorship in the diseases of women and children, a decision based solely upon Michigan's leadership nearly 30 years earlier in opening medical education to women.

Bates' foresight in establishing the endowment has strengthened women's medicine at Michigan for more than a century. Timothy R.B. Johnson, M.D., chair of the Department of Obstetrics and Gynecology, is the current Bates Professor of Diseases of Women and Children. m



The Women's Health Registry

The Women's Health Registry — a database that's unique to U-M — is a list of women who've volunteered themselves as potential research subjects. The idea grew from the results of a survey that U-M investigators used to identify obstacles that stood in the way of women's health research. Two prominent responses were clear. One: People needed more funding. Two: It was hard to find female subjects who fit the studies and would commit themselves to participate from beginning to end.

In response to the funding problem, the Women's Health Program centralized information that's helpful to investigators, creating a clearinghouse for funding announcements. Previously, it was only by chance that researchers got the right announcement at the right time.

The answer to the second problem — finding appropriate female subjects who were willing to participate and stay to the end — took a bit more creativity.

It was obvious that women in the community were interested in participating: of the 6,000 calls that the Women's Health Program gets each year, about 10 percent are women looking for research studies to participate in. The Program also tried one week of local advertising — on radio and in print media — and more than 600 women enrolled in what became known formally as the Women's Health Registry. Since that first effort, the number of women in the Registry has grown to more than 900, about 800 of whom live within a hundred miles of U-M. And because of the Registry's presence on the Web, there are volunteers from as far away as Israel and Norway. Eleven investigators have applied to use it in its pilot phase, and four have already enrolled women to participate in their studies.

How the Registry Works

The Women's Health Registry is a collaborative effort of the U-M Center of Excellence in Women's Health and the Center for Clinical Investigation and Therapuetics, a Medical School initiative. Together the team has devised a system to qualify, sort and link volunteers and investigators in the Registry database.

The potential subject simply fills out a form that asks for demographic information and health history. The number of women interested in volunteering — and the fact that enrollment is free — has produced a registry that houses a huge database of women with highly diverse characteristics.

Investigators are required to apply, and a committee reviews applications closely. Researchers have to prove that they have funding to complete their studies, then they must provide inclusion-exclusion criteria that the Registry team can use to search the database.

When a woman matches the criteria necessary for entering an investigation, the Registry team sends a letter saying she has qualified for the study. The letter also contains a one-paragraph description on which the woman must base her decision to be contacted or not. The woman has 10 days to contact the Registry if she wishes not to be contacted regarding *this* study. If the woman decides to participate, the Registry releases her name to the investigator.

At that point, the Registry withdraws from the process – it becomes the investigator's responsibility to do additional screening and enrollment. But the investigator has to report every two weeks to tell the Registry who has enrolled and who hasn't, because if someone chooses not to enroll, she goes right back into the pool. If a woman does enroll, then she's out of the pool until that study is finished — a woman in the Registry can participate in only one study at a time.

Juliet Rogers points out that investigators can't use information from the Registry as a random sample, because it isn't. "The point of it," she says, "is to help investigators find a proportion of their sample population."

Privacy, of course, is a huge issue. Those who oversee the Women's Health Registry take every precaution to meet — and sometimes surpass — the legal requirements for protecting each person's privacy.

For more information about the Registry, call toll-free at 1-877-220-0694 or visit the Registry Web site at http://www.womenshealthregistry.org. m