

Trusted Health Information from the National Institutes of Health

# NIIH MedlinePlus

SUMMER 2016

the magazine

**Padma Lakshmi,**  
host and producer of the hit  
TV show *Top Chef*, endured a  
23-year struggle to find  
relief from the pain of  
endometriosis.

## Confronting **Endometriosis**

**Zika Virus:  
Assessing the Threat**

**Avoiding Drug and Alcohol  
Interactions**

**Colorectal Cancer  
Screening**

## NLM Supports Outreach Efforts to Diverse Communities



Photo: Bill Branson, NIH

Betsy Humphreys, acting director of the National Library of Medicine (NLM); Donald A.B. Lindberg, MD, director emeritus of the NLM; and Nainoa Thompson, master navigator of the Hokule'a.

In May, the National Library of Medicine (NLM) hosted two events that highlight how the Library promotes National Institutes of Health (NIH) outreach efforts to diverse communities.

### Native Hawaiian Health

The Hokule'a is an iconic double-hulled canoe from Hawaii that is on a journey of 47,000 nautical miles around the world. It will stop at 85 ports in 26 countries, including landing in Old Town Alexandria, Virginia, on May 15, 2016.

During that stop, Nainoa Thompson, master navigator of the Hokule'a, keynoted a special presentation on Native Hawaiian health at the NLM. Thompson told a packed audience in the Library's Lister Hill Auditorium about:

- The rich history of deep sea voyaging, exploration, and oceanic way finding
- The indigenous system of orientation and navigation at sea
- Efforts to use these experiences to revitalize Native Hawaiian culture and health

He explained the symbiotic relationships between land, sea, sky, and people, and their cultural, ecological, and personal health.

Follow the journey of the Hokule'a at [www.hokulea.com](http://www.hokulea.com).

### Science Pathfinders Day

NIH was the site of the Third Annual Science Pathfinders Day. The event, sponsored by the NLM, the Friends of the NLM, and Mentoring in Medicine (MIM), seeks to promote diversity in the biomedical workforce. It brings hundreds of middle and high school students from the Washington, D.C., metropolitan area to the NIH campus to hear NIH scientists and researchers tell about the work they do and the scientific process.

MIM is a national nonprofit organization that has reached more than 50,000 parents, students, and educators since 2008 with in-class and after-school electives focused on bringing science to inner-city and rural public schools. Funded in part by the NLM, MIM has organized programs in New York; Washington, D.C.; Florida; Maryland; Montana; Michigan; and Georgia. To learn more about MIM, visit [www.mentoringinmedicine.org](http://www.mentoringinmedicine.org).

**Glen P. Campbell, Chairman**

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Photos: Bill Branson, NIH

Dr. Lynne Holden (upper right), president of Mentoring in Medicine, with scenes from Science Pathfinders Day.

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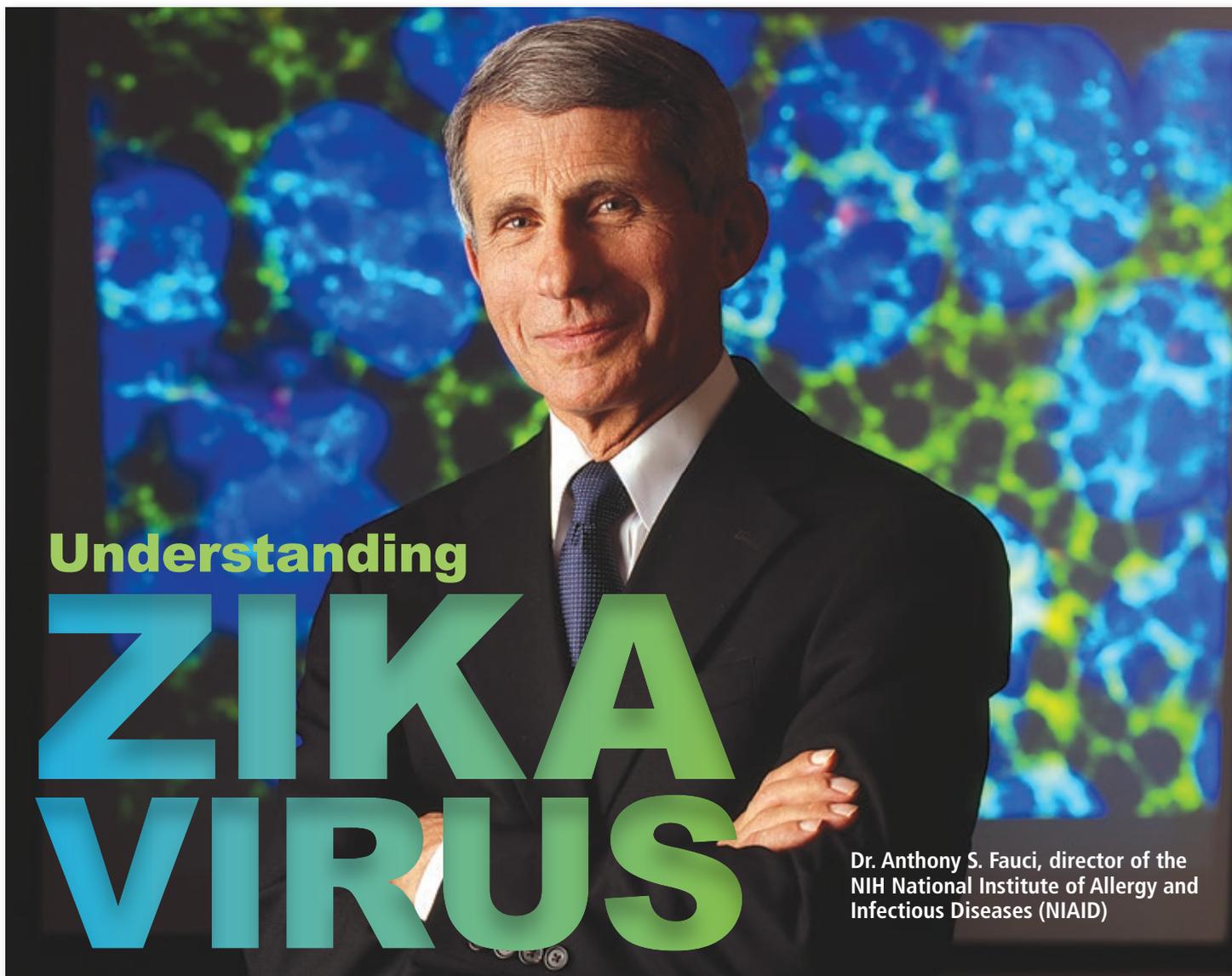


Photo: NIAID

Dr. Anthony S. Fauci, director of the NIH National Institute of Allergy and Infectious Diseases (NIAID)

Discovered in the Zika Forest of Uganda in 1947, the mosquito-borne Zika virus has very recently become a public health concern in the United States and throughout Latin America and the Caribbean. *NIH MedlinePlus* magazine spoke about Zika with **Dr. Anthony S. Fauci**, director of the NIH National Institute of Allergy and Infectious Diseases (NIAID).

### What does the American public need to know about Zika virus?

It is a bit complicated because as a disease—excluding the presentation in pregnant women—Zika is relatively mild. It is characterized by a few days or a week of aches, pains, fever, rash, and inflamed eyes—called conjunctivitis. The majority of people do not show symptoms.

Zika is a flavivirus, part of the same family of viruses that cause yellow fever and dengue fever. *Aedes* mosquitoes spread all three viruses. In terms of severity, yellow fever and dengue fever are deemed more serious than Zika.

### What about the Zika virus and pregnant women?

If you are a pregnant woman and get infected with Zika during pregnancy, there is a chance—perhaps as high as one in three—that your fetus will have a congenital abnormality. The virus can cause

microcephaly, a condition in which the fetus's head is abnormally small and can be associated with incomplete brain development and destruction of brain cells. We are also seeing other Zika-associated fetal developmental problems such as eye defects, hearing loss, and impaired growth.

## What risks does Zika pose for average Americans?

I use the analogy of the relative risk of those who frequently, or daily, drive on the Washington, D.C., Beltway, where serious accidents happen every day. That kind of accident happening to you is much more likely than getting infected in this area by some of the diseases people are concerned about, like dengue fever, chikungunya, or Zika.

By June 8, the Centers for Disease Control and Prevention (CDC) had identified Zika cases in 46 states. So far, none of these infections was acquired locally through infected mosquitoes. So far, all of these cases have been acquired through travel (or sexual contact with someone who has traveled) to countries or territories where Zika is circulating. In the continental U.S., it is almost certain that mosquito bites will spread Zika virus—but I do not expect we will see widespread or sustained outbreaks.

## Are there other Zika-related conditions?

There are some other conditions that have been associated with Zika infection. One is Guillain-Barré syndrome (GBS), which occurs following an infection (like Zika) in the neurological system. The peripheral nerves (those nerves outside the brain and spinal cord) become diminished and can lead to severe neurological problems. Most people fully recover from GBS, although recovery can be lengthy. In very rare cases GBS results in permanent paralysis or death; NIH is gathering information to determine the percentage of people with Zika infection who develop GBS.

## What institute is covering the research on Zika virus?

NIAID is predominately the institute involved with supporting the development of a Zika vaccine, but other institutes such as NICHD and NINDS are also researching aspects of the disease. At NIAID, we have decades of experience in developing vaccines for many types of infections, including those that fall in the same family as Zika, namely yellow fever, dengue, and West Nile virus. Vaccine development is something that ranks among our highest priorities and responsibilities.

## What is NIAID's timetable for developing a vaccine?

Likely in September, NIAID will begin a Phase I vaccine trial to determine whether the experimental vaccine is a safe vaccine and induces the predicted protective response. The trial will likely enroll about 80 people and take about four months for preliminary results. By the first quarter of 2017, NIAID could begin a much larger safety and efficacy trial to see if the vaccine can prevent disease.

The amount of time needed to determine efficacy will depend on the infection rate of the location where we test the vaccine. We could know as early as the beginning of 2018, but it may take much longer. Nonetheless, we are moving ahead expeditiously on the vaccine.

## Any additional thoughts?

In collaboration with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, we're conducting the Zika in Infancy and Pregnancy Study—referred to as ZIP. We're doing a lot of basic work to determine the natural history of the condition and associated congenital abnormalities, particularly microcephaly.

## Find Out More

- ✓ **National Institute of Allergy and Infectious Diseases (NIAID):** [www.niaid.nih.gov/topics/zika/Pages/default.aspx](http://www.niaid.nih.gov/topics/zika/Pages/default.aspx)
- ✓ ***Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD):** <http://go.usa.gov/chQHh>
- ✓ **NIH Fogarty International Center:** [www.fic.nih.gov/ResearchTopics/Pages/infectiousdiseases-zika-virus.aspx](http://www.fic.nih.gov/ResearchTopics/Pages/infectiousdiseases-zika-virus.aspx)
- ✓ **Zika Virus Health Information Resource Guide:** <https://disasterinfo.nlm.nih.gov/dimrc/zikavirus.html>
- ✓ **NIH MedlinePlus:** [www.nlm.nih.gov/medlineplus/zikavirus.html](http://www.nlm.nih.gov/medlineplus/zikavirus.html)
- ✓ **Zika Virus Disease in the United States, 2015–2016:** [www.cdc.gov/zika/geo/united-states.html](http://www.cdc.gov/zika/geo/united-states.html)
- ✓ **Clinical Trials:** <https://clinicaltrials.gov> (search for Zika Virus)

# Know Before You Go

If your summer vacation plans include travel to areas where Zika is a threat, keep these CDC recommendations in mind.



## What is Zika?

Zika is a disease primarily spread by mosquitoes, but a man with Zika can spread it to his sex partners as well. Learn more about Zika at [www.cdc.gov/zika](http://www.cdc.gov/zika). To find out if your travel destination has Zika, check [www.cdc.gov/travel](http://www.cdc.gov/travel).

## Pack to prevent

- Insect repellent (look for DEET, picaridin, IR3535, OLE, or PMD among the ingredients)
- Long-sleeved shirts and long pants
- Clothing and gear treated with permethrin
- Infant carrier mosquito net (if needed)
- Bed net (if mosquitoes can get to where you're sleeping)
- Condoms (if you might have sex)



## Protect yourself

- Use insect repellent. Reapply as directed. Remember to apply sunscreen first and then insect repellent.
- Cover exposed skin when possible.
- Stay and sleep in screened-in or air-conditioned rooms. Use a bed net if you're sleeping outside.
- Use condoms if you have sex.



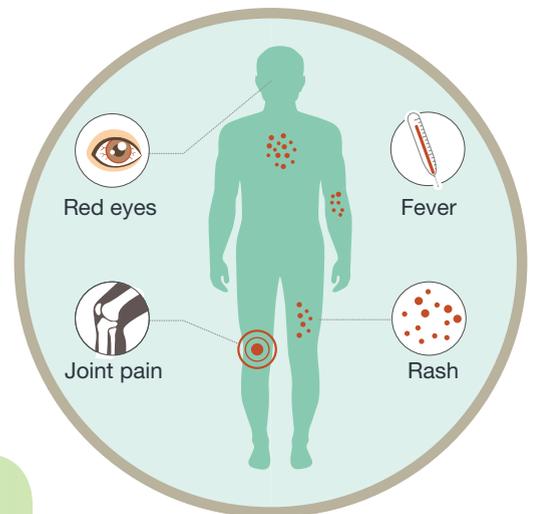
## Stop the spread

- Watch for symptoms when you get home.
- Call your doctor immediately if you suspect Zika.
- Use insect repellent for 3 weeks after travel.
- Use condoms when you have sex.

## Zika symptoms

(are mild and last about a week)

- Red eyes
- Fever
- Joint pain
- Rash



## Pregnant or trying to conceive?

- Zika is linked to birth defects.
- If you're pregnant, you should consider postponing travel to any area with Zika.
- If your male partner travels to these areas, either use condoms or don't have sex for the rest of your pregnancy.
- If you are trying to become pregnant, talk to your doctor about your travel plans.

[www.cdc.gov/zika](http://www.cdc.gov/zika)



U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention

# Alcohol, Medicines, and Aging



Photo: iStock

You've probably seen warnings on medicines about mixing them with alcohol. Doing so can cause nausea and vomiting, headaches, drowsiness, fainting, or loss of coordination. You can be at risk for internal bleeding, heart problems, and difficulty breathing. Alcohol can make a medication less effective or even useless, or it may make it harmful or toxic to your body.

## Stay Informed, Stay Safe

Knowing what's in your medications—and how they interact with alcohol—will help keep you safe and your medicines working effectively.

Medications typically are safe and effective when used appropriately, and your pharmacist or other health care provider can help you determine which medications interact harmfully with alcohol. You should also read the label on the medication bottle to find out exactly what ingredients a medicine contains.

Some medications, including many that can be purchased without a prescription, contain one or more ingredients that can react with alcohol. In particular, sedative-hypnotic drugs (e.g. sleep aids, anti-anxiety drugs, and drugs that suppress arousal) amplify the depressant effects of alcohol, and drinking alcohol while taking these drugs may be especially dangerous. Other medications that can react with alcohol include many popular painkillers and cough, cold, and allergy remedies. Even some herbal remedies can have harmful effects when combined with alcohol. And it is very important to remember—alcohol and medicines can interact harmfully even if they are not taken at the same time.

## Older Adults and Women Need To Be Particularly Vigilant

Even without medication interactions, alcohol can pose a particular risk for certain groups, including women and older people. Women have a higher risk of alcohol-related problems than men do, because women's bodies generally have proportionately less water than men's. This means that when a woman drinks, the alcohol in her bloodstream typically reaches a higher level than a man's even if both are drinking the same amount.

*continued on page 6*

## FastFacts

- ✓ You can become more sensitive to alcohol as you get older.
- ✓ Heavy drinking can make some health problems worse.
- ✓ Medicines and alcohol don't mix.
- ✓ Taking aspirin and drinking alcohol can raise the chance of bleeding in your stomach.
- ✓ You can get very sleepy if you drink alcohol and take cold or allergy medicines.
- ✓ Drinking alcohol while taking some sleeping pills, pain pills, or anxiety or depression medicine can be very dangerous.
- ✓ You can hurt your liver if you drink and take a lot of painkillers that have the word "acetaminophen" on the label. Always check warning labels.

—National Institute on Aging

*continued from page 5*

Because the amount of water in the body declines with age, older people reach higher blood alcohol concentrations after each drink than younger people. Meanwhile, as we age we become more sensitive to some of the impairments alcohol produces. On tests that require quick and accurate responses, older adults are affected more than younger adults after a few drinks. Similarly, balance, concentration, attention, and driving skills also are impaired more in older versus younger adults after a few drinks.

Adding medication to the equation can make the situation even more complicated. Larger impairments in older drinkers could contribute to injuries (especially from falls) and can make already harmful medication interactions more dangerous. Older people also are more likely to take a medication that interacts with alcohol—they often need to take more than one of these medications.

Paying attention to your drinking patterns and your medications—particularly for women and older adults—is an easy way to stay healthy and safe.

**“The risks of excessive drinking increase as we age, in part because older drinkers are more sensitive to the sedative (sleep-inducing) effects of alcohol, as well as its effects on cognitive function including balance, coordination, attention, decision making, and driving skills.”**

—George F. Koob, PhD, Director, National Institute on Alcohol Abuse and Alcoholism



Photo: NIH

## Improper Medication Use Rising Among Older Adults

### Problems Taking Medications

Many older adults take medications that treat health conditions like pain and heart disease. Most take their medications properly, but some older adults have problems taking them the way they should. This includes unintentionally taking a medication the wrong way, as well as intentional abuse.

### Unintentional Abuse

Some people accidentally take medicines incorrectly, often without knowing it. They may forget their medicine, take it too often, or take the wrong amount. As people age, trouble with vision or memory can make it hard to use medications correctly.

Taking lots of medications at different times of the day can be confusing. Another common problem is having more than one doctor who prescribes medicines, but no single doctor who monitors them all and checks for any interactions.

Taking a prescription medication as directed by a doctor is generally safe and effective. But lately there has been a rise in the number of older adults who use medicines improperly,

including for non-medical reasons, and suffering the consequences. Recent reports show increased hospitalizations and visits to emergency rooms by older people involving improper use of prescription as well as illicit drugs.

### Intentional Abuse

Intentional abuse is when a person knowingly uses prescription medications the wrong way, takes medicines not prescribed for him or her, or combines them with alcohol or illicit drugs. People may do this to feel good, feel better, or calm down.

Sometimes a big change, such as retirement, the death of a loved one, or failing health, can lead to loneliness, boredom, anxiety, or depression. That can prompt a person to begin, continue, or increase the abuse of medications or other drugs.

Medication-related hospital admissions for older adults are mostly linked to overdoses from pain medication and withdrawal symptoms from other addictive drugs, such as sleeping pills.

## Take this Quick Quiz: Alcohol and Medications

- Older people are more sensitive to alcohol's effects than younger people.**
  - true
  - false
- Which of these is considered to be one alcoholic drink?**
  - 12 ounces of regular beer
  - 5 ounces of wine
  - 1.5 ounces of 80-proof distilled spirits
  - none of the above
  - all of the above
- An older adult can safely have three alcoholic drinks each day, totaling 21 per week.**
  - true
  - false
- Drinking alcohol and/or mixing medications with alcohol can put older adults at higher risk of falls and fractures.**
  - true
  - false
- Drinking alcohol and taking medications for which of the following conditions can make the condition worse?**
  - high blood pressure
  - diabetes
  - gout
  - heart failure
  - all of the above

Find answers on page 23

### Risks for Older Adults

Older adults may suffer serious consequences from even moderate drug abuse because of several risk factors. As the body ages, it cannot absorb and break down medications and drugs as easily as it used to.

As a result, even when an older adult takes a medication properly, it may remain in the body longer than it would in a younger person. As people age, they may also become more sensitive to alcohol's effects.

Aging brains are also different than young ones and may be at greater risk for harmful drug effects (on memory or coordination, for example). Having other medical conditions (such as heart disease) that require medications for treatment while abusing prescription drugs at the same time also presents unique risks for older adults, many of whom have chronic medical conditions.

### Find Out More

- ✓ **Harmful Interactions: Mixing Alcohol with Medicines:** <http://pubs.niaaa.nih.gov/publications/Medicine/medicine.htm>
- ✓ **Older Adults and Alcohol: You Can Get Help:** [www.nia.nih.gov/health/publication/older-adults-and-alcohol/get-facts-about-aging-and-alcohol](http://www.nia.nih.gov/health/publication/older-adults-and-alcohol/get-facts-about-aging-and-alcohol)
- ✓ **MedlinePlus:** [www.nlm.nih.gov/medlineplus/alcohol.html](http://www.nlm.nih.gov/medlineplus/alcohol.html)  
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- ✓ **Alcohol Use and Older Adults:** <http://go.usa.gov/chU3W>
- ✓ **Improper Use of Medications:** <http://go.usa.gov/chU3R>

# TOP CHEF

*Top Chef host Padma Lakshmi speaks out about her decades-long battle with endometriosis.*



Padma Lakshmi (in yellow), flanked by *Top Chef* co-stars Richard Blais, Tom Colicchio, and Gail Simmons.

**Padma Lakshmi**, author, actress, model, and Emmy-nominated host and executive producer of the hit TV show *Top Chef*, endured a 23-year struggle to find relief from endometriosis. The condition occurs when tissue that normally lines the inside a woman's uterus grows outside the uterus, and can cause pain, infertility, and very heavy periods. From her teen years into adulthood, she suffered with severe monthly cramping, shooting pains, and numbness without knowing why. In her mid-30s, she was finally diagnosed with endometriosis. She recently revealed to *NIH MedlinePlus* magazine how the experience shaped her advocacy efforts for those with the condition.

# Confronting Endometriosis

## Would you share your personal history with endometriosis?

My symptoms started with my first period when I was 13. I had severe cramps and excessive bleeding, which were present throughout my adolescence and got worse and increasingly difficult to manage while I was in college. Sometimes it was so severe my pelvis was numb and pain shot down my legs. I tried to relieve the pain using heating pads, hot water bottles, acupuncture—but nothing worked. I was bedridden up to a week every month, missing out on family time, social engagements, and professional opportunities. Worse than not finding relief for my pain was that no doctor could tell me what was wrong.

It wasn't until I was 36—23 years after my symptoms began—that I finally got some answers. I was referred to a great gynecological specialist who examined me and suggested that my pain might be the result of something I had not even heard of: endometriosis.

My endometriosis had advanced so much that it was wrapped around my abdomen. I have had four laparoscopic excision surgeries. My endometriosis isn't gone, but it is manageable.

## What was your reaction when you received your diagnosis?

I realized I wasn't a drama queen and I didn't have a low threshold for pain. I actually had a condition that made a lot of different issues in my life finally make sense to me. I knew my

pain was real, but I did have a feeling like why can't I handle one of the basic aspects of being a woman? You start to feel weak and emotionally isolated. I was conditioned to expect discomfort and pain because I had witnessed my mother experiencing the same thing.

It is terrible that I am a college-educated woman with good health insurance and it took me well into my mid-30s to get a good diagnosis. I lost time, but I resolved that no girl should have to suffer like I did. That is why I started the Endometriosis Foundation of America (EFA) with my surgeon, Dr. Tamer Seckin, to increase recognition of endometriosis, provide advocacy, facilitate expert surgical training, and fund landmark research.

## How do we help both women and men get more comfortable talking about endometriosis?

We need to listen to and support these girls and young women who are going through this. Endometriosis is a family issue. When a woman has chronic pain, the whole family is impacted. We want to empower girls about their own bodies when changes are occurring.

One of the things I am most proud about at EFA is our ENPOWR™ (ENDometriosis: Promoting Outreach and Wide Recognition) Project. We have educated more than 15,000 young girls and boys about the illness.

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We talk to boys and girls together to remove the stigma. The boys are just as inquisitive as girls. One young boy told me, “You know I think my mom has this. Everything you were talking about I have seen my mom go through. How can I help her?” That meant everything, because not only were we sending him home to help his mother, we were helping to make him a compassionate ally for women throughout his life.

We also have conferences for health professionals to educate them and start a dialogue about endometriosis.

### What are your hopes for the future and endometriosis?

Research including the EFA’s work with the ROSE (Research Outsmarts Endometriosis) study is looking to identify improved diagnostic and treatment techniques. We want everyone to know about endometriosis. Information about the signs and symptoms of endometriosis should be on every tampon box, along with information about where you can go for help. I want to prevent women from suffering.



Photo: Christina Paige

“We need to listen to and support girls and young women who are going through this.”

# What Is Endometriosis?

A problem common in women, endometriosis affects an estimated 5 million in the United States alone. The condition affects a woman’s uterus—the place where a baby grows during pregnancy.

The tissue that normally lines the inside of the uterus grows outside the uterus, causing pain, infertility, and very heavy periods. While the pain is usually in the abdomen, lower back, or pelvic areas, some women have no symptoms. For them, having trouble getting pregnant may be the first sign.

The cause of endometriosis is not known. Pain medicines and hormones often help. Severe cases may need surgery. There are also treatments to improve fertility in women with endometriosis.

Researchers used to think that patches growing outside the uterus caused the pain. In fact, the size and location of these patches are not related to the severity of pain or to the location of the pain.

## What causes endometriosis?

The exact cause of endometriosis is not known, but researchers have some theories:

- **Genes** are most likely involved to some degree, because the condition runs in families,
- **Estrogen** (a hormone involved in the female reproductive cycle) also likely contributes to it, because it is an estrogen-dependent, inflammatory disease.
- **Progesterone resistance** may be the cause. This is where the mucus membrane lining the uterus doesn’t respond as it should to progesterone, another hormone involved in the female reproductive cycle.
- **Immune system dysfunction** plays a role in some cases, where the immune system fails to destroy endometrial tissue, which enables it to grow outside the uterus.
- **Environmental exposures** in the womb, such as to chemicals like dioxin, may also cause the condition.

## What are the risk factors of endometriosis?

Studies show that women are at higher risk for endometriosis if their:

- Mother, sister, or daughter had endometriosis (raises the risk about six times)
- Periods started at an early age (before age 11)
- Monthly cycles are short (less than 27 days)
- Menstrual cycles are heavy and last more than 7 days

## What are the symptoms of endometriosis?

While the primary symptoms of endometriosis are pain and infertility, other common symptoms include:

- Painful, even debilitating, menstrual cramps, which may get worse over time
- Pain during or after sex
- Pain in the intestine or lower abdomen
- Painful bowel movements or painful urination during menstrual periods
- Heavy menstrual periods
- Premenstrual spotting or bleeding between periods

## What are the treatments for endometriosis?

Treatments for endometriosis pain fall into three general categories:

- Pain medications
- Hormone therapy
- Surgical treatment

Research shows that some surgical treatments can provide significant, although short-term, pain relief from endometriosis.

Treatments for infertility related to the condition include in vitro fertilization (IVF), which makes it possible to combine sperm and eggs in a laboratory to make an embryo. The resulting embryos are placed into the woman's uterus.

Not all treatments work well for all women with the condition. Similarly, there is always the chance that the symptoms may return after the treatment is stopped.

For more information on treatment options, visit: [www.nichd.nih.gov/health/topics/endometri/conditioninfo/Pages/treatment.aspx](http://www.nichd.nih.gov/health/topics/endometri/conditioninfo/Pages/treatment.aspx).

## Endometriosis: A Personal Story

# Finding Relief After Diagnosis and Treatment

**Melissa McGaughey**, a 36-year-old grant writer in Milwaukee, Wis., began her journey with endometriosis when she was only 13.

"Throughout high school and college, my pain got worse," says McGaughey, who had pain throughout her pelvic region that extended through her thighs all the way to her knees. She stayed home often and had to drag herself to school, unable to participate in gym or hang out with friends because she was in so much pain.



Photo: Courtesy of Melissa McGaughey

Melissa McGaughey

## The Diagnosis

The condition is often difficult to diagnose, and it can be challenging for young patients to decide whether to get a diagnostic surgery which might find no endometriosis. "My OB-GYN told me pretty early on that endometriosis might be the reason for my pain, but years passed before I was ready to move forward with surgery. I hope the next generation doesn't require surgery for a diagnosis," says McGaughey, who underwent diagnostic surgery soon after graduating from college.

The first procedure helped, but she had surgery a second time because the severe pain eventually returned. "The surgeon who did my first procedure had done some of these procedures, but wasn't a specialist in endometriosis," she says. "I've since learned that you can get better outcomes from surgeons who specialize in endometriosis."

## Managing Symptoms

While she still has pain, McGaughey has less pain since her surgeries. She's been able to get pregnant after struggling with infertility, and now has a two-year-old daughter. "I've been helped by taking a strong anti-inflammatory medicine several days a month," says McGaughey, who has also tried acupuncture, xi gong (a form of meditative exercise), continuous birth control pills, and diet changes to control her symptoms.

McGaughey suggests finding a doctor who specializes in endometriosis if you're experiencing symptoms.

"It's important to do your own research and be your own advocate," McGaughey advises. "Be brave in talking about it. Too many women and girls feel they can't say it out loud. It's not a secret. We need to take girls' pain seriously!"

# NIH Seeks Answers for Endometriosis

**Dr. Louis DePaolo**, Chief of the Fertility and Infertility Branch at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), spoke with **NIH MedlinePlus** magazine about developments in endometriosis research.

## Why is it sometimes difficult to diagnose endometriosis?

Several of its symptoms, such as pain and infertility, mimic symptoms of other conditions. However, some women with endometriosis show no symptoms. Currently, the diagnosis is confirmed with surgery. Unfortunately, this procedure is expensive and may not be covered by all insurance plans.

## What are the suspected causes of endometriosis? Who is at risk for this condition?

Multiple factors appear to cause endometriosis. For years, the theory was that tissue fragments “shed” from the lining of the uterus during menstruation and then were propelled backwards into a cavity of the abdomen. But we now know that this process, called “retrograde menstruation,” is a normal process experienced by many reproductive-age women. Newer theories speculate that some women may have an underlying condition—such as certain defects in the tissue of the endometrium or possibly inflammation—that leads to the development of the shed-tissue fragments.



▲ Dr. Louis DePaolo, Chief, Fertility and Infertility Branch, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development

It is estimated that six to 10 percent of women during reproductive age have endometriosis—about 5 million women in the U.S. In 2011, an NICHD study found that 11 percent of a group of women had the disorder, but presented no symptoms. This finding could mean that many more women have the disorder without realizing it.

Although all women of reproductive age are at risk for developing endometriosis, genetics and possibly exposure to toxins in the environment may be significant factors in the development of the disease.

## How is research on the genetic components of endometriosis helping with diagnosis?

Over the past two decades, researchers have worked to discover whether certain genetic modifications may be involved in endometriosis by examining tissue from the

## What's the future of endometriosis research?

Dr. DePaolo highlights these research efforts in endometriosis:

- Developing ways to diagnose the disease without surgery
- Identifying new treatments using randomized clinical trials with patients who have been screened for disease severity, pelvic pain, and infertility
- Continuing to mine and integrate various databases to help uncover novel theories of how lesions begin, develop, and progress
- Increasing the study of how epigenetic (changes to gene function not involving DNA) factors relate to the frequency of disease. These epigenetic factors may be influenced by environmental exposures that can be transmitted to future generations
- Investigating the stem cell origins of the disease
- Researching ways to better understand how endometriosis and infertility effect and relate to each other
- Continuing development of animal and *in vitro* models to study how the disease begins, progresses, and responds to new treatment

endometrium in women with and without the disease. This work has led to the development of “genetic signatures” that may be useful in diagnosing endometriosis. Research also has helped identify certain proteins found in the blood that might serve as biomarkers, predicting the development of the disease. Ultimately, the goal is to develop noninvasive or minimally invasive approaches to diagnose endometriosis, instead of surgery.

### What does research tell us about how endometriosis is involved with fertility in some women?

This is one of the most perplexing aspects of the disease, confronting researchers and patients alike: What is the relationship between endometriosis and infertility? An estimated 30 to 50 percent of infertile women may have endometriosis. Not only do some of these women have difficulty conceiving and carrying a live birth to term, they are less likely to conceive following assisted reproduction, such as fertility medication, artificial insemination, and *in vitro* fertilization. Studies to address the link between endometriosis and infertility have just begun. These studies suggest that women with endometriosis may have implantation defects (abnormalities of the environment that make it difficult for the embryo to attach and survive) and/or low quality eggs. These conditions, in turn, could be related to an abnormal immune environment that some suspect exist in women with endometriosis.

### Many women with endometriosis have intense pelvic pain. What treatment options are available for endometriosis-related pain?

Most treatments for ending or reducing the pelvic pain involve hormonal treatments. These treatments interfere with the menstrual cycle and may interrupt or halt menstruation temporarily or permanently. Interestingly, the size of the endometriotic lesion does not correlate well with pain severity.

### Find Out More

- ✓ **Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD):** [www.nichd.nih.gov/health/topics/endometri](http://www.nichd.nih.gov/health/topics/endometri)
- ✓ **MedlinePlus:** [www.nlm.nih.gov/medlineplus/endometriosis.html](http://www.nlm.nih.gov/medlineplus/endometriosis.html)
- ✓ **National Center for Biotechnology Information (NCBI):** [www.ncbi.nlm.nih.gov/pubmedhealth/PMHT0024650](http://www.ncbi.nlm.nih.gov/pubmedhealth/PMHT0024650)
- ✓ **Clinical Trials:** <https://www.nlm.nih.gov/medlineplus/endometriosis.html#cat27>
- ✓ **Endometriosis Foundation of America:** [www.endofound.org](http://www.endofound.org)
- ✓ **Endometriosis Association:** [www.endometriosisassn.org](http://www.endometriosisassn.org)

# Oral Health and Aging

**Jerrold H. Epstein, DDS**, a general dentist in Alexandria, Virginia, has been in practice for 35 years. He spoke with *NIH MedlinePlus* magazine about oral health issues common in older adults.

## What has been your experience in seeing patients with dry mouth?

Most dry mouth cases I've seen seem to be a side effect of medications. Since it is usually associated with medications that are helping the patient, physicians often don't want to alter the regimen. Artificial saliva, chewing gum or lozenges with xylitol, special mouth rinses, and drinking plenty of water can help these patients.

## Do you perform a check for oral cancer as part of your preventive visits?

Yes I do. I hope all dentists are performing oral cancer exams. While the risk of oral cancer increases with age, it is not just a disease of older people. Unfortunately, I have discovered oral cancer in a couple of my patients, both far from being senior citizens. However, in both cases it was discovered early enough, and the patients sought medical treatment immediately so that the outcome has been very favorable. It is very important to have regular oral examinations and avoid tobacco products.

## Do some patients really think losing teeth is a natural part of life?

Not as much now as when I first started practicing 35 years ago. Many older people, especially those from rural areas, just assumed losing their teeth due to gum disease and tooth decay would necessitate their getting dentures as a part of growing older. Most of my senior patients are now so well educated about dental problems and treatments that they go to great lengths to try and keep their teeth. When I began practicing, patients would often say it wasn't necessary to save a tooth because they were going to get false teeth eventually anyway. Now most patients say that they want to save their teeth.

## What are the biggest dental concerns of your older patients?

Living longer than they ever expected, many of my older patients are concerned about their teeth lasting as long as they do. They did not have the benefits of fluoridated water and toothpastes until well into their adult years. This has resulted in major amounts of tooth decay and tooth loss. Fillings don't last forever and every time they are replaced they get bigger. This, plus the fact that a filling is more susceptible to decay than a pristine tooth, means that eventually these teeth will need crowns and maybe even root canals. Most of these patients have a limited income, and they are worried if they can afford all the dental care they may need.



# 4 Myths About Oral Health and Aging

Is dry mouth a natural part of the aging process? Is tooth decay just kid stuff? Separate fact from fiction. Having the right information can help you keep your mouth healthy for a lifetime. **Here are four myths about oral health and facts to set them straight from the National Institute of Dental and Craniofacial Research (NIDCR).**

## Tooth Decay

**Myth:** Only school kids get cavities.

**Fact:** Tooth decay can develop at any age.

Tooth decay is not just a problem for children. It can happen as long as you have natural teeth. Dental plaque—a sticky film of bacteria—can build up on teeth. Plaque produces acids that, over time, eat away at the tooth's hard outer surface and create a cavity. Even teeth that already have fillings are at risk. Plaque can build up underneath a chipped filling and cause new decay.

If your gums pull away from the teeth, the exposed tooth roots are also vulnerable to decay.

## Gum Disease

**Myth:** Gum disease is just a part of growing older.

**Fact:** You can prevent gum disease—it does not have to be a part of getting older.

Gum (periodontal) disease is a chronic infection of the gums and surrounding tissues that hold teeth in place. Gum disease develops when plaque is allowed to build up along and under the gum line.

The two forms of gum disease are:

- **Gingivitis**, a mild form that is reversible with good oral hygiene. In gingivitis, the gums become red, swollen, and can bleed easily.
- **Periodontitis**, a more severe form that can damage the soft tissues and bone that support teeth. In periodontitis, gums pull away from the teeth and form spaces (called "pockets"). If not treated, the bones, gums, and tissue that support the teeth are destroyed. The teeth may eventually become loose and have to be removed.



Photo: Kathleen Cravedi, NLM

▲ Jerrold H. Epstein, DDS, says today's patients go to great lengths to save their teeth.

## Dry Mouth

**Myth:** Dry mouth is a natural part of the aging process. You just have to learn to live with it.

**Fact:** Dry mouth is not a part of the aging process itself; it's important to find the cause of dry mouth so you can get relief.

Dry mouth is the condition of not having enough saliva, or spit, to keep the mouth wet. Without enough saliva, chewing, eating, swallowing, and even talking can be difficult. Dry mouth also increases the risk for tooth decay because saliva helps keep harmful germs that cause tooth decay and other oral infections in check. Saliva also contains minerals (calcium and phosphate) that can help reverse early decay.

It's important to know that dry mouth is not part of the aging process itself. However, many older adults take medications that can dry out the mouth. Older adults are also more likely to have certain conditions that can lead to oral dryness.

Here are some causes of dry mouth:

- Side effects of medicines.
- Diseases such as Sjögren's syndrome and HIV/AIDS.
- Radiation therapy or chemotherapy for cancer.
- Nerve damage. Injury or surgery to the head or neck can damage the nerves that tell salivary glands to make saliva.

If you think you have dry mouth, see a dentist or physician. He or she can try to determine what is causing your dry mouth and what treatments might be helpful.

## Oral (Mouth) Cancer

**Myth:** If you don't use chewing tobacco, you don't need to worry about oral cancer.

**Fact:** It's not just smokeless tobacco ("dip" and "chew") that can increase your chances of getting oral cancer.

Tobacco use of any kind, including cigarette smoking, puts you at risk. Heavy alcohol use also increases your chances of developing the disease. The likelihood of oral cancer increases with age. Most people with these cancers are older than 55 when the cancer is found. Also, recent research has found that infection with the sexually transmitted human papillomavirus (HPV) has been linked to a subset of oral cancers. It's important to catch oral cancer early, because treatment works best before the disease has spread.

If you have any of the following symptoms for more than two weeks, be sure to see a dentist or physician:

- A sore, irritation, lump, or thick patch in the mouth, lip, or throat
- A white or red patch in the mouth
- A feeling that something is caught in the throat
- Difficulty chewing or swallowing
- Difficulty moving the jaw or tongue
- Numbness in the tongue or other areas of the mouth
- Swelling of the jaw that causes dentures to fit poorly or become uncomfortable
- Pain in one ear without hearing loss

Most often, these symptoms do not mean cancer. An infection or other problem can cause the same symptoms. But it's important to get them checked out.

## Prevention

Here are some things you can do to keep your mouth healthy:

- Brush your teeth twice a day with a fluoride toothpaste.
- Floss regularly to remove plaque from between teeth. Or use a device such as a special brush or wooden or plastic pick recommended by a dental professional.
- Visit the dentist regularly for a checkup and professional cleaning.
- Don't smoke or use chewing tobacco or snuff.
- Limit alcohol use.
- Limit sugar and eat a well-balanced diet.

## Find Out More

- ✓ **National Institute of Dental and Craniofacial Research (NIDCR) – Older Adults:** [www.nidcr.nih.gov/OralHealth/OralHealthInformation/OlderAdults](http://www.nidcr.nih.gov/OralHealth/OralHealthInformation/OlderAdults)
- ✓ **NIHSeniorHealth:** <http://nihseniorhealth.gov> (search for Dry Mouth and Periodontal Disease)
- ✓ **MedlinePlus:** [www.medlineplus.gov](http://www.medlineplus.gov) (search by topic)
- ✓ **Clinical Trials:** [www.nlm.nih.gov/medlineplus/dentalhealth.html#cat27](http://www.nlm.nih.gov/medlineplus/dentalhealth.html#cat27)

# NIH Research Addresses Aging Issues and Disparities in Oral Health

The NIH National Institute of Dental and Craniofacial Research (NIDCR) is the nation's leading funder of research on dental, oral, and craniofacial health and disorders. NIDCR also conducts research in its own laboratories and clinic, supports research training, and promotes the timely transfer of knowledge gained from research to health professionals, patients, and the general public.

*NIH MedlinePlus* magazine recently spoke with NIDCR Director **Dr. Martha Somerman** about the importance of research on oral health and older adults.

## Why is it important to have a research focus on older adults?

One reason is that older adults make up a rapidly growing segment of our population. In fact, America's 65-and-older population is projected to more than double to almost 100 million by 2060.

The risk of developing certain diseases and conditions increases with age, and those conditions, or their treatments, can negatively affect oral health. Poor blood glucose control in diabetes, for example, can put you at risk for periodontal (gum) disease. Cancer treatments can cause a host of oral problems. Medications can damage oral tissues and/or decrease salivary flow, causing dry mouth.

It's also important to know that some oral conditions are more common in older adults; periodontal disease is one example. And the risk of oral cancer increases with age.

## What does the latest data tell us about older adults' oral health?

It gives us some good news, but also shows us there is room for improvement. The good news is the number of people with complete tooth loss continues to decline. The latest data show us that 19 percent of adults aged 65 and over have lost all their teeth. In the early 1960s that number was more than 50 percent! The overall trend continues in the right direction.



Photo: NIH

▲ Martha Somerman, DDS, PhD, NIDCR Director

But there are still disparities. Twenty-nine percent—or almost one-third—of older African Americans have lost all their teeth, compared with 17 percent of white older adults and 15 percent of Hispanic older adults. Although the general trend is good, there is clearly still work to be done.

## What types of research is NIDCR conducting on aging and oral health?

We're currently funding basic research on the biology of the aging mouth, which will help us understand how diseases and their treatments impact oral health.

NIDCR-funded researchers are also working with older adults in publicly funded housing to determine how to help residents maintain oral health. The research is evaluating motivational interviewing, counseling, and oral hygiene skills-building to establish which approach(es) is most effective.

We are also in active discussions with NIH Institutes dedicated to research on older adults. Moving forward, we'll seek out additional opportunities to expand our research on oral health and aging, including research aimed at reducing oral health disparities, and also explore partnerships with organizations that are committed to improving the health of older Americans.



American designer Carmen Marc Valvo is an outspoken voice for colorectal cancer screening.

# *Colorectal Cancer*

## *A Personal Journey*

**Designer Carmen Marc Valvo says "it's always fashionable to get screened."**

Designer Carmen Marc Valvo was readying his fall collection in 2001 when he noticed something wasn't quite right.

"I didn't have any specific symptoms or warning signs," Valvo says. "I usually have more energy and am so excited because I'm in the moment. I didn't have that energy. Something was missing."

His doctor ran a number of tests, including a colonoscopy, and discovered Valvo had colorectal cancer. It was difficult to hear his doctor tell him "there seems to be something wrong."

### **Determined to Fight**

He remembers experiencing a number of feelings that are often associated with the diagnosis. "My first emotional feeling was one of determination to rid myself of this unwanted attacker and enemy of my body and soul," recalls Valvo, who had surgery at the time.

"To deal with the concept of cancer, I turned to gardening, specifically weeding," Valvo says. "I was metaphorically weeding the cancer from my body with every little stalk of grass I removed from the ground. I wanted to make sure the garden



“If you’re a survivor, please join the chorus and share the word of how important early detection is.”

flourished, so I made sure to plant new things and took delight in watching them grow.”

A proponent of talking about the disease and getting it into the open, Valvo was surprised to learn that colon cancer ran in his family. “I had no knowledge there was a history of colon cancer within my family,” Valvo says. “While discussing it with my siblings [after surgery], I discovered there were two cases of colon cancer in my family, one on my father’s side and one on my mother’s.”

### Spreading the Word on Screening

Fast-forward 15 years and Valvo is healthy—his cancer is in remission. He now eagerly talks about the disease, because he wants others to know the importance of early detection.

“If you’re a survivor, please join the chorus and share the word of how important early detection is,” Valvo says. “Be an advocate for others who may not be as fortunate as we are.”

Reflecting what research has proven, Valvo’s message is clear. “Screening is so important! Early detection is early cure!”

# The Importance of Early Detection

Cancer of the colon or rectum is called colorectal cancer. The colon and the rectum are part of the large intestine, which is part of the digestive system. Colorectal cancer occurs when tumors form in the lining of the large intestine.

Colorectal cancer accounts for almost 10 percent of all cancer deaths in the United States. It is common in both men and women.

Today there are more ways than ever to treat colorectal cancer. As with almost all cancers, **the earlier it is found, the more likely that the treatment will be successful.** If colon cancer is detected in its early stages, it is up to 90 percent curable.

## Risk Factors

Scientists don’t know exactly what causes colorectal cancer, but they have been able to identify some risk factors for the disease.

- **Age:** Colorectal cancer is more likely in people over age 50.
- **Polyps:** Polyps are benign, or non-cancerous, growths on the inner wall of the colon and rectum. They are fairly common in people over age 50. Some types of polyps increase a person’s risk of developing colorectal cancer. Not all polyps become cancerous, but nearly all colon cancers start as polyps.
- **Diet:** The link between diet and colorectal cancer is not firmly established. However, there is evidence that smoking cigarettes and drinking three or more alcoholic beverages daily may be associated with an increased risk.
- **Personal history:** Research shows that women with a history of cancer of the ovary, uterus, or breast have a somewhat increased chance of developing colorectal cancer.
- **Family history:** The parents, siblings, and children of a person who has had colorectal cancer are somewhat more likely to develop this type of cancer themselves.
- **Ulcerative colitis:** Having this condition increases a person’s chance of developing colorectal cancer.
- **Genetic mutations:** Researchers have identified genetic mutations, or abnormalities, that may be linked to the development of colon cancer. They are working to unravel the exact ways these genetic changes occur.

### Common Signs and Symptoms

When colorectal cancer first develops, there may be no symptoms. But as the cancer grows, it can cause changes that people should watch for:

- Changes in the frequency of bowel movements
- Diarrhea, constipation, or feeling that the bowel does not empty completely
- Bright red or very dark blood in the stool
- Stools that are narrower than usual
- General abdominal discomfort such as frequent gas pains, bloating, fullness, and/or cramps
- Weight loss with no known reason
- Constant tiredness
- Vomiting

### Standard Treatments

The three standard treatments for colon cancer are surgery, chemotherapy, and radiation. The choice of treatment depends on the size, location, and stage of the cancer and on the patient's general health. Doctors may suggest several treatments or combinations of treatments.

#### Surgery

Surgery is the most common first step in the treatment for all stages of colon cancer. A doctor may remove the cancer using several types of surgery.

- **Local excision:** If the cancer is found at a very early stage, the doctor may remove it without cutting through the abdominal wall. Instead, the doctor may put a tube up the rectum into the colon and cut the cancer out. This is called a local excision.
- **Colectomy:** If the cancer is larger, the surgeon will remove the cancer and a small amount of healthy tissue around it. This is called a colectomy. The surgeon may then sew the healthy parts of the colon together.
- **Colostomy:** If the doctor is unable to sew the two ends of the colon back together, an opening called a stoma is made on the abdomen for waste to pass out of the body before it reaches the rectum. This procedure is called a colostomy. Sometimes the colostomy is needed only until the lower colon has healed, and then it can be reversed. But if the doctor needs to remove the entire lower colon or rectum, the colostomy may be permanent.

#### Chemotherapy

Chemotherapy is the use of anti-cancer drugs to kill cancer cells. Chemotherapy may be taken by mouth, or it may be put into the body by inserting a needle into a vein or muscle.

One form of chemotherapy is called systemic treatment because the drugs enter the bloodstream, travel through the body, and can kill cancer cells throughout the body. The other form of chemotherapy is called targeted therapy because the drug affects only the factors that are causing the cancer and does not perturb the rest of the body.

#### Radiation Therapy

Radiation therapy is the use of X-rays or other types of radiation to kill cancer cells and shrink tumors. Most often, doctors use it for patients whose cancer is in the rectum.

Doctors may use radiation before surgery to shrink a tumor in the rectum and make it easier to remove. Or they may use it after surgery to destroy any cancer cells that remain in the treated area.

The radiation may come from a machine or from implants placed directly into or near the tumor. Radiation that comes from a machine is called external radiation. Radiation that uses implants is known as internal radiation. Some patients have both kinds of therapy.

### Find Out More

- ✓ **National Cancer Institute:** [www.cancer.gov/types/colorectal/patient/colon-treatment-pdq](http://www.cancer.gov/types/colorectal/patient/colon-treatment-pdq)
- ✓ **MedlinePlus:** [www.nlm.nih.gov/medlineplus/colorectalcancer.html](http://www.nlm.nih.gov/medlineplus/colorectalcancer.html)
- ✓ **NIH Senior Health:** [nhseniorhealth.gov/colorectalcancer/colorectalcancerdefined/01.html](http://nhseniorhealth.gov/colorectalcancer/colorectalcancerdefined/01.html)
- ✓ **Clinical Trials:** [www.nlm.nih.gov/medlineplus/colorectalcancer.html#cat27](http://www.nlm.nih.gov/medlineplus/colorectalcancer.html#cat27)
- ✓ **Colon Cancer Alliance:** [www.ccalliance.org](http://www.ccalliance.org)

# Developments in Colorectal Cancer Screening

**Asad Umar, DVM, PhD**, Chief of the Gastrointestinal and Other Cancers Research Group at the National Cancer Institute, shared developments in colorectal cancer screening methods with *NIH MedlinePlus* magazine.

## What should patients know to help determine the best colon cancer screening test for them?

Colonoscopy is considered the gold standard. It is effective for screening and detection, and it is therapeutic as well since adenomas (a type of precancerous polyp) that are found during colonoscopy can be removed. That's the biggest advantage of colonoscopy as opposed to all other techniques. Another advantage is it is needed only once every 10 years if results are negative.

Other less invasive tests include flexible sigmoidoscopy. It is less invasive and takes less time than colonoscopy. In NCI's study called the Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial, flexible sigmoidoscopy was found to be reasonable in detection of adenomas, and acceptance of screening flexible sigmoidoscopy was high among participants.

The fecal occult blood test—FOBT—is one of the older screening methods. It looks for blood in the feces, which can indicate polyps or tumors. A newer version called the fecal immunochemical test—FIT—looks for only human blood, so there is no need for dietary restrictions such as not eating meat before the test. FIT or FOBT are recommended annually.

## Are there other screening methods?

A couple of new tests approved recently by the FDA are called Cologuard® and ColoVantage®. Cologuard is a DNA panel combined with FIT. A stool sample is collected and examined for genetic mutations that indicate possible cancers or adenomas. ColoVantage, on the other hand, is a blood-



Photo: Ernie Branson, NIH

▲ Dr. Asad Umar, Chief of the Gastrointestinal and Other Cancers Research Group, National Cancer Institute

based test that detects circulating DNA from adenomas and colorectal cancers. It is offered to individuals who refuse or are non-adherent to other testing options.

CT colonography, also known as virtual colonoscopy, uses X-ray technology to look for polyps. It is less invasive than colonoscopy but you still have to go through the same prep, and most people really dislike that prep. That's where the issues are in the general population, not getting enough people to go for a colonoscopy.

## Are there genetic markers that might help identify those who could benefit from being tested earlier than generally recommended?

Colonoscopy is recommended at age 50 for the general population. But for African Americans it is recommended starting at age 45 and for Alaska Natives at age 40. They are reported to have more adenomas as well as colorectal cancer, and mortality is higher in both groups.

In terms of family history, other than familial cancer syndromes including hereditary non-polyposis colorectal cancer (HNPCC or Lynch syndrome) and familial adenomatous polyposis (FAP), there are no clear-cut recommendations and no genetic marker has been identified. But it would not hurt for people with a family history to get tested at age 45.

# Cancer Survivor Eric Dishman Is On a Precision Medicine Mission

“I am totally motivated to support precision medicine because I am one of the early prototype patients whose life was saved by it,” said **Eric Dishman**.

Dishman is the first Director of the Precision Medicine Initiative (PMI) Cohort Program. He is leading NIH’s effort to build the PMI landmark research study of one million or more U.S. volunteers to improve health and treat disease through precision medicine.

“After battling a rare form of kidney cancer for 23 years,” said NIH Director Francis S. Collins, “and advocating personally for more than a thousand other cancer patients, Dishman became cancer-free thanks to early access to precision medicine that clarified the right treatment plan for him.”

## What Is Precision Medicine?

Precision medicine is a medical approach that takes into account individual differences in people’s genes, environments, and lifestyles. It gives medical professionals resources to target the specific treatments of the illnesses we encounter, develops scientific and medical research, and keeps families healthier.

As Dishman said, “I had a whole genome sequence, and a chance encounter with a scientist, and after 23 years of trial and error chemotherapy that I had to suffer through, they, suddenly, with precision medicine, said ‘We didn’t understand



▲ Eric Dishman, Director, Precision Medicine Initiative (PMI) Cohort Program

what was wrong with you; now we do.’ Months later, I had chemotherapy. Cured my cancer. A kidney transplant. And I’m healthier at age 47 than I was at age 19. That was the power of precision medicine.”

## PMI Cohort Program

The PMI Cohort Program seeks to extend precision medicine to all diseases by building a research cohort of one million or more U.S. participants. Many factors make now the right time to begin this program—Americans are working to improve their health and participating in health research more than ever before, electronic health records have been widely adopted, genomic analysis costs have dropped a lot, data science has become increasingly sophisticated, and health technologies have become mobile.

## A Thought Leader

In naming Dishman director of the PMI Cohort Program, NIH Director Collins noted Dishman’s unique background “as a social scientist and researcher, entrepreneur and business leader, patient and patient advocate, and policy advocate and thought leader.

“He has pioneered and co-founded some of the nation’s

*continued on page 23*

## Goals of the Precision Medicine Initiative

The near-term goals of the Precision Medicine Initiative include intensifying efforts to apply precision medicine to cancer through:

- Innovative clinical trials that target drugs for adult and children's cancers
- Use of combination therapies
- Expanding our knowledge on how to overcome drug resistance

The longer-term goal is for research based on data generated from the group of more than 1 million participants to:

- Help target the right drug for the right patient at the right dose
- Identify new targets for treatment and prevention of disease
- Test whether mobile devices can encourage healthy behaviors
- Lay the scientific foundation for precision medicine for many diseases

**“I have been put on this earth—and survived a seemingly impossible cancer journey—to help bring precision medicine to everyone.”**

*continued from page 22*

first and largest research/policy programs focused on telehealth, personal health records, independent living technologies for seniors, and behavioral markers for Alzheimer's, Parkinson's, diabetes, and heart disease,” Collins said. “Dishman is widely recognized as a global leader on home and community-based care and personalized care, as well as for inventing innovation techniques that incorporate ethnography, the systematic study of people and cultures, and other social methods into the design and development of new technologies.”

“I have been put on this earth—and survived a seemingly impossible cancer journey—to help bring precision medicine to everyone,” Dishman said.

### Find Out More

- ✓ **National Center for Advancing Translational Sciences (NCATS):** <https://ncats.nih.gov>
- ✓ **MedlinePlus:** [www.nlm.nih.gov/medlineplus](http://www.nlm.nih.gov/medlineplus) (search for Precision Medicine)
- ✓ **National Cancer Institute:** [www.cancer.gov/research/key-initiatives/precision-medicine](http://www.cancer.gov/research/key-initiatives/precision-medicine)
- ✓ **The NIH Director:** <https://www.nih.gov/about-nih/who-we-are/nih-director>

## Alcohol and Medications Quiz Answers from page 7

**1. True.** One reason that older adults are more sensitive to alcohol's effects is that the amount of water in the body drops with age. As a result, older adults will have a higher percentage of alcohol in their blood than younger people after drinking the same amount of alcohol.

**2. All of the above.** A “standard” drink contains about 0.6 fluid ounces of pure alcohol. A single drink is one 5-ounce glass of wine. It also can be one 12-ounce can or bottle of regular beer, ale, or wine cooler; one 8- or 9-ounce can or bottle of malt liquor; or one 1.5-ounce shot glass of 80-proof distilled spirits such as whiskey, gin, vodka, or rum.

**3. False.** In general, to be at low risk for alcohol use disorder, healthy men and women over age 65 can have three drinks a single day, but should not exceed a total of seven drinks in a week. Drinking more than these amounts puts people at risk of serious alcohol problems. However, people can still have problems within these limits. Depending on their health and how alcohol affects them, older adults may need to drink less than these limits or not at all.

**4. True.** Alcohol, like some medicines, can make you sleepy, drowsy, or lightheaded. Drinking even small amounts of alcohol while taking medicines can intensify these effects. In older adults, this can lead to balance problems and falls, which can result in hip or arm fractures and other injuries. Older people have thinner bones than younger people, so their bones break more easily. Studies show that the rate of hip fractures in older adults increases with alcohol use.

**5. All of the above.** Drinking alcohol and taking medications for high blood pressure, diabetes, gout, and heart failure can make those conditions worse.

Photo: iStock

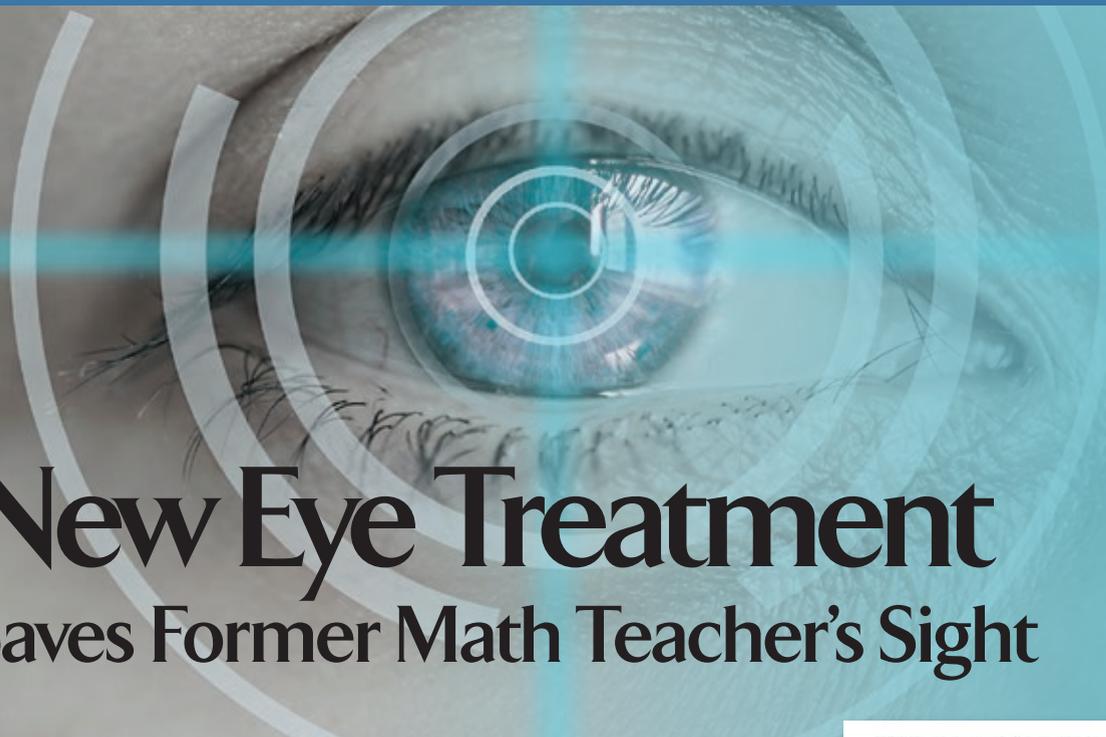


Photo: Courtesy of  
Rebecca Hatcher

Rebecca Hatcher

# New Eye Treatment Saves Former Math Teacher's Sight

**Rebecca Hatcher, a retired math teacher from Virginia, is an example of the recent strides made to treat age-related macular degeneration (AMD).**

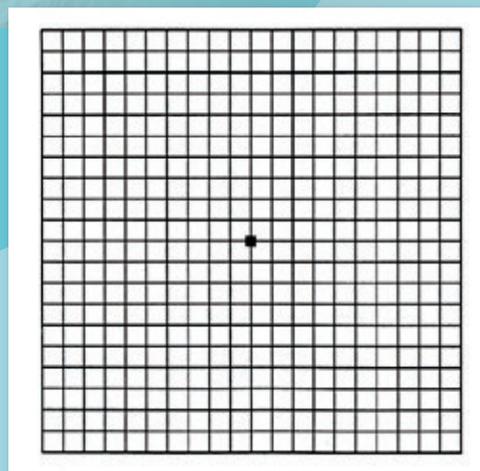
In 2007, she was diagnosed with neovascular AMD (also called wet AMD) in her left eye. Eventually, both eyes became involved. In neovascular AMD, abnormal blood vessels grow underneath the retina, a layer of tissue in the back of your eye that senses light and sends images to your brain. ("Neovascular" means "new vessels.") These vessels can leak fluid and blood, which may lead to swelling and damage of the macula, the part of the eye that allows you to see fine detail. The damage can be rapid and severe.

She was scared.

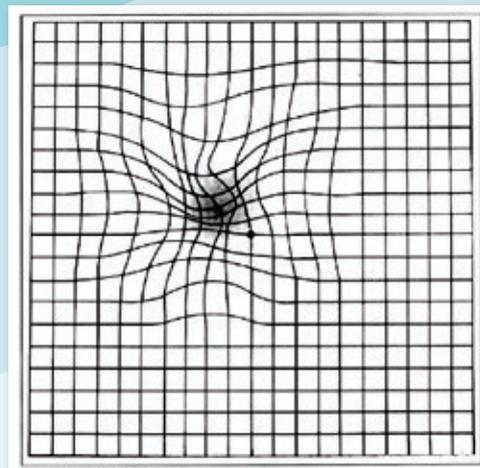
Just 10 years ago, people diagnosed with neovascular AMD almost always lost their vision in the affected eye and were likely to lose vision in their other eye, too.

Fortunately for Hatcher, her diagnosis came just as new drugs were helping people preserve their vision. She reached out to the National Eye Institute (NEI) for help.

Today Hatcher enjoys a corrected vision of 20/35 in her left eye and 20/20 in her right.



Amsler grid with normal vision



Amsler grid as it might appear with AMD

Illustrations: NEI

## Family History

Her journey with AMD began in 2000 when her older sister developed wet AMD and totally lost central vision in her left eye, despite treatment. Hearing that, Hatcher contacted NEI and said she would like to participate in any AMD-related studies.

Her doctor was already monitoring her condition and had given her an Amsler grid to use every day.

By early 2001, she was part of a study of the dietary supplement lutein. At the end of that study, she made herself available for any future study for which she qualified.

## Treatment Begins

"In 2007, I was asked to be in the five-year AREDS2 study at NEI," Hatcher recalls. "At one of my first examinations I was told that I now had wet AMD and would need to start injections of Lucentis in my left eye. To that point, I had no symptoms that I noticed. No one wants to hear that kind of diagnosis, but I knew I was in the best facility in the country.

"On June 16, 2010, I received the first injection in my right eye. In 2016, after having received almost 100 injections, I am doing OK. I can still drive, which is the most important thing for me."

## Research Advocate

Hatcher also participated in the Comparison of AMD Treatments Trials (CATT) study. It was a clinical trial that compared the safety and effectiveness of Lucentis and Avastin, two drugs used to treat advanced AMD.

"I hope that NEI has received some information from me to help with research," Hatcher says. "I continue with my treatment there as part of the Age-Related Eye Disease Study 2 extension. My advice to anyone with an AMD diagnosis is to remain diligent with treatment. See your doctor every three months as changes happen. Get the injections as often as necessary. They do not hurt."

# What Is Age-Related Macular Degeneration?



Photo: iStock

**Age-related macular degeneration (AMD) is a common eye condition and a leading cause of vision loss among people age 50 and older. It causes damage to the macula, a small spot near the center of the retina and the part of the eye needed for sharp, central vision, which lets us see objects that are straight ahead.**

In some people, AMD happens so slowly that vision loss does not occur for a long time. In others, the disease progresses faster and may lead to a loss of vision in one or both eyes. As AMD progresses, the appearance of a blurred area near the center of vision is common. Over time, the blurred area may grow larger, causing blank spots in your central vision.

AMD by itself does not lead to complete blindness, with no ability to see. But the loss of central vision in AMD can interfere with simple everyday activities, such as seeing faces, driving, reading, writing, or doing close work, such as cooking or fixing things around the house.

## Who Is At Risk?

Age is a major risk factor for AMD. The disease is most likely to occur after age 60, but it can occur earlier. Other risk factors include:

- **Smoking.** Research shows that smoking doubles the risk of AMD.
- **Race.** AMD is more common among Caucasians than among African-Americans or Hispanics/Latinos.
- **Family history and genetics.** People with a family history of AMD are at higher risk. At last count, researchers had identified nearly 20 genes that can affect the risk of developing AMD. Many more genetic risk factors are suspected.

You might be able to reduce your risk of AMD or slow its progression by making these healthy choices:

- Exercise regularly.
- Maintain normal blood pressure and cholesterol levels.
- Eat a healthy diet rich in green, leafy vegetables and fish high in omega-3 fatty acids.

### How Is AMD Detected?

The early and intermediate stages of AMD usually start without symptoms. Only a comprehensive dilated eye exam can detect AMD.

AMD has few symptoms in the early stages, so it is important to have your eyes examined regularly. If you are at risk for AMD because of age, family history, lifestyle, or some combination of these factors, you should not wait to experience changes in vision before getting checked for AMD.

### How Is AMD Treated?

Currently, no treatment exists for early AMD, which in many people shows no symptoms or loss of vision. Your eye care professional may recommend you get a comprehensive dilated eye exam at least once a year. The exam will help determine if your condition is advancing.

Researchers at NEI tested whether taking nutritional supplements could protect against AMD in the Age-Related Eye Disease Studies (AREDS and AREDS2). They found that daily intake of certain high-dose vitamins and minerals can slow progression of the disease in people who have intermediate AMD and those who have late AMD in one eye.

If you have intermediate or late AMD, you might benefit from taking such supplements. Consult your doctor or eye care professional about which supplement, if any, is right for you.

The introduction of anti-VEGF drugs for treatment of neovascular, or wet, AMD a decade ago has proved to be effective in preserving vision for many with the condition. (See article on page 27.)

## AMD Research Roundup

...with Kapil Bharti, PhD, a Stadtman Investigator at the National Eye Institute (NEI) Unit on Ocular & Stem Cell Translational Research. Bharti leads efforts to grow and transplant a patient's own tissue to halt or reverse retinal diseases like age-related macular degeneration (AMD).

Aiming to restore damaged eyesight, Bharti says his work is "a dream that came true in my life." He won a Therapeutic Challenge Award through the NIH Common Fund in 2014 to develop a treatment for AMD. He leads research using induced pluripotent stem (iPS) cell technology, where cells are genetically reprogrammed to an embryonic stem cell-like state.



▲ Researcher Kapil Bharti, PhD, at work in a National Eye Institute laboratory.

Like embryonic stem cells, iPS cells can be used to make virtually any cell in the body. But because they are sourced from patients, there's less potential for rejection. The ethical issues around the use of embryonic stem cells are also avoided.

"We know that if you replace the damaged tissue in the eye with healthy tissue from another part of the eye, we're able to restore vision in some patients," Bharti says. "So, if we're able to make these cells—not from the eye itself—but from another part of the body, it may have beneficial results for AMD patients."

That's where the iPS technology comes in. It allows Bharti and his team to take cells from another part of the patient's body and differentiate those cells into tissue that can be transplanted into the eye. "In this case, we're using iPS cells to make retinal pigment epithelium (RPE)—the layer of tissue in the retina that breaks down, causing AMD," Bharti says.

With the first clinical trial set to begin in 2018, Bharti believes that once the lab-grown RPE is mature, the tissue can be transplanted into the patient with the goal of slowing, reversing, or halting AMD. The new cells will serve as replacement tissue in the eye.

Photo: Rhoda Baer, courtesy of NIH Intramural Research Program

### Find Out More

- ✓ **National Eye Institute:** [https://nei.nih.gov/health/macularden/gen/armd\\_facts](https://nei.nih.gov/health/macularden/gen/armd_facts)
- ✓ **NIHSeniorHealth:** <http://nihseniorhealth.gov/agerelatedmacularden/gen>
- ✓ **MedlinePlus:** [www.nlm.nih.gov/medlineplus/macularden/gen.html](http://www.nlm.nih.gov/medlineplus/macularden/gen.html)
- ✓ **Clinical Trials:** [www.nlm.nih.gov/medlineplus/macularden/gen.html#cat27](http://www.nlm.nih.gov/medlineplus/macularden/gen.html#cat27)



Paul A. Sieving, MD, PhD,  
Director, National Eye Institute

Photo: NEI

## New Treatment Greatly Improves Prognosis for Patients with AMD

In a new study of nearly 650 people with age-related macular degeneration (AMD), half still had 20/40 vision or better, typically good enough to drive or to read standard print, after five years of treatment with anti-VEGF drugs that are injected into the eye. The authors of the study, funded by the National Eye Institute (NEI), say those outcomes would have been unimaginable about 10 years ago, before the drugs' availability.

Results of the study were presented in May 2016 at the annual meeting of the Association for Research in Vision and Ophthalmology in Seattle.

"This is the most comprehensive study of anti-VEGF therapy for AMD to date," said NEI Director Paul A. Sieving, MD, PhD. "It points to the importance of long-term follow-up in studies evaluating disease treatments."

There are two types of late AMD—geographic atrophy, also known as dry AMD, and the more common neovascular AMD, also known as wet AMD. In wet AMD, fragile blood vessels

grow under the retina and leak fluid. This usually starts in one eye, and is stimulated by a protein called VEGF. Just 10 years ago, people diagnosed with neovascular AMD were almost certain to develop severe vision loss in their affected eye and likely to lose vision in their other eye, too.

The new study looked at people with AMD who had regular treatment with the drugs Avastin and Lucentis, which are designed to block VEGF. After five years, 50 percent of them had 20/40 vision or better, 20 percent had 20/200 vision or worse, and the rest were in-between.

Ten years ago, the best available treatment for AMD was photodynamic therapy, in which an intravenous drug (injected into a vein) and laser seal off leaking blood vessels. Past studies have found that just one year after diagnosis, less than 15 percent of patients given this therapy alone retain 20/40 vision, and up to 40 percent decline to 20/200 vision. Without any treatment, less than 10 percent of patients retain 20/40 vision at one year, and up to 75 percent of untreated patients decline to 20/200 vision.

## Sex and Gender: Their Roles in Health and Disease

Scientists are taking a closer look at the links between sex, gender, and health. Many people use the words sex and gender interchangeably, but they're distinct concepts to scientists.

While both sexes are similar in many ways, sex and social factors can make a difference when it comes to your risk for disease, how you respond to medications, and how often you seek care.

Sex is biological. Males have one X and one Y chromosome in every cell of the body. Females have two X chromosomes in every cell. These cells make up tissues and organs, including your skin, heart, stomach, muscles, and brain.

Gender is a social or cultural concept. It refers to the roles, behaviors, and identities that society assigns to girls and boys, women and men, and gender-diverse people. Gender is determined by how we see ourselves and each other and how we act and interact with others.

Scientists are uncovering the influences of both sex and gender in many areas of health.

Women and men can have different symptoms during a heart attack, different responses to pain, and even differences responding to medication. For example, women metabolize nicotine faster than men, so nicotine replacement therapies can be less effective in women.

"NIH now requires scientists to ask: 'What are my research results for males and for females?'" says Dr. Janine Austin Clayton, who heads research on women's health at NIH. "We need to learn more about the roles of sex and gender in health and disease."

Learn more: <https://newsinhealth.nih.gov/issue/may2016/feature1>

## Healthy Diet May Reduce HBP Risk after Gestational Diabetes

Sticking to a healthy diet in the years after pregnancy may reduce the risk of high blood pressure among women who had pregnancy-related (gestational) diabetes, according to a study by researchers at NIH and other institutions. The study was published in *Hypertension*.

"Our study suggests that women who have had gestational diabetes may indeed benefit from a diet rich in fruits, vegetables, and whole grains and low in red and processed meats," said the study's senior author, Dr. Cuijin Zhang, a senior investigator in the Epidemiology Branch at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development.

The current study is the first to show that adopting a healthy diet—known to reduce high blood pressure risk among the general population—also reduces the risk among women with prior gestational diabetes.

Learn more: [www.nlm.nih.gov/medlineplus/diabetesandpregnancy.html](http://www.nlm.nih.gov/medlineplus/diabetesandpregnancy.html)

## Going Gluten Free? Necessary for Some, Optional for Others

Sidestepping gluten can be a lifestyle choice for many. But for those with a condition known as celiac disease, it's a medical necessity. Gluten is a protein found in wheat, barley, rye, and sometimes oats. Some people who may not have celiac disease get gas, diarrhea, or bloating after eating gluten. These symptoms could be caused by intolerance to the protein or a wheat allergy, but celiac disease is different.

When a person with celiac disease eats or drinks anything with gluten, the body's immune system attacks the inside of the small intestine. The damage from this attack keeps the body from absorbing needed nutrients. Left untreated, celiac disease can lead to malnutrition, depression, anxiety, anemia, or weakened bones. It can also delay children's growth.

Celiac disease can be hard to spot, because its symptoms can be similar to other disorders. The condition affects about 1 percent of people worldwide; nearly 80 percent of them haven't been diagnosed, says Dr. Alessio Fasano, a celiac disease specialist at Massachusetts General Hospital. "Celiac disease is a clinical chameleon. This creates tremendous confusion and challenging situations for both health care professionals and people who are trying to understand what's wrong with them," Fasano says.

Going on a strict 100 percent gluten-free diet for life remains the only treatment now for people with celiac disease. "We can't take the genes out, so we remove the environmental trigger," Fasano says. If you suspect you may have celiac disease, talk with your doctor. Waiting too long for a diagnosis might lead to serious problems.

As many as one in 141 Americans has celiac disease.

Learn more: <https://newsinhealth.nih.gov/issue/may2016/feature2>



Photo: iStock

# NIH Is Here to Help

## Institutes

- **National Library of Medicine (NLM)**  
[www.nlm.nih.gov](http://www.nlm.nih.gov)  
1-888-FIND-NLM (1-888-346-3656)
- **National Cancer Institute (NCI)**  
[www.cancer.gov](http://www.cancer.gov)  
1-800-4-CANCER (1-800-422-6237)
- **National Eye Institute (NEI)**  
[www.nei.nih.gov](http://www.nei.nih.gov) | (301) 496-5248
- **National Heart, Lung, and Blood Institute (NHLBI)**  
[www.nhlbi.nih.gov](http://www.nhlbi.nih.gov) | (301) 592-8573
- **National Human Genome Research Institute (NHGRI)**  
[www.genome.gov](http://www.genome.gov) | (301) 402-0911
- **National Institute on Aging (NIA)**  
[www.nia.nih.gov](http://www.nia.nih.gov)  
Aging information 1-800-222-2225  
Alzheimer's information 1-800-438-4380
- **National Institute on Alcohol Abuse and Alcoholism (NIAAA)**  
[www.niaaa.nih.gov](http://www.niaaa.nih.gov) | (301) 443-3860
- **National Institute of Allergy and Infectious Diseases (NIAID)**  
[www.niaid.nih.gov](http://www.niaid.nih.gov) | (301) 496-5717
- **National Institute of Arthritis and Musculoskeletal and Skin Diseases**  
[www.niams.nih.gov](http://www.niams.nih.gov)  
1-877-22NIAMS (1-877-226-4267)
- **National Institute of Biomedical Imaging and Bioengineering (NIBIB)**  
[www.nibib.nih.gov](http://www.nibib.nih.gov) | (301) 451-6772
- **Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)**  
[www.nichd.nih.gov](http://www.nichd.nih.gov) | 1-800-370-2943
- **National Institute on Deafness and Other Communication Disorders (NIDCD)**  
[www.nidcd.nih.gov](http://www.nidcd.nih.gov)  
1-800-241-1044 (voice)  
1-800-241-1055 (TTY)
- **National Institute of Dental and Craniofacial Research (NIDCR)**  
[www.nidcr.nih.gov](http://www.nidcr.nih.gov) | (301) 480-4098
- **National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**  
[www.niddk.nih.gov](http://www.niddk.nih.gov)  
Diabetes 1-800-860-8747  
Digestive disorders 1-800-891-5389  
Overweight and obesity 1-877-946-4627  
Kidney and urologic diseases  
1-800-891-5390
- **National Institute on Drug Abuse (NIDA)**  
[www.nida.nih.gov](http://www.nida.nih.gov) | (301) 443-1124
- **National Institute of Environmental Health Sciences (NIEHS)**  
[www.niehs.nih.gov](http://www.niehs.nih.gov) | (919) 541-3345
- **National Institute of General Medical Sciences (NIGMS)**  
[www.nigms.nih.gov](http://www.nigms.nih.gov) | (301) 496-7301
- **National Institute of Mental Health (NIMH)**  
[www.nimh.nih.gov](http://www.nimh.nih.gov) | 1-866-615-6464
- **National Institute on Minority Health and Health Disparities (NIMHD)**  
[www.nimhd.nih.gov](http://www.nimhd.nih.gov) | (301) 402-1366
- **National Institute of Neurological Disorders and Stroke (NINDS)**  
[www.ninds.nih.gov](http://www.ninds.nih.gov) | 1-800-352-9424
- **National Institute of Nursing Research (NINR)**  
[www.ninr.nih.gov](http://www.ninr.nih.gov) | (301) 496-0207

## Centers & Offices

- **Fogarty International Center (FIC)**  
[www.fic.nih.gov](http://www.fic.nih.gov) | (301) 402-8614
- **National Center for Complementary and Integrative Health (NCCIH)**  
[www.nccih.nih.gov](http://www.nccih.nih.gov) | 1-888-644-6226
- **National Center for Advancing Translational Sciences (NCATS)**  
[www.ncats.nih.gov](http://www.ncats.nih.gov) | (301) 435-0888
- **NIH Clinical Center (CC)**  
<http://clinicalcenter.nih.gov> | (301) 496-2563
- **Office of AIDS Research (OAR)**  
[www.oar.nih.gov](http://www.oar.nih.gov) | (301) 496-0357
- **Office of Behavioral and Social Sciences Research (OBSSR)**  
[obssr.od.nih.gov](http://obssr.od.nih.gov) | (301) 402-1146
- **Office of Rare Diseases Research (ORDR)**  
[rare diseases.info.nih.gov](http://rare diseases.info.nih.gov)  
Genetic and Rare Disease Information Center  
1-888-205-2311
- **Office of Research on Women's Health (ORWH)**  
[orwh.od.nih.gov](http://orwh.od.nih.gov) | (301) 402-1770

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