

COOK COUNTY MWCCS Newsletter

MACS/WIHS COMBINED COHORT

Winter 2024/Spring 2025

Newsletter



A Message from the MWCCS Principle Investigators

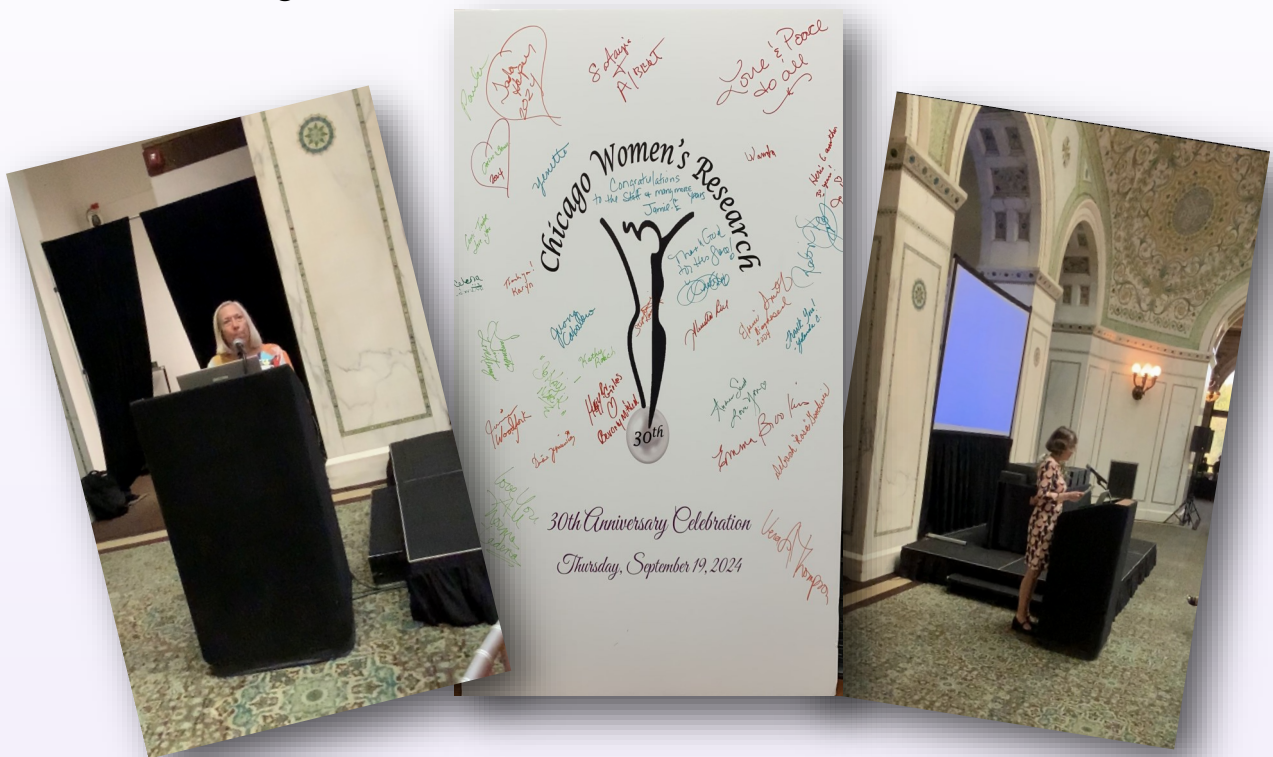
We are truly grateful that you have been on this journey with us for the past 30 years. Your participation throughout the years has been instrumental to the success of our Chicago Women's Health Study. You have helped us learn how HIV affects women and helped improve the lives of ALL women. We celebrate YOUR amazing resilience and the wonderful achievements that have been made during these past 30 years. With your help, we look forward to eradicating and mitigating the effects of HIV in the years to come.

THANK YOU

30th Anniversary Luncheon Chicago Cultural Center

On September 19th, 2024 MWCCS (Formerly WIHS) participating Chicago sites gathered together with study participants, current and former staff, along with our Principal Investigators at the Chicago Cultural Center to celebrate 30 years of dedication to the study of women and HIV research.

Anchored by Dr. Mardge Cohen who started the WIHS study in 1994, the luncheon included a historical retrospect, current strides in the field of HIV research, guest speakers, letters of support and recognition from Senators Dick Durbin and Tammy Duckworth, a state proclamation from Governor J.B. Pritzker, a musical tribute in memory of participants we've lost throughout the years, participant and staff honors, pictures and more to round out a great fall afternoon.



Left to right: Dr. Mardge Cohen (PI)—Dance of Life Anniversary Luncheon signature board—Dr. Audrey French (PI)

How We Started

A Historical Retrospect from Dr. Mardge Cohen

Over 35 years ago I was an internist working with others at the Cook County Women and Children's HIV Program. After activists and health care workers protested that not enough attention was going to studying the impact of HIV on women with and at risk for HIV in the United States, the National Institute of Health (or NIH) put out an announcement of new research dollars to study HIV in women. Our citywide group included Cook County, Rush, UIC and Northwestern applied and we became one of the 6 sites across the country to be awarded a grant to begin this work.

By 1994, when the first participants enrolled in the Women's Interagency HIV Study (WIHS), AIDS was the leading cause of death for all Americans aged 25-44. There was enormous stigma towards those who were infected with HIV or loved or cared for those who were. Men who had sex with men, people who used drugs, women who had sex with men who used drugs, bisexual men, people who were incarcerated—there was a lot of blame rather than compassion. But for those of us who were part of that first group of patients, providers, and activists, struggling to survive and stay well enough for the next discovered drug that might work, and deciding who to confide in about the fear and uncertainty, there was an intimacy that developed that helped us stay focused and realize what was most important.

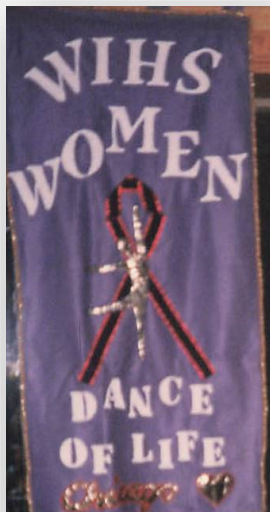
And this collaborative approach underscored the beginnings of WIHS and the approach we took in Chicago. From early on and with each wave of enrollment, you, the participants, agreed to let us ask you every question under the sun and take your blood, and do exams and you kept coming back every 6 months! We tried to respect the time and effort of every participant. We offered transportation, child care early on in the study, parking, food (which sometimes you like and sometimes you didn't). Our research team included women who didn't just interview you, but knew you, your family and what mattered to you, it included phlebotomist who knew what you liked and what you needed. It included examiners who wanted to help you even when you might not have wanted that colposcopy at all. Our team cared about you and we know you cared about us as well. We tried to share with you what we learned after we collected all that information from you and women all over the country. You asked more and more wonderful questions, steering us to the areas that most mattered to you and in the end these areas mattered to everyone because you knew what mattered.

How We Started A Historical Retrospect from Dr. Mardge Cohen

As part of a team who cared deeply for the women and children in the County Program, when not that many others did, we were able to hear what women and children were telling us –what they wanted when they came to the clinic. And we were able to be creative and take chances. We built a program that addressed fear and loneliness, substance use, intimate partner violence, being incarcerated, punitive policies of DCFS, children's concerns at school and within the family, getting SSI, flexible appointments and group support.

But when it came to NIH research I definitely needed some help to make things run smoothly through the huge bureaucracy of Cook County and the other Chicago hospitals and the NIH. Back in the early 1990s we were lucky enough to have Kathleen Weber monitoring some of the early HIV studies at the County Women and Children's clinic. Her ability to manage all those institutions and the rules of the NIH and understand and care about the women in the study was the key to our success. And even though she dreamed about going around the world in a boat she built, you and the study anchored her back here year after year.

But Kathleen and I also needed some additional help. We needed to have the ear of someone participating in the study who would make sure we knew how the study felt to participants, what was needed to make it work and who could challenge us to continuously make it better.



Dance of Life Quilt



WIHS Holiday Party 1997



Marta Santiago 1998

There's Still More to Come for MWCCS... Dr. Mardge Cohen

Marta Santiago. Marta wrote the first letter in the original application saying that she would participate in a community advisory board to raise the voices of participants as the study continued, and she has from the very beginning until now as she works with the National Advisory Board of the MWCCS.

Of all the sites in WIHS, the Chicago site has always had the best or second best retention. Do you know that almost 1 out of every 4 women in the current study started with the first wave in 1994 and most of those have come to all their visits over the past 30 years! That means you have come back to the most visits and contributed important data more than any other group in the other cities. And as the study has now combined with the study of men with and at risk for HIV, Chicago continues to shine so brightly. You've completed those echos and pulmonary function tests and neurocognitive testing faster and better than the other sites as well. You are indeed incredibly special!

What have we accomplished? Together, we have shown that taking antiretroviral therapy can reduce cervical abnormalities and disease in women with HIV; we learned that cardiovascular disease may be made worse by HIV and we should start therapy early, along with stopping smoking, we learned that mental health and trauma are important factors influencing cognitive function as we age, and we learned that mutuality (caring for others and letting others care for us), agency (asserting oneself to have healthy habits), and having available resources and services make for a higher quality of life.

I'm struck by something in the news this week related to the divisiveness we are seeing in the campaign and in our country. Thirty years ago when WIHS began, Haitians were being stigmatized and blamed for bringing HIV in to this country. And now, Haitians are again being stigmatized and used by racists to divide our country over immigration and jobs and values in our communities. When I think of you and this study I see the opposite as we come together for the common purpose of a healthier population and society.

IF YOU HAVE PICTURES FROM THE ANNIVERSARY PHOTO BOOTH AND YOU WANT TO ADD TO THE MWCCS EVENT ARCHIVES PLEASE CALL CRYSTAL 312-206-0965.

Proclamation from the Office of the Governor's Office

Governor J.B. Pritzker



Senator Dick Durbin

RICHARD J. DURBIN

ILLINOIS

MAJORITY WHIP

United States Senate
Washington, DC 20510-1304

COMMITTEE ON AGRICULTURE,
NUTRITION, AND FORESTRY

COMMITTEE ON APPROPRIATIONS

COMMITTEE ON THE JUDICIARY

September 19, 2024

Dear Friends:

It is my pleasure to welcome you to the Chicago Women's HIV Research Cohort's 30th Anniversary Luncheon. This gathering is an opportunity to recognize the work of the HIV Research Cohort and its advancements in women's health.

Since 1994, the Chicago Women's HIV Research Cohort has focused on addressing the impact of HIV on women and the risk factors associated with it. By providing child care and transportation to participants, the HIV Research Cohort has made participation in its studies more accessible to all. For three decades, these contributions have provided valuable insights into how HIV affects women's physical, reproductive, and mental health, shedding light on an underrepresented population. I applaud your commitment to advancing HIV research and improving women's health outcomes.

Again, I would like to extend my warmest wishes to today's attendees for your dedication to the Chicago Women's HIV Research Cohort and for the positive impact your research has had on the lives of women. Congratulations on all your work and achievements.

Very truly yours,



Richard J. Durbin
United States Senator

711 HART SENATE OFFICE BUILDING
WASHINGTON, DC 20510-1304
(202) 224-2152

230 S. DEARBORN STREET
SUITE 3892
CHICAGO, IL 60604
(312) 353-4952

525 SOUTH EIGHTH STREET
SPRINGFIELD, IL 62703
(217) 492-4062

1504 THIRD AVENUE
SUITE 227
ROCK ISLAND, IL 61201
(309) 786-5173

250 W. CHERRY STREET
SUITE 115-D
CARBONDALE, IL 62901
(618) 351-1122

durbin.senate.gov

Senator Tammy Duckworth

TAMMY DUCKWORTH
ILLINOIS

United States Senate

COMMITTEES
ARMED SERVICES
COMMERCE, SCIENCE,
AND TRANSPORTATION
FOREIGN RELATIONS
SMALL BUSINESS
AND ENTREPRENEURSHIP

September 4, 2024

Women's Interagency HIV Study (MWCCS)
2225 West Harrison Street, Suite B
Chicago, IL 60612

Dear Friends at the Women's Interagency HIV Study:

Congratulations to the Women's Interagency HIV Study on your 30th Anniversary! Your organization's dedication and commitment to excellence have significantly contributed to the betterment of public health and the fight against HIV.

This significant milestone is a testament to the hard work and collaborative spirit of your team. It is organizations like yours that drive progress, inspire positive change and set a standard of excellence for others to follow.

Once again, congratulations on your 30th Anniversary. I look forward to seeing the Women's Interagency HIV Study continue to thrive and make impactful contributions in the future.

Sincerely,



Tammy Duckworth
United States Senator

SUITE 524
HART BUILDING
WASHINGTON, DC 20510
(202) 224-2854

SUITE 3900
KLUCZYNSKI FEDERAL BUILDING
230 S. DEARBORN STREET
CHICAGO, IL 60604
(312) 886-3506

8 SOUTH OLD STATE CAPITOL PLAZA
SPRINGFIELD, IL 62701
(217) 526-6124

EURMA C. HAYES CENTER
441 EAST WILLOW STREET
CARBONDALE, IL 62901
(618) 677-7000

SUITE 2
1823 2ND AVENUE
ROCK ISLAND, IL 61201
(309) 606-7060

SUITE 460
23 PUBLIC SQUARE
BELLEVILLE, IL 62220
(618) 722-7070

The Three Stages of Menopause

Are you going through the “change”? Menopause marks the point in a woman’s life when she hasn’t had a period in twelve consecutive months. But it’s so much more than that.

There are physical, mental and emotional symptoms that may accompany the change of life marked by menopause. And the years immediately before and after menopause can be challenging as well. That’s because menopause takes place in three stages. Perimenopause, menopause and post menopause.

Let’s start with perimenopause. This is when your ovaries begin to make less of the hormone estrogen. Perimenopause usually occurs between 8-10 years before the start of menopause, but this timeline varies. It tends to happen in the mid-forties but can begin as early as the thirties. And perimenopause can last from a few months to up to ten years.

Because of the drop in hormone production, you might experience symptoms. They can include:

- Hot flashes and night sweats
- Breast tenderness
- Worse premenstrual (pms) symptoms
- Lower sex drive
- Fatigue
- Irregular periods
- Vaginal dryness or discomfort during sex
- Leaking pee when you cough or sneeze
- Having an urgent need to pee more frequently · Mood swings
- Trouble sleeping
- Short-term memory problems
- Trouble concentrating

While these symptoms are typical for perimenopausal women, some irregular periods can indicate other health problems. A trip to your primary care doctor can confirm perimenopause and rule out other problems, such as uterine fibroids.

Menopause Facts (cont.)

Although hormone levels are lower during perimenopause, women can still get pregnant. So, it is important to continue using birth control during this phase.

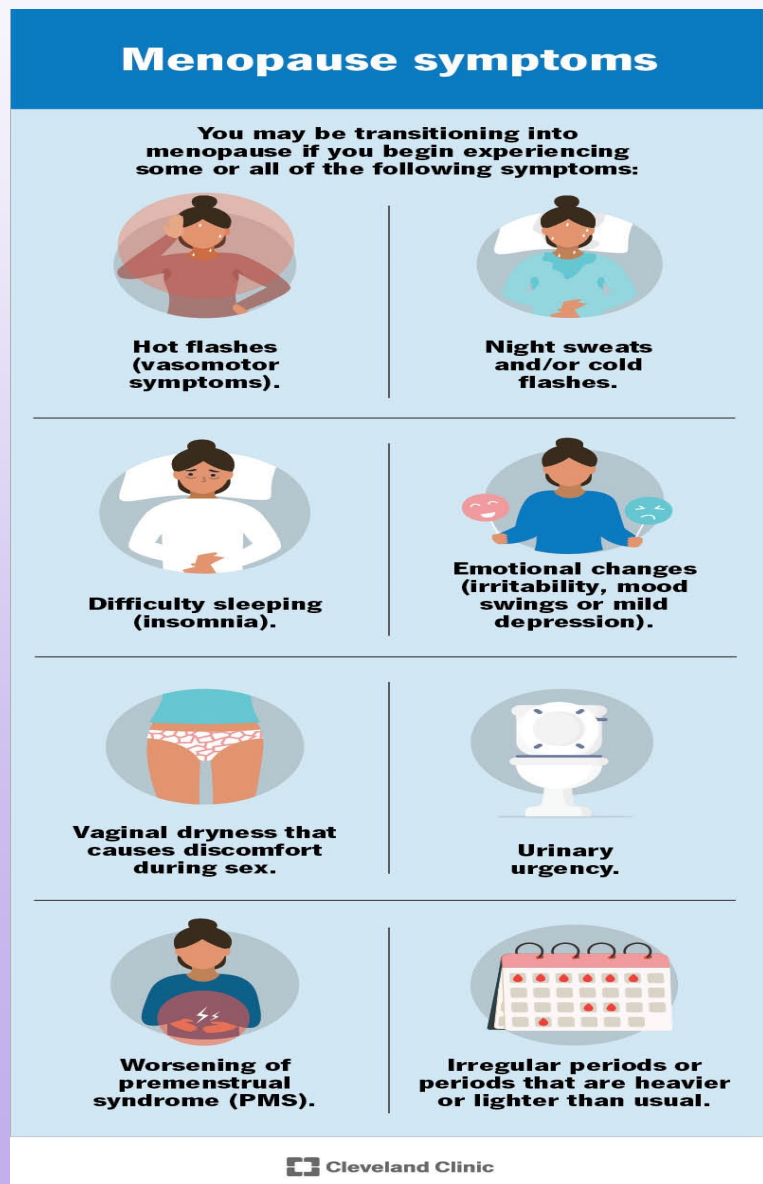
A full year after your last period, menopause begins. Some symptoms common to perimenopause may continue or intensify the closer you get to menopause such as hot flashes and trouble sleeping. Your doctor may ask questions, run blood tests and check your hormone levels to determine if you are in menopause.

Once menopause starts, some women find relief from symptoms. But the loss of hormone production can contribute to continuing issues, such as hot flashes and night sweats as well as some new difficulties. Postmenopausal symptoms might include:

- Depression
- Changes in sex drive
- Dry skin
- Weight changes
- Hair loss
- Urinary incontinence

Your doctor may prescribe medications to treat postmenopausal symptoms. Hormone therapy might be recommended for women under sixty for a short period. Antidepressants, Gabapentin and vaginal creams are sometimes prescribed to treat mood swings, hot flashes and vaginal dryness. Additionally, there are lifestyle changes, such as exercise, meditation and a diet rich in phytoestrogen that can help manage postmenopausal symptoms.

Every woman experiences menopause. Becoming aware of the stages of this change in life can make the transition easier.



Have a Heart: Women and Heart Disease



Did you know that women have a greater chance of dying from heart disease than men? In fact, according to the Department of Health and Human Services, heart disease is the number one killer of American women. But studies have shown that many women don't realize that conditions such as Coronary Artery Disease (CAD) are a danger. Despite the fact that CAD -- where plaque builds up on the walls of the arteries carrying blood to the heart, causing them to narrow and harden -- is the most common type of heart disease.

Another problem is that there often are no symptoms. The Office on Women's Health says that two out of every three women who die suddenly from heart disease did not have symptoms.

So, what can women do about CAD and other heart diseases? Start by minimizing the risks you can control and managing the risks you can't. These are steps you can take on your own to reduce your risk of heart disease.

- Not smoking. If you don't, good. If you do, stop. It increases your risk at any age.
- Eating a heart healthy diet, such as fruits, vegetables and whole grains.
- Heart pumping aerobic exercise, such as cycling, swimming or even brisk walking for at least 30 minutes a day three to five times a week can strengthen your heart.
- Limit alcohol. Excessive drinking can lead to alcoholic cardiomyopathy (a heart disease caused by chronic alcohol intake) and other health problems.
- Maintain a healthy weight. If this means losing some weight, know that doing so is good for your heart.

Have a Heart: Women and Heart Disease

There are other risks you can manage with a health care provider's help. They include:

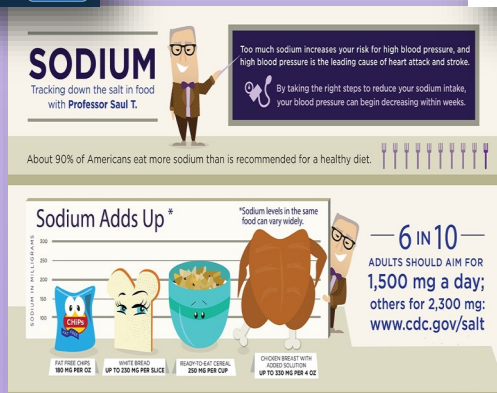
- High Blood Pressure. If uncontrolled, it can lead to heart disease and heart attack.
- High Cholesterol is another health problem that can worsen heart disease if it goes untreated.
- Diabetes can raise your risk of heart disease up to four times

Work with your health care provider so these issues doesn't get out of hand.

Finally, there heart risk factors that you can't really control. But knowing what they are can increase your awareness of potential disease.

- Family History. Genetic and environmental factors can lead to higher risk for heart disease. Tell your doctor if a parent or sibling has been diagnosed with premature heart disease.
- Age and Menopause. Women can develop heart disease at any age but, post menopause, their bodies make less estrogen. The female hormone provides some protection against heart disease. Talk with your doctor about post-menopausal tests for your heart health.

Bottom line, women need to take heart disease seriously. Now that you know the facts, you can manage your risks.



A Message from the Heart—Q & A with Calvine Thompson

Heart disease is serious and for our longtime MWCCS RA Calvine Thompson, it has hit home. She has been dealing with a new diagnosis of heart disease and was kind enough to answer some questions about her experience.

Q: Many women with heart problems don't have any symptoms. How did you find out about your condition?

A: I was diagnosed during a routine physical required for Medicare yearly. One of the tests that they did was an angiogram (a scan to show blood flow through the body's blood vessels and heart), which showed that I had a 90% blockage in the arteries leading to my heart. I had no symptoms whatsoever.

Q: What was your treatment?

A: The treatment was open-heart surgery. I had a triple bypass with a valve replacement. *Triple bypass with valve replacement surgery involves a surgeon using a blood vessel from another part of your body to create a bypass route for blood to go around blocked artery sections; then a diseased heart valve is removed and replaced.*

Q: How was your recovery journey?

A: Recovery has been slow. Although I feel fine, they also discovered blockages in both carotid arteries. One is so severely blocked that it requires surgery and the other one needs a stent (*a tiny tube to hold a hollow structure in the body open*).

Q: What lifestyle changes have you made as a result?

A: The only changes that I have made to my lifestyle so far is trying to watch my diet. I had stopped smoking 2 years ago, which I believe played a huge part in my illness. I should be exercising but I haven't been cleared by my doctor for anything more than walking.

Q: What are you learning about this experience?

A: I encourage all of the participants to stop smoking and try to follow a heart healthy diet. And make sure you keep up with all your doctor's appointments. Even if you feel fine.

Winter's Coming

READ/WATCH/LISTEN (Staff Picks)

Winter-time temperatures in Chicago are not for the weak. There are plenty of outdoor activities. But what if all you want to do is stay curled up on the couch? Here are our staff picks for your reading, viewing and listening pleasure.

What to Read (Books/Magazine/Articles)

Our Pick!

The Neighbor Favor a romance by Kristina Forest
Shy Lily asks her charming but secretive neighbor Nick for help getting a date. Laughter and romance follow.
(available in paperback/Kindle/Audible)



What to Watch (TV/Movies/Online)

Our Pick!

Hard Knocks: Training Camp with the Chicago Bears
The popular documentary series goes behind the scenes with the Chicago Bears as they prepare for the 2024-25 season with a new quarterback.
(available on HBO, streaming on MAX)



Have a Listen (Music/Podcast)

Our Pick!

Her Dinero Matters
Jen Hemphill's bilingual podcast features interviews, tips and strategies for women who want to take charge of their money.
(available on iTunes, Spotify, Apple Podcasts)



Clinic Rules

When MWCCS staff usher our participants into the clinic, we like to present as welcoming an atmosphere as possible. For that reason, we have a few clinic rules.

Rule #1 – No smoking in the clinic. This includes common areas, such as the bathroom. In the interest of health and safety, the entire MWCCS clinic is smoke-free.

Rule #2 – No vaping in the clinic. It's really no healthier than smoking. And neither smoking or vaping is legal indoors.

Rule #3 – No alcoholic beverages in the clinic. We are at the beginning of Visit 105. The clinic will be busier than ever and alcohol consumption can lead to disruptive behavior.

Rule #4 – Don't bring non-prescription drugs for use in the clinic. The results of illicit drug use can be unpredictable.

Rule #5 – No firearms or other weapons. Again, for everyone's safety, the clinic is a gun-free zone.

These simple guidelines are meant to make MWCCS visits pleasant for everyone.

Word to the WIHS...

Here's a tip for all participants who signed up to receive texts or emails about your up-coming visits:

The reminder will inform you that your appointment is with Dr. Audrey French. When you receive this reminder, come to 2225 W Harrison for your clinic visit.