

# Advocacy Toolkit

Raising Wisconsin Women's  
Voices for the Health Care we  
Need and Deserve



**RAISING  
WOMEN'S  
VOICES**

for the health  
care we need



## high cost coverage

Where Eva worked, there were only 4 employees and they did not get small group health insurance coverage because of the high cost. She was the only woman who worked there that was in 'childbearing years' and maternity coverage was making the insurance too expensive to purchase. Eva finally agreed to waive her maternity care so that they could all get covered.

eva

## Acknowledgements

This *Raising Wisconsin Women's Voices Advocacy Toolkit* is an adaptation of the *Reform Matters Toolkit* created by the National Women's Law Center. Adaptations were made, with permission, by Wisconsin Alliance for Women's Health (WAWH) Director, Sara Finger, Board Member, Amy Olejniczak and Spring 2009 Intern, Sara Eskrich.

The *Reform Matters Toolkit* was a collaborative endeavor that relied upon the work of many individuals. Brigette Courtot, Lisa Codispoti, and Judy Waxman were primary authors, along with Gretchen Borchelt for the "Reproductive Health Care and Health Reform" section; and Adrienne Ammerman for the "Dos and Don'ts: Talking About Health Care Reform" section. These authors were greatly assisted by Marcia Greenberger, Joan Entmacher, Lisa M. LeMair, Julia Kaye, Ellen Newcomb, Sarah McGinnis, and Diana Santos. Celinda Lake of Lake Research Partners developed the "What Women Want: How to Talk to Women Voters about Health Care" section. Copyright for these materials is that of the respective authors. The authors would also like to acknowledge the helpful advice and guidance provided by Cheryl Fish-Parcham of Families USA and Terry Fromson of the Women's Law Project.

**About the Wisconsin Alliance for Women's Health** WAWH is an independent, statewide network of organizations and individuals dedicated to broadening the base of awareness and support for reproductive health as a critical component of women's health in Wisconsin. WAWH supports a woman's right to control her own sexuality, fertility, health and well-being. The mission of the Alliance is advancing women's health by creating an environment in which the public and elected officials confidently support women's health policy.

**About Raising Women's Voices** Raising Women's Voices works to engage women from diverse constituencies in identifying their health needs and those of their families and articulating a vision of health care that meets these needs. This campaign hopes to create partnerships between women's health advocates and consumer health advocacy organizations to strengthen the understanding of each other's perspectives on health care.

**Storytellers** WAWH would like to thank all of the wonderful Wisconsin women who offered to share their stories live in Milwaukee at the Raising Wisconsin Women's Voices Speak-Out Event, and in print throughout this toolkit: Holly Dziondzak, Katie Jesse, Mary Welch-Donovan, LaShawndra Vernon, Maria Merrill, Mary Kay Wagner, Jody Freckmann, Kathy Waligora, Teri Micholowski, Eva Robar-Orlich, Sheryl Raether, Christine Wieseler, Rosalie and Rachel.

**Photos** The photos in this Toolkit were taken at the Raising Milwaukee Women's Voices Health Reform Speak Out in Milwaukee, WI on July 22, 2009.

**Disclaimer** While text, citations, and data are, to the best of the authors' knowledge, current during the release of this report, there may be subsequent developments including legislative actions that could alter the information provided herein. This report does not constitute legal advice. Individuals and organizations considering legal action should consult with their own legal counsel before deciding on a course of action. In addition, this report does not constitute medical advice. Individuals with health problems should consult an appropriate health care provider.

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## insurance coverage limits

Jody & her husband, Scott, have insurance through his employer. He has Leukemia and is in remission. They have various options, such as continuing chemo, but a transplant would be his best bet. Jody is having a very hard time getting answers about her insurance as far as what is covered and how much they will cover. Every time her husband gets chemo it costs about \$15,000 and Jody is worried they are close to their capitation.

They recently decided to do a transplant from an umbilical cord. The insurance would cover the procedure in full if they went to the Mayo Clinic in Minnesota. However, all of the care that he would need relating to the transplant would also have to be done there, so they would have to make the long drive often, which is unrealistic. Instead, they chose Froedtert hospital in Milwaukee. Since Froedtert has never done this type of procedure, they are unsure whether it will be covered, and if it is, how much it will cost and what the capitation is. Jody is very worried about her husband’s transplant and whether they can afford to pay for it.

jody

# Women and Health Reform: Now is the time!

There is no doubt that women and our families need health reform, and soon! As federal legislative leadership presses forward to pass health reform legislation **this year**, now becomes a crucial time for action. These coming months—from now until health reform is passed—provide an important opportunity for women to **speak out** about getting the health care they need and deserve, seek advocacy opportunities and get involved with the political process by letting lawmakers know what is important to women and their families.

## Many Wisconsin women unfortunately have:

- » not been able to afford health insurance coverage;
- » not been able to afford to use health insurance coverage because of expensive co-pays or deductibles;
- » found that health insurance coverage will not pay for needed services, such as birth control, or for the type of health provider they want to use, such as a midwife;
- » lost health insurance because of a divorce;
- » had difficulty understanding the rules of managed care plans or choosing which plan;
- » been frustrated that doctors at the local clinic don't speak their language or understand their culture.

To learn more about the health care legislation process and current proposals, visit: [www.kff.org/healthreform/sidebyside.cfm](http://www.kff.org/healthreform/sidebyside.cfm)

This is unacceptable. Women are the heart of the health care system making 80% of all health care decisions<sup>1</sup> and spending four of every five health care dollars.<sup>2</sup> Wisconsin has significant room for progress, and now is the time for action. Women's advocates must ensure that health reform addresses the specific health needs of women and the unique challenges they face in getting high-quality, comprehensive, and affordable health care.

In this **Raising Wisconsin Women's Voices Advocacy Toolkit** you will find tools for addressing current health reform issues, learn how they relate to women, and **read real, personal stories from Wisconsin women** who have faced unacceptable obstacles when dealing with our current health care system. We invite you to use these tools and share these stories over the coming months as health care reform is discussed, and encourage you to connect with health policy leaders like the Wisconsin Alliance for Women's Health.

## individual coverage

Holly was fully insured when she worked as a cashier at Kohl's, but when Kohl's closed she lost her job. Even though she was unemployed, Holly did the responsible thing and bought an individual policy. It was only catastrophic coverage because that was all she could afford. During this period, she broke her leg in 28 places. The insurance had a \$5000 deductible, \$250 premium, and 80/20 split on costs over the deductible. Her injury required three surgeries to insert titanium rods and pins. Holly's 20% share was \$22,000. She had to take out a second mortgage to help pay down the debt and now, although she has a new job and a new insurance plan, she can barely afford to pay off the interest on her medical debt every month.

holly



## health care for all

“ I am an advocate for myself as well as others. I have recently graduated from benefit and entitlement eligibility based on my income. This is a great thing, for I am reaching for the stars, but the struggle continues as I strive to avoid recidivating into the poverty cycle.

As a struggling middle-class parent, sometimes I don't know what to tell the people I work so hard to help. I am grateful for health care, but I struggle to meet the costs of my children's medications. I negotiate with my landlord, my bill collectors, my family members in order to ensure that ends meet and the needs of my family are met. And in the midst of this entire struggle, my profession is to advocate for this community. And I am tired of politics keeping my people in limbo. I am tired of telling people that they have no benefits available to them because their situation is one that policy and decision makers did not find to be emergent enough. Meanwhile our community organizations have become an ER for the lost.

We need health care for all. The longer we spend tabling this issue, the more our community members are at risk. The activists in this community have consistently done our part, bringing up the issues and presenting suggestions for redesigning the systems. Many of us speak from experience. I am a former recipient of BadgerCare, WisconsinShares, and WIC. I understand how vital these programs were to my ability to escape the situational poverty I was faced with. I now advocate for that same group of people. I try and give them the tools to advocate for themselves.

Without addressing the obvious cycles of generational poverty in this state we are doing our population a disservice. It is what I work towards every day with such an amount of passion that it occasionally causes me sleepless nights. But I refuse to stop. Because I am certain that my loud voice has caused a ripple, and when I bring that voice to a group of passionate individuals, it creates a tidal wave. ”

lashawndra

## 7 Reasons Why Health Care Reform is a Women's Health Issue:

1. Women are more likely than men to need medical services.
2. Women are less able than men to afford medical services and supplies.
3. Women are less likely than men to be offered employment-based health insurance. That is partly because women are more likely than men to work at part-time jobs.
4. Many women are unable to work at jobs that provide health insurance because of the time they spend providing unpaid care to sick, disabled, very young and very old family members.
5. Women pay 68% more in out-of-pocket health care costs than men, in part because of reproductive health-related supplies and services.
6. Women are vulnerable to losing health care coverage because of changes in marital status.
7. Latinas, immigrant women, young women, rural women and women with disabilities face particularly severe obstacles to obtaining medical care.

# Making Health Care Affordable

Women’s advocates encounter both challenges and opportunities when considering how cost control fits into progressive health reform. Some opponents of health reform propose alternatives they claim would be just as good, such as health savings accounts, but in fact these plans would actually shift the burden of health care costs to the enrollee. Advocates must work to ensure that cost containment does not come at the expense of access to high-quality and affordable health care for women and their families. At the same time, cost control initiatives present an opportunity for system improvements and the delivery of more efficient and higher-quality care.

## Women and Health Coverage: The Affordability Gap<sup>3</sup>

Women face unique barriers to becoming insured. In particular, women are less likely to have coverage through their own employer and more likely to obtain coverage through their spouses as dependents. More significantly, women have greater difficulty affording health care services even once they are insured. Women are more likely to have lower incomes than men and therefore have greater difficulty paying premiums, and are more likely to use more health care and to have higher out-of-pocket health care expenses. Given these factors, policy proposals that provide comprehensive benefits at affordable cost would help more women obtain meaningful coverage. Conversely, reforms that result in higher out-of-pocket expenses and limited benefits will not significantly improve the health and financial security of women.



### To Contain Costs, Health Reform Plans Can...

- » Incorporate initiatives that will improve health care quality.
- » Emphasize preventive and primary care.
- » Promote the widespread use of health information technology.
- » Support the role of public coverage programs as a way to expand access to health insurance, including a public health plan option for individuals and employers.

## paying for prescriptions

Teri and her husband are on AARP Medicare. AARP Medicare just changed their policy and no longer cover the prescriptions that Teri and her husband need. They also have an adult daughter who has no health insurance. They pay for her prescriptions as well. They looked into the private market but could not find insurance that would be affordable and are worried that she would have pre-existing conditions. Teri gets social security and her husband works, but they only earn enough money to pay their mortgage and get groceries—they are living paycheck to paycheck and cannot afford the prescriptions.

Teri is trying to get her daughter on BadgerCare Plus as a childless adult, but she is very frustrated at how complicated the process is. “You have four days to complete the entire form or you have to start over. However, after you do the first part you have to wait for an e-mail that highlights your mistakes. You then have to start over and try to get everything done in 4 days.” Teri is worried about how she will be able to continue to afford their prescriptions in the future.

teri

# Promoting Comprehensive, Quality Care

What is “Quality” Health Care? Put simply, it’s the right care, at the right time for the right reason. It’s the care we all deserve—but sadly, it’s not the care we can count on in the United States today. Even for those of us fortunate enough to have insurance coverage, too often quality health care is elusive or even out of reach. Poor quality care causes serious harm, wastes precious resources, drives up costs and increases disparities.<sup>4</sup>

## An Opportunity to Address Health Disparities among Women

A woman’s access to quality health care in the U.S. is a function of where she lives, her race and ethnicity, her family income, and her citizenship status, among other things. Women who are poor, disabled women, those who live in rural areas, immigrant women, and women who identify as lesbian, gay, bisexual, or transgender (LGBT) face particularly severe obstacles in obtaining medical care.

Health reform presents a unique opportunity to address the health disparities that have long troubled the U.S. health care system. Women’s advocates can work to ensure that health reform proposals include measures that will make the health system more equitable, so that health disparities among women are reduced. Women’s advocates should inquire how health reform plans will affect populations that experience health disparities, promote health reform measures that explicitly address health disparities and partner with groups that represent or serve groups that experience health disparities.

### prosthetic parity

“ I have bilateral below knee amputations. Fortunately, I have Medicare and Medicaid (for now) which cover basic needs including a wheelchair, prosthetic legs, necessary socks, etc—though not as often as components really should be replaced. When I started my last job, I was very excited because I was told in my job interview about a woman at the company who had been able to get a state of the art prosthetic leg. I was overjoyed that I might be able to get legs that would help me to walk better and with less pain. When I started the job, I asked human resources about the health insurance only to find out that the insurance would only cover \$2,500.00 for the cost of prosthetics. I was incredulous. A basic leg costs thousands more than that. I ended up declining the company insurance because it didn’t make sense to pay for it when my major expenses would not be covered. I started to wonder how insurance companies could have limits like this. What kind of society allows this? I realized that I probably would not have learned about this issue if I had not needed prosthetic legs. So, I decided that I needed to talk to people about this: legislators and other citizens. What I am asking for should not be considered a privilege. I just want to be able to walk, which allows me to have a higher quality of life, to work and to pay taxes. I think it is unfortunate that I have to depend on Medicaid and Medicare because there is no other way I would be able to afford my health care needs. Furthermore, since I am not receiving Social Security benefits, there is a limit on how long I can receive this health care coverage. There is also an asset limit for Medicaid. I want it to be mandatory for insurance companies to cover prosthetics, so that people with amputations will have options and will not have to depend upon government benefits. ”



christine

## Reproductive Health Care and Health Reform

Women's reproductive health is too often segregated from women's health care in general, and women's reproductive needs have come to be seen as a secondary set of concerns rather than an integral part of their health and well-being. Yet, reproductive health is a key determinant of overall women's health. To be truly comprehensive, health care must include women's reproductive health needs.

Advocates have an important role to play in ensuring that reproductive health is not marginalized in health reform. It is essential that they are armed with facts about the importance of reproductive health to women's health, how reproductive health services are covered in the current health care system, and how different health reform proposals might affect that coverage.



### Reproductive Health in Wisconsin: The Facts

- » 62 counties in Wisconsin have no abortion provider.
- » Publicly funded family planning clinics in Wisconsin avert 35,200 unintended pregnancies and 17,600 abortions every year.
- » There are 634,250 women in Wisconsin in need of contraceptive services and/or supplies. Of these, 294,440 women—including 95,340 teenagers—are in need of publicly supported contraceptive services.
- » Nearly 1/2 of all births in Wisconsin were paid for by Medicaid in 2005.

## reproductive health

“ My mother was diagnosed with endometriosis in her teens, resulting in a full hysterectomy in her twenties. My sister was tested for polycystic ovarian syndrome just last week. As a young woman who hopes to, one day, become a mother, I know that I absolutely cannot go without regular reproductive care. Yet, in most cases, this is barely covered or completely disregarded by insurance providers. That is a huge blow to women. My roommate's health insurance doesn't cover birth control. This past year she had to forgo purchase of textbooks so she could use her student loans to cover the outrageous cost of the prescription.

Of course, even when your insurance covers these services, its not easy to access them. I am one of the lucky few college students with health insurance—and a policy which covers reproductive care. However, that doesn't mean seeking that care has been an easy process. The most difficult thing for me has been working within the confines of the providers that my insurance company covers. I had to look at a short list of providers covered by my mother's insurance company and rule out those who were unacceptable. This meant I had to nix anyone off of a bus line, or simply too far down a bus line to count. Then I had to try and guess from clinic names I had never heard which ones were likely to be staffed with highly qualified doctors. Finally, I had to guess which of the people listed was going to make me feel most at ease while I was in such a vulnerable position. I decided to throw the list out and go to Planned Parenthood.

First, no one should ever have to break the bank when seeking any basic health services—reproductive services included. Second, this is an incredibly personal service for women. We should have the right to choose a doctor using whatever criteria we deem important. ”

kathy

## student health

“ I was sideswiped by a car while riding my bike. Four hours in the emergency room, six stitches in my forehead and nearly \$5,000 in hospital bills later, I sat with an ice pack on my face, grateful to have made it out relatively unscathed. Two years later and my hospital bill is still close to \$2,000. I just graduated college, am unemployed and, in a time of severe economic recession, am wondering how I’m going to deal with getting the most basic of health services. I’m happy that Wisconsin just expanded the qualifications for BadgerCare and am now, for the first time since I moved to this state, not being punished for staying childless. I’m glad that there are places like Planned Parenthood and programs like the Family Planning Waiver, so I never have to worry about whether to get my annual exam or buy dinner. But it’s not enough. Soon I’m going to have to start paying back my student loans and what little spending money I have will be gone. What will I do in an emergency? It’s a question that I don’t have an answer to and one that I don’t even really think about because it’s just plain scary. ”

katie

# Talking about Health Reform

To build support for health care reform among Wisconsin women, it is important for advocates to be aware of what women believe and value when it comes to the health care system. In addition, we must understand how to talk with women about health care reform, including which words and concepts to emphasize, and which to avoid.

## How to Talk About Health Reform

### Understanding the Context for Health Reform:

- » Health care is very important to voters, and is the top issue after the war in Iraq and the economy.
- » Rising costs are the top concern for voters, the majority of whom are insured.
- » Voters often support reform proposals in principle, but pull away from policy specifics fearing higher costs or lower quality for them personally. They don’t want to lose what they have; choice is key.
- » The concept of “quality, affordable health care” is more appealing than “universal coverage.” It connects the needs of the underinsured to those of the insured, who are worried about rising costs.
- » Health care is a core value for women—linked to the pursuit of the “American Dream,” our country’s destiny and each family’s well-being and future.
- » Female voters talk about health care in moral terms—no American should be denied access to health care. Yet, just calling health care a “moral issue” does not motivate women support health reform.

### Health Reform Concepts that Resonate with Women Voters:

- » Health care should be affordable and secure, so that access is not compromised by life transitions such as widowhood, a change in job status or divorce.
- » Women want a choice of health care providers, as well as the ability to maintain a relationship with their current physician.
- » Women see a role for government in regulating, rather than providing, health care.
- » Small businesses should be protected so that reform efforts do not burden these employers.
- » Part-time workers should have access to health insurance.
- » Women are in favor of eliminating rules that allow health insurers to deny coverage for preexisting medical conditions.

The above comes from polling conducted by the Herndon Alliance in November 2007.

# The Barriers, and How to Overcome Them

Despite their recognition of the many problems within the current health care system, some people have major concerns about health care reform. Women’s advocates must be aware of these concerns. When crafting messages, keep these possible barriers in mind and focus on messages that will overcome those barriers.

Barriers to Health Reform	Overcoming the Barriers
Cynicism about government and “red-tape”	Incorporate element of personal responsibility
Fear of higher costs, higher taxes	Include options and choices—make sure it’s employee choice, not just employer choice
Loss of quality	Use preventative care as a stepping stone
Undocumented immigrants and other “undeserving people”	Emphasize security, piece of mind, control
Perceived impact on small businesses	Focus on how reforms will help small businesses, or small business support for health reform
The ability of powerful interests to block action	Define a role of government as a watchdog and rule-maker

## Health Care Reform: Words to Use

Advocates can communicate more effectively by tailoring messages about reform to include words that are familiar to their audience and that promote positive associations.

Health Care Reform: Words to Use
Quality, affordable health care
American health care
A choice of public and private plans
Sliding scale
Prevention
Smart investment; investing in the future
Choice
Rules
Guaranteed
Giving people control; piece of mind
Standard package; affordable health plans
Government enforcement/watchdog



For an online copy of The Herndon Alliance presentation, visit: <http://action.nwlc.org/site/DocServer/LakePresentation121207.pdf?docID=381>

# How Will Women Be Affected by Reform?

## A Few Scenarios:

Scenarios from Community Catalyst: [www.communitycatalyst.org](http://www.communitycatalyst.org)

Model Woman	Situation Without Health Reform	Situation With Health Reform (As proposed in the House Tri-Committee bill released on July 18th*)
<p><b>A 57 year old breast cancer survivor.</b> Just divorced and lost her previous coverage from her ex-husband's employer. She works for herself, and earns \$40,000 a year.</p>	<p><b>She is uninsured.</b> She could—and likely would—be denied coverage on the individual market because of her medical history. Alternatively, she might be offered extremely expensive coverage both because of her medical history and because she is a woman. This coverage would likely have lifetime or annual caps, and may not cover basic services like cancer screenings.</p>	<p><b>She could not be denied coverage because of her medical history.</b> Insurers could not charge her more expensive rates because of her gender or her history of cancer. Her coverage would not have lifetime or annual benefit caps and would cover a full range of services. Screenings, such as mammograms, would have no co-pay. If her premiums are more than 11% of her income, she would receive subsidies to help pay for her coverage.</p>
<p><b>A 22 year old recent college graduate</b> with no past medical problems. She is looking for a job, and has some savings but no income.</p>	<p><b>She depletes her savings to pay full cost for an insurance policy on the individual market.</b> The average premium on the individual market is \$217 per month. She also likely faces a deductible of \$1,747, which is the average deductible for most common type of individual plan purchased. Because she does not have children, she cannot qualify for Medicaid in most states.</p>	<p><b>She would qualify for Medicaid,</b> which would provide her with comprehensive coverage with no premium, no deductible, and little cost-sharing, until she is able to find a job.</p>
<p><b>A single mother with two children</b> and no health problems. She earns \$35,000 per year, but is not offered coverage from her employer.</p>	<p><b>She is uninsured, and her children may or may not have coverage</b> depending on public program eligibility levels in her state. The average premium on the individual market for family coverage would cost her \$5,799/year, or 17% of her income, which she cannot afford along with rent and other necessities.</p>	<p><b>Both she and her children would have access to low-cost coverage.</b> Her children qualify for coverage through the Children's Health Insurance Program. She would get subsidies to purchase her own private insurance, and she would only be required to spend 3-5% of her income on her premiums. **</p>

\*The House bill was amended to increase the affordability level from 11% to 12%, but it is not clear whether this change will survive further negotiations.

\*\*House bill: Sec. 1701. Eligibility for individuals with income below 133-1/3 percent of the Federal poverty level. (a) Requires State Medicaid programs to cover non-disabled, childless adults under age 65 with income at or below 133% of FPL (\$14,400 per year for an individual). Effective in 2013.

- Source of individual market premiums: America's Health Insurance Plans, [www.ahipresearch.org/pdfs/Individual\\_Market\\_Survey\\_December\\_2007.pdf](http://www.ahipresearch.org/pdfs/Individual_Market_Survey_December_2007.pdf)

# Questions to Ask about Health Reform Plans

Armed with the knowledge of women's unique relationships with the health care system, advocates can analyze current reform proposals and make informed assessments about how they would affect women. Below is a list of questions to ask as you consider whether state or federal reform proposals address women's distinct health care needs.

**Does the plan expand access to ensure that health coverage is available to all?** Health insurance coverage provides women with greater access to health care and improves health outcomes, but does no good when millions of women are still uninsured and underinsured in our current health system. Health reform plans must expand access to health coverage for all women, regardless of age, disability, geography, sexual orientation, income, health, work or marital status.

**Does the plan provide care that is affordable?** Women have lower incomes than men, in general, and a greater share of their income is consumed by health care costs.<sup>5</sup> Regardless of whether they have health coverage, women are more likely to delay or avoid getting care they need because they cannot pay for it.<sup>6</sup> Health coverage must be affordable relative to income. Moreover, affordability should be based on all the costs of a women's health care, including her insurance premiums and out-of-pocket costs. There should be adequate subsidies for those who are ineligible for programs like Medicaid but can't afford the total cost of their health coverage.

**Does the plan ensure comprehensive health coverage?** Health insurance must cover the services that women need to stay healthy and to treat physical and mental illnesses at all stages of life. Health reform plans should set a standard for health benefits that require coverage for all necessary care, including preventative care and a full range of reproductive health services.

**Does the plan adopt insurance market reforms to end unfair practices?** Women and their families are often at the mercy of insurance companies, especially if they must purchase coverage directly from the insurers through the individual insurance market. In many states, insurers can deny coverage to people with pre-existing health conditions; charge people more for their coverage because of their gender, age or health status; raise premiums significantly without oversight; refuse to cover treatment for certain conditions; and even revoke insurance policies for people who have been paying premiums for years.<sup>7</sup> Reform proposals must end these unfair practices and promote a strong watchdog role for government to ensure that the reforms are implemented.

**Does the plan expand the role of public health insurance programs?** In Wisconsin, public health insurance programs like Badger Care Plus cover over 640,000 women and their families.<sup>8</sup> Badger Care Plus, Medicare, Medicaid, and the Family Planning Waiver provide a vital safety net to families in Wisconsin, and must be expanded as part of any comprehensive health reform proposal.

# Top 3 Things You Can Do Today

## 1. Learn and Stay Informed About Health Care Reform Options!

For current information on the different health care reform proposals, visit [www.raisingwiwomensvoices.org](http://www.raisingwiwomensvoices.org).

Get side-by-side comparisons of health care reform proposals: [www.kff.org/healthreform/sidebyside.cfm](http://www.kff.org/healthreform/sidebyside.cfm)

**2. Contact your Policymakers!** Call your US Representative and Senators and ask them to support health reform that guarantees quality, affordable health care for ALL women. See page 13 for additional contact information and visit the WAWH website for effective communication tips. [www.supportwomenshealth.org](http://www.supportwomenshealth.org).  
**Congressional Hotline: 1-877-264-4226**

Understand the health care reform legislation process (as of July 2009): [nwlc.org/reformmatters/pdf/NWLCdetailedHCRdiagram.pdf](http://nwlc.org/reformmatters/pdf/NWLCdetailedHCRdiagram.pdf)

**3. Tell Your Story!** More than ever, we need to raise our voices for health reform. Join the Wisconsin women who have told their stories throughout this toolkit by sharing yours. Fill out the story form on page 19 or simply email [info@wiawh.org](mailto:info@wiawh.org).

## care for victims

“ As a woman, I care about reproductive health. I was raped, multiple times in one week, by someone I trusted. I was sixteen and there was nowhere to turn. No one cared to even try to understand what I was going through; not friends, not family, not anyone at school. We must let everyone who is affected by rape understand that there are places like Planned Parenthood that can help them. I thank God that I can have options if I need them. Five minutes ago, I set up an appointment for an annual exam, that I wouldn't be able to have signed up for if Planned Parenthood did not exist. Truth is, I can't afford a doctor visit, but I want to be as healthy as I can be, so that someday, when I do decide to have a child, I am physically able to do so. ”

rachel

## maternal & child health

Sheryl had premature triplets, one of whom (Mira) has kidney disease and needs a transplant. The family's insurance has a lifetime cap of \$500,000. Mira is only 3 years old and has already required \$250,000 in care. She is on dialysis until she reaches 22 pounds, which costs \$15,000 per month. Mira may get a transplant within the year but Sheryl and her family had to independently raise funds just to stay on the transplant list. After the transplant, Mira's health care costs will be \$25-40,000 per year, including \$300-400 per week for anti-rejection drugs. The family's premium is about \$1000 per month, and approximately \$6/hr. of each paycheck goes to health care coverage. Unfortunately the coverage is not even good! For example, the insurance pays for Mira's feeding tube/pump but not for the special food needed for the device. Sheryl's family can't get new insurance for Mira because she is considered uninsurable due to a pre-existing condition. Currently, Mira has Medicare coverage for 3 years. However, Sheryl is worried about what will happen after the 3 years are up—they will have very little insurance left.

sheryl

# Wisconsin Congressional Delegation

Speaking out to your policymaker is critical to the success of health reform. Let them know you support comprehensive, affordable health care for all Wisconsin women! **Congressional Hotline: 1-877-264-4226**

## U.S. Senators

### Herbert Kohl (D)

**District Phone:** 414-297-4451

**E-mail/Web:** <http://kohl.senate.gov>

### Russ Feingold (D)

**District Phone:** 608-828-1200

**E-mail/Web:** <http://feingold.senate.gov>

### District 4: Gwen Moore (D)

**District Phone:** 414-297-1140

**E-mail/Web:** [www.house.gov/gwenmoore](http://www.house.gov/gwenmoore)

**Counties:** Milwaukee

### District 5: James Sensenbrenner (R)

**District Phone:** 262-784-1111

**E-mail/Web:** <http://sensenbrenner.house.gov/>

**Counties:** Jefferson, Milwaukee, Ozaukee, Washington, Waukesha

## U.S. Representatives

### District 1: Paul Ryan (R)

**District Phone:** 608-752-4050

**E-mail/Web:** [www.house.gov/ryan](http://www.house.gov/ryan)

**Counties:** Kenosha, Milwaukee, Racine, Rock, Walworth, Waukesha

### District 2: Tammy Baldwin (D)

**District Phone:** 608-258-9800

**E-mail/Web:** <http://tammybaldwin.house.gov>

**Address:** Columbia, Dane, Green, Jefferson, Rock, Sauk, Walworth

### District 3: Ron Kind (D)

**District Phone:** 608-782-2558

**E-mail/Web:** [www.kind.house.gov](http://www.kind.house.gov)

**Counties:** Buffalo, Clark, Crawford, Dunn, Eau Claire, Grant, Iowa, Jackson, Juneau, La Crosse, Lafayette, Monroe, Pepin, Pierce, Richland, Sauk, St. Croix, Trempealeau, Vernon

### District 6: Thomas E. Petri (R)

**District Phone:** 920-922-1180

**E-mail/Web:** <http://petri.house.gov/>

**Counties:** Adams, Calumet, Dodge, Fond du Lac, Green Lake, Jefferson, Manitowoc, Marquette, Outagamie, Sheboygan, Waushara, Winnebago

### District 7: David R. Obey (D)

**District Phone:** 715-842-5606

**E-mail/Web:** [www.obey.house.gov](http://www.obey.house.gov)

**Counties:** Ashland, Barron, Bayfield, Burnett, Chippewa, Clark, Douglas, Iron, Langlade, Lincoln, Marathon, Oneida, Polk, Portage, Price, Rusk, Sawyer, Taylor, Washburn, Wood

### District 8: Steve Kagen (D)

**District Phone:** 920-437-1954

**E-mail/Web:** <http://kagen.house.gov>

**Counties:** Brown, Calumet, Door, Florence, Forest, Kewaunee, Langlade, Marinette, Menominee, Oconto, Oneida, Outagamie, Shawano, Vilas, Waupaca

Contact information from: [http://www.alllaw.com/state\\_resources/wisconsin/congress/default.asp](http://www.alllaw.com/state_resources/wisconsin/congress/default.asp)

## access to coverage

“ When I was pregnant with my daughter 22 years ago I experienced a high-risk pregnancy. At seven months I had an NG tube surgically inserted, as this was the only nourishment I could receive. I had already lost 25+ lbs. The insurance company did not want to pay for the solution that was going into the tube because it was classified as a “dietary supplement.” I told the woman I was NOT trying to lose weight, but that I was pregnant and trying to put weight on. I then told her they could either pay the bill or read about the death of myself and my unborn baby. Her response? “I’m sorry I can’t help you.” Eventually this solution was covered as it is the same medication used with stomach cancer. Luckily, the bill was finally paid by my husband’s insurance, just before it was sent to collection.

Twenty-one years later on September 6, 2008, I was involved in a car accident with a drunk driver. I was transported to Froedtert Hospital via ambulance and was released from the hospital several hours later with severe bruising of the torso and a very bad dislocated finger. I carried the health insurance for my daughter and I, as my husband had passed away eighteen months before from lung cancer. Almost one month to the day of my accident I was terminated from my job. Because I was still under a doctor’s care for the injured finger, I had to purchase COBRA health insurance. The premium was almost \$750, which I paid with money I had received from my husband’s life insurance policy. I had to put the premium for my daughter’s private individual insurance on my credit card.

As of today, I am still on COBRA thanks to President Obama who passed a bill in February of 2009 that extended my coverage for an additional nine months. I was recently diagnosed with blood pressure issues and am currently being treated for arthritis in my left hip. The possibility of hip replacement surgery scares me because it may be considered a pre-existing condition if I get a new job. I am still unemployed. Do I live with the pain, or with the possibility of losing the home that my husband purchased thirty years ago so I can have the surgery? Also, because of the accident, I am responsible for bills that my insurance company did not pay. These monies are coming out of the budget I need to pay other bills. To keep my credit rating in good standing the bills are being paid, but at a low amount I can afford. Some months I have to dip into the money from my husband’s insurance policy to pay these bills—since his death, my income is the only income I depend on. I’m just lucky I was able to pay off my house the day before my husband passed away. At least that’s one less thing to worry about. ”

mary

## Did you know?

Non-Hispanic black women have the highest infant mortality rate in the U.S.

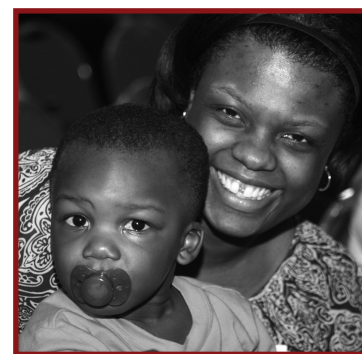
The AIDS case rate for Latinas is more than 5 times that of white women.

Women with major mobility problems are 70 percent less likely to be asked about contraception, 40 percent less likely to receive a Pap smear and 30 percent less likely to have a mammogram.

Lesbians are at an increased risk for certain cancers (lung, cervical and breast cancer), due to inadequate risk assessment and screening by providers.

Breast cancer is the leading cause of cancer incidence and mortality among Asian American and Pacific Islander women in the U.S.

- Reproductive Justice Collective, 2009



## Helpful Online Resources

**ABC for Health:** Has helped thousands of Wisconsin families solve problems paying for health care. Health Benefits Counselors suggest coverage or payment options and help with applications. [www.safetyweb.org](http://www.safetyweb.org)

**Alan Guttmacher Institute:** Working to advance sexual and reproductive health in the U.S. and worldwide through an interrelated program of social science research, policy analysis and public education. [www.guttmacher.org](http://www.guttmacher.org)

**Community Catalyst:** A non-profit advocacy organization whose first priority is quality, affordable health care for all. [www.communitycatalyst.org](http://www.communitycatalyst.org)

**Families USA:** The Voice for Health Care Consumers offers many tools for advocates. <http://familiesusa.org/resources/tools-for-advocates/tips/impressive.html>

**Kaiser Family Foundation:** A non-partisan source of facts, information, and analysis for policymakers, the media, the health care community, and the public. [www.kff.org](http://www.kff.org) and [www.kaiseredu.org](http://www.kaiseredu.org)

**National Partnership for Women and Families:** A vocal and effective advocate on the issues most important to women and families. [www.nationalpartnership.org](http://www.nationalpartnership.org)

**National Women's Law Center:** Leading the charge for quality comprehensive, affordable health care that meets the needs of women and their families. The Center's "Reform Matters" website provides women's policy advocates with the tools to be active and vocal advocates in the fight for progressive health care reform on the national and state levels. [www.nwlc.org](http://www.nwlc.org) and [www.nwlc.org/reformmatters](http://www.nwlc.org/reformmatters)

**Planned Parenthood of Wisconsin:** The state's largest reproductive health care provider, also providing community education about sexual and reproductive health. (800) 230-PLAN [www.ppwi.org](http://www.ppwi.org)

**Raising Women's Voices:** A national initiative to support quality, affordable health care for all by engaging a broad array of women's health advocates in local, state and national health reform discussions. [www.raisingwomensvoices.net](http://www.raisingwomensvoices.net)

**Wisconsin Alliance for Women's Health:** A network of organizations dedicated to broadening the base of awareness and support for reproductive health as a critical component of women's health in Wisconsin. [www.supportwomenshealth.org](http://www.supportwomenshealth.org)

### Need Health Care Coverage?

**ACCESS** Provides a quick and easy way for people who live in Wisconsin to see if they qualify for Wisconsin's health and nutrition programs. (Information also provided En Espanol). Visit <https://access.wisconsin.gov> or call (800) 362-3002.



## health insurance bureaucracy

“ My husband, Phil, died of brain cancer in 2000. The battle to get him the care he needed was a full time job. But my story is not about the nerves of steel you have to have to navigate the byzantine health care system. My story is about the battle we waged with the bureaucracy that is health insurance.

Phil was an administrator for the University of Minnesota; as such, he was an employee of the state. None of the state health plans would cover his treatment. My insurance would. However, state law required that state employees carry one of the state plans. We petitioned to be released from this requirement but were denied. I get really angry when someone asks me, “Do you really want a government bureaucrat making decisions about your health care?” It can’t be worse than having an insurance company bureaucrat making those decisions. Our petition was denied because keeping Phil made the bureaucrat’s population numbers look good and it was too much work to authorize his release.

This meant that we had to insure him under both his plan and mine. His plan rejected 90% of his bills and mine paid all but our \$2,500 deductible, co-pays, and out-of-pocket expenses. We were lucky; we could manage this financially with help from his family. What we could not manage was the bureaucracy. It could take up to 9 months, even longer for bills to get paid. We fought this for 2 years until we were able to get out from under the state plan. We did this when my husband went on permanent disability and began collecting social security. No longer receiving a pay check from the University, we were expected to mail our contribution to the state, which we did not do. After 2 months, we received a letter saying we would be dropped from the plan if we did not make the required payments within 30 days. The following month, we were dropped. That was 3 months before my husband died. It ruined my credit rating, a small price to pay.

Before that happened Phil went through 35 rounds of stereotactic radiation, a dozen hospitalizations, two more rounds of surgery, a stroke, a month-long stay in a rehab unit, 10 rounds of chemotherapy, 18 more rounds of radiation (different kind) and a sleep apnea study plus hundreds of doctor visits. Each of those providers had to go through the process I described for each occurrence. The second round of radiation was the worst. After receiving the denial in April of 2000, the provider’s representative called me. I explained to her that she would now have to send a copy of the denial along with a claim to my insurance company. I assured her that she would receive payment from my insurance. She called again in May, June and then July, on the Monday after we buried Phil. My insurance provider, again, walked her through the process. A year later, she called back. Then the bill collector calls started.

Over two years after my husband died he received a certified letter saying that if he did not pay this bill, the provider would sue him. I replied to the letter letting the provider know that Phil had passed away. My insurance company would pay the bill just as soon as they submitted a claim for payment. Several months later, another certified letter—again addressed to Phil—announced that an arrest warrant had been issued.

Six months later I received another call from a bill collector, a woman who, as it turned out, had lost her husband to cancer. I explained the situation to her. She told me she would take care of the situation. I never heard from the provider or any representative again. That was 6 years ago. However, in 2003 I left Minnesota. I still have all my husband’s medical bills. I plan to keep them for another year. I hope the statute of limitations will run out in 2010. ”

mary kay

## worker's compensation

“ I am a 62 year old registered nurse. This winter I fell on ice while doing my job—a home visit—and broke my right wrist in 4 places. I had emergency surgery and will permanently have a titanium plate and 11 screws in my wrist. Though my injury was covered by worker's comp, I received numerous phone calls and medical bills almost daily. After being off work 2 1/2 months due to my injury, my boss called to tell me she was posting my position. By law, the company I work for only has to give me a job when I can return to work. I am a registered pediatric nurse with 27 years experience and may have to answer telephones for a living—at any salary they want to pay me. If I refuse, my benefits stop and I have no job.

Five weeks into recovery, worker's comp started harassing both me and my doctor. My bones weren't even healed yet, I was still taking narcotics for the pain, I couldn't drive and was spending over 40 hrs/week in physical therapy, but was told I needed to go back to work from an insurance person that never saw me. My physical therapist thought this was outrageous. My doctor wrote that I was totally disabled, and still the insurance company continued to call and send letters. Bucking under the constant harassment, my doctor's PA wrote that I could go back for 4 hours doing ONLY left handed work. I was assigned to answer the phones—which included charting (using my injured hand since I'm right-handed). I further injured my hand by overuse, had less mobility, and increased pain from working two 4 hour days. My doctor took me off work again.

Nearly 4 months after my injury and surgery, I was able to go back to work part-time using a special keyboard and mouse. I will never have full use of my wrist—my doctor is hoping for 70%. My husband is self employed, age 66 years, and gets Medicare. I carry the insurance for our family and am not eligible for Medicare. So, no matter what, I can't quit my job because we need insurance. ”

rosalie

## pre-existing conditions

Maria is an audiologist. She works mostly with people who have hearing issues and sees patients who struggle to find insurance due to pre-existing conditions. Maria is very passionate about pre-existing conditions and does not believe that health insurance companies should be able to discriminate based on them.

maria

## Share your own story!

The stories told throughout this toolkit embody just a few of the many Wisconsin women's voices that need to be heard. Raise your voice, the time is now!

To share your own story, fill out the form on page 19, or email WAWH at [info@wiawh.org](mailto:info@wiawh.org).







**Wisconsin Alliance for Women's Health**  
P.O. Box 1726  
Madison, WI 53701  
(608) 251-0139  
[www.supportwomenshealth.org](http://www.supportwomenshealth.org)

**Raising Women's Voices**  
[www.raisingwomensvoices.net](http://www.raisingwomensvoices.net)  
[www.raisingwiwomensvoices.org](http://www.raisingwiwomensvoices.org)

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