

# NIH MedlinePlus

Trusted Health Information  
from the National  
Institutes of Health

SUMMER 2014

the magazine

*Amy Robach of ABC's  
Good Morning America  
speaks out on breast  
cancer early detection  
and screening after her  
own surprise diagnosis.*

## Screening for **Breast Cancer**

### **Treating Cataracts**

With surgery, this common clouding of the lenses of the eyes can be cured. Find out the facts.

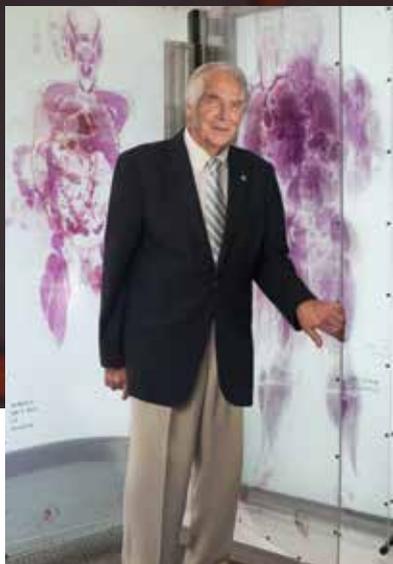
### **Celebrating 25 Years of The Children's Inn**

Keeping families together during life-saving medical research.

### **Steps to End Paralysis**

Groundbreaking NIH research helps heal those with paralyzing spinal cord injuries.

# National Library of Medicine Celebrates 30 Years of Progress and Charts the Future



▲ NLM Director Donald A.B. Lindberg, M.D., stands with one of NLM's signature accomplishments, the Visible Human Project, a digital library of the human anatomy.



◀ The Honorable Louis Sullivan, M.D., former Secretary of Health and Human Services, told those assembled, "It's hard for me to imagine a world without the National Library of Medicine."

On Wednesday, May 14, 2014, leaders in medicine, science, IT, and librarianship convened at the Natcher Center on the NIH campus in Bethesda, Maryland, to reflect on the contributions the National Library of Medicine has made over the last 30 years, and help chart its course for the future.

They were drawn to "The National Library of Medicine, 1984–2014: Voyaging to the Future" symposium, co-sponsored by the NLM Board of Regents, the Friends of the NLM, and the Medical Library Association. The event was the library's first step in developing its next long-range plan.

NLM Director Donald A.B. Lindberg, M.D., reflected on major achievements he said stemmed from the ideas of the people who served on NLM's long-range planning groups and advisory committees, many of whom were in the audience.

"If you hear something you like, take credit for it," he said as he described the genesis of the National Center for Biotechnology Information (NCBI); the Visible Human Project (a digital library of the human anatomy); the Unified Medical Language System (UMLS), which helps computer systems work together; outreach to the underserved; and 24/7 access to information.

The Honorable Louis Sullivan, M.D., former Secretary of Health and Human Services who served on an NLM planning group, said, "It's hard for me to imagine a world without the National Library of Medicine."

He added, "The NLM has, over the past 30 years, radically altered how scientists, health professionals, and the public find the information they need for research, practice, and personal use."

"NLM has been characterized as one of the jewels in the crown of the Public Health Service, and I certainly agree with that."

The event was videotaped and archived. It can be viewed in its entirety at <http://videocast.nih.gov/>.

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NIH MedlinePlus the Magazine is published by  
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Greensboro, NC 27407  
(336) 547-8970

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NIH research is giving hope to paralyzed patients with spinal cord injuries.

## 6 Treating Cataracts

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More and more women are surviving breast cancer. Early detection is a crucial key in the fight, notes Amy Robach.

Photos: (Cover and Bottom) Ida Mae Astute, ABC, (Top) University of Louisville, (Center) Kathy Lubbers.

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Kathy Lubbers hasn't let rheumatoid arthritis stop her. Thanks to the right medication, she is running marathons.

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The National Institutes of Health (NIH)—the Nation's Medical Research Agency—includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical, and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit [www.nih.gov](http://www.nih.gov).

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# Paralyzed Patients Regain Voluntary Movement

▲ Kent Stephenson does voluntary training while Katelyn Gurley tracks his level of muscle activity and force at the Human Locomotion Research Center laboratory, a part of the University of Louisville's Kentucky Spinal Cord Injury Research Center, Frazier Rehab Institute, Louisville, Kentucky.

▼ Dustin Shillcox (below) also undergoes voluntary leg movement training at the same facility.



## Groundbreaking NIH study spurs hope for those with spinal cord injury

Flex a muscle, any muscle? Certainly, it's second nature. But not if you're paralyzed.

Now, thanks to a novel combination of electrical stimulation of their spinal cords and long-term physical therapy, four young people, each paralyzed for more than two years, can voluntarily flex their toes, ankles, and knees. They participated in a groundbreaking research study supported by the National Institute of Biomedical Imaging and Bioengineering (NIBIB), the National Institute of General Medical Sciences (NIGMS), the Christopher & Dana Reeve Foundation, and others.

"The evidence suggests that a large number of people with little realistic hope of any meaningful recovery from spinal cord injury may benefit from this intervention," says NIBIB Director Dr. Roderic Pettigrew.

The new findings build upon a 2009 pilot trial that tested whether spinal stimulation, in conjunction with daily treadmill training, could help patients with paralysis regain some movement. In the pilot, Rob Summers, a young man paralyzed from the chest down, had a 16-electrode array implanted on his spinal cord. It delivered electrical pulses just below his injury while he underwent daily training, suspended from a harness over a treadmill. During training, researchers supported his legs, helping him to stand and walk.



Photos: University of Louisville

Although not strong enough alone to activate muscles, the researchers believed the electrical stimulation combined with the sensory input from walking could lead to movement. The goal was to increase the sensitivity of the spinal cord's local circuits controlling basic motor functions such as the knee jerk from stepping on a tack, or even more complex patterned movements like stepping.

With the electrical stimulation turned on, Summers gradually could bear his own weight and stand as long as four minutes without assistance. Eventually, he realized that he had even

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## The evidence suggests that a large number of people with little realistic hope of any meaningful recovery from spinal cord injury may benefit from this intervention

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regained some voluntary leg control in the presence of stimulation. Amazingly, intentional movement like this requires that information travel from the brain to the lower spinal cord, a path that was blocked in Summers. Also, other impairments from his injury began to improve, including bladder and blood pressure control, body temperature regulation, and sexual function, even with the stimulator turned off.

Three additional paralyzed patients joined Summers in the new study, which was conducted by Claudia Angeli, Ph.D., a senior researcher at the Human Locomotion Research Center at Frazier Rehab Institute and assistant professor at the University of Louisville's Kentucky Spinal Cord Injury Research Center, and colleagues. Two patients had complete motor and sensory paralysis. Because of this, one of them was meant to serve as the baseline patient. The third, like Summers, had complete motor paralysis but some sensation below his injury. Researchers had assumed at least some of the sensory pathway needed to be intact for their therapy to have worked. Surprisingly, all three regained some voluntary muscle control just a few days after starting stimulation.

"What was astounding about our 'baseline' patient was that not only was there voluntary movement, but we saw it in the first week of stimulation. We then saw it in the next two patients," recalls Susan Harkema, Ph.D., director of rehabilitation research at the Kentucky Spinal Cord Injury Research Center. Although much remains to be done, she believes these results provide enough evidence to challenge the current prognosis of patients with severe spinal cord injuries.

According to V. Reggie Edgerton, Ph.D, a UCLA distinguished professor of integrative biology and physiology who originated the new approach, the speed at which each patient regained voluntary control may mean that there are dormant connections in patients with complete motor paralysis. "The spinal stimulation could be reawakening these connections," he says.

In a further landmark, all four participants were able to synchronize leg, ankle, and toe movements in unison with the rise and fall of a wave on a computer screen, and three out of the four were able to change the force at which they flexed their leg.

By the end of the study, which lasted several months and included home-based training, some of the patients were able to make voluntary movements with greater force and under reduced stimulation. Others had enhanced movement accuracy. Whether these improvements were due to the training or to the cumulative effects of the stimulation is unclear and await further study.



Photo: National Institute of Biomedical Imaging and Bioengineering

▲ (l to r) V. Reggie Edgerton, Ph.D., of UCLA, Roderic I. Pettigrew, Ph.D., M.D., director of NIBIB, and Claudia Angeli, Ph.D., of the University of Louisville's Kentucky Spinal Cord Injury Research Center.

With support from NIBIB, Edgerton is leading development of a new high-density, 27-electrode array that may provide finer, more robust motor control. "For a given type of movement, we want to be able to select exactly where and how to stimulate the spinal cord," he explains. He and others also are exploring ways to help patients with upper-limb paralysis, and working to develop a new technology that can deliver spinal stimulation through the skin, bypassing the need for surgical implantation.

"This is a wake-up call for how we see motor complete spinal cord injury," said Edgerton. "We don't have to necessarily rely on regrowth of nerves in order to regain function. The fact that we've observed this in all four patients suggests that this is actually a common phenomenon in those with complete paralysis."

Dr. Pettigrew says the results from this study represent a medical milestone. "It means that a spinal cord injury may no longer mean a lifelong sentence of permanent paralysis."

# NIH Research

By NIBIB Director Dr. Roderic I. Pettigrew

Roderic I. Pettigrew, Ph.D., M.D., is the first Director of the NIH's National Institute of Biomedical Imaging and Bioengineering (NIBIB). Prior to his appointment at the NIH, Dr. Pettigrew was Professor of Radiology, Medicine (Cardiology), at Emory University and Bioengineering at the Georgia Institute of Technology and Director of the Emory Center for MR Research, Emory University School of Medicine, Atlanta, Georgia. He is known internationally for his pioneering work involving four-dimensional imaging of the cardiovascular system using magnetic resonance imaging (MRI). His current research focuses on integrated imaging and predictive biomechanical modeling of coronary atherosclerotic disease.

## Progress on Paralysis

### Is paralysis a major health problem?

Yes, it is. The Christopher Reeve Foundation published a study in 2009 that found far more Americans are paralyzed than originally thought. The study indicated that 5.6 million (1 in 50) Americans are paralyzed to some degree and that 1.275 million of those cases resulted from spinal cord injury. This is five times the previous estimate.

### What does this new study mean for the average paralyzed person?

Spinal stimulation therapy is still in the research phase. This means that before it can become available to the average person, its safety and effectiveness will have to be established in a large number of patients, and it will need to be approved by the FDA. In addition, the technology used in this study has limitations because it was designed for another purpose, to suppress back pain. Researchers are currently working to develop an optimized stimulator that could help patients achieve more controlled movements. That said, the results from this study challenge the conventional wisdom that patients with complete paralysis have almost no chance of meaningful recovery. Now for paralyzed patients, there is more hope than ever.

### What surprises you most about the study?

The fact that the spinal stimulation therapy was able to generate voluntary movement in four out of four patients with complete paralysis is truly remarkable. The researchers initially



Photo: National Institute of Biomedical Imaging and Bioengineering

Roderic I. Pettigrew, Ph.D., M.D., first Director of the NIH's National Institute of Biomedical Imaging and Bioengineering (NIBIB)

expected that only patients with the ability to experience sensation below their injury would be able to benefit from the therapy. That notion was thrown out the window when the first patient, who had no sensation below his injury, moved almost immediately in the presence of stimulation. Statistically, the fact that all four men regained some voluntary movement of their lower extremities suggests that many other patients with spinal cord injuries are also likely to benefit. Another impressive outcome was that all four patients also experienced improvements in involuntary nervous system function. This included control of blood pressure, body temperature regulation through sweating, and return of bladder, bowel, and sexual function.

### Do you think people who have been paralyzed for years may someday walk again?

That is our hope, and that is what we are working toward. However, it will take more research. The spinal stimulation and physical therapy approach to rehabilitation used in this most-recent study is the product of decades of NIH-funded research on the spinal cord, carried out by Dr. V. Reggie Edgerton (UCLA) and his collaborators. Walking is a complicated process that requires multiple muscles to produce controlled contractions in both legs and in a specific pattern. This will require more extensive recovery than was realized in this initial study, but it is now conceivable that this can be achieved in the future.

## And what about those people who can't use their arms and hands? How much research is being done for them?

NIBIB is also supporting Dr. Edgerton and his colleagues to determine whether spinal stimulation can be used to help patients with paralysis of the upper limbs.

## Do you see any benefits from this research flowing to people with Parkinson's disease or other neurological disorders?

The mechanism of dysfunction in spinal cord injury is not completely understood but is believed to be different from that in Parkinson's and some of the other neurological disorders. Consequently, it is difficult to predict how many types of populations will ultimately benefit from this therapy. This will require further research.

## What other breakthroughs do you see happening in the next few years?

In addition to optimizing the spinal stimulator, researchers are working to develop a new device that can deliver electrical stimulation through the skin, so that the stimulator doesn't have to be surgically implanted. A non-invasive spinal stimulator will make it easier to reach patients in remote settings, away from large medical centers.

Besides spinal stimulation, there are other technologies being developed with support from NIBIB that show promise for helping patients with paralysis perform essential activities of daily living. For example, researchers have developed and are now evaluating an implantable Networked Neuroprosthesis (NNP) to restore hand grasp in those with tetraplegia. This next generation Functional Electrical Stimulation (FES) neuroprosthesis couples sensors—implanted in the muscle that interprets the intention to move—with more intense stimulators that electrically activate the nerves controlling the target muscles. Researchers are also developing Brain-Computer Interfaces (BCI) that allow patients to control a computer and other devices such as a robotic arm using only their thoughts. Another NIBIB-funded researcher has developed a system that allows patients to control devices and even navigate a wheelchair using only tongue movements.

## Do you believe there will ever be a cure for paralysis?

This report of remarkable recovery in 4 of 4 patients with long-standing, complete motor paralysis is a medical milestone that has been reached; but it is not the end of the research. The more we learn about the mechanisms of spinal cord injury and dysfunction, the better we will be able to innovate and craft definitive treatments. It is my belief that this systematic process will eventually lead us to a cure.



▲ Left to right is Andrew Meas, Dustin Shillcox, Kent Stephenson, and Rob Summers, the first four to undergo task-specific training with epidural stimulation at the Human Locomotion Research Center laboratory, Frazier Rehab Institute, as part of the University of Louisville's Kentucky Spinal Cord Injury Research Center, Louisville, Kentucky. Photos courtesy of the University of Louisville.

Photos: University of Louisville



## What Are Cataracts?

A cataract is a clouding of the lens in your eye. It affects your vision. Cataracts are very common in older people.

A cataract can occur in either or both eyes. Common symptoms are blurry vision, colors that seem faded, glare and halos from lights, and reduced night vision.

Cataracts usually develop slowly. New glasses, brighter lighting, anti-glare sunglasses, or magnifying lenses can help at first.

Surgery is an option. It involves removing the cloudy lens and replacing it with an artificial lens.

Source: National Eye Institute

# Treating Cataracts

Claudine Klose, 63, lives on a farm in New York's Hudson Valley. She had successful cataract surgery in 2013 and shared her experience recently with *NIH MedlinePlus* magazine.

## What did you notice about your vision that told you something was wrong?

In the fall of 2012, my vision began to blur, and I was seeing double images of bright lights at night. I even saw three moons. It was very disturbing.

Even though I'd been treated for iritis (an inflammation of the colored part of the eye surrounding the pupil) since the early 1990s, and I'd been diagnosed with small cataracts in 2004, I had no idea it was the cataracts. Until I had my annual eye exam in early 2013, that is.

## How bad was your vision?

My vision had deteriorated so badly that I was unable to legally drive, even with my glasses on. So my ophthalmologist sent me to an eye surgeon, who explained that surgery was the best—and only—option; that there are no drugs to treat cataracts.

## Were you worried about having surgery?

Yes. Having never had eye surgery, my major concerns were how painful it would be and how long it would take to recover.

## Where did you go for information about cataracts and surgery?

I used MedlinePlus ([www.medlineplus.gov](http://www.medlineplus.gov)) to check on the procedure and any drawbacks. Also, the New York City cataract specialists that my local surgeon referred me to (a father-and-son team) gave me lots of helpful information in advance.

## Did the procedure take long?

No. I had both eyes done two weeks apart. The procedures were completely painless and took about 15 minutes each, with brief follow-up visits the next morning.

◀ Rachel J. Bishop, M.D., M.P.H., of the NIH's National Eye Institute, performs cataract surgery.



Photos: Christopher Klose

▲ Claudine Klose had successful cataract surgery on both eyes in 2013. Photo: National Library of Medicine

## What kind of lenses did you have implanted?

Because of the iritis, I could not have them implant multifocal lenses, which would allow me to see both near and far. So I chose lenses for clear distance sight, and I wear reading glasses to see up close.

## What was the result?

Immediately, I could read the signs across the street from the clinic. There weren't any complications either, although I did have to use a lot of drops for several months after to control the iritis.

Today, when I'm driving, I see every leaf on every tree. It's great!

## What would you tell others?

1. Don't be afraid of cataract surgery.
2. Learn as much as possible before you have surgery.
3. Use your eye drops as prescribed after surgery.
4. Always wear sunglasses (to protect against ultraviolet light).
5. Get regular comprehensive dilated eye exams.

## Dr. Rachel Bishop's Top Tips for Your Eyes

A specialist in general ophthalmology and cataract surgery, Dr. Rachel Bishop is chief of consult services at the National Eye Institute (NEI), National Institutes of Health (NIH). She examines the eyes of people participating in clinical trials at the NIH. This involves monitoring medication and treatment effects, managing eye diseases, and performing surgeries.

- **Make eye care a part of your regular health care routine.** Your eye care professional will tell you how often you should have a comprehensive dilated eye exam.
- **Live a healthy lifestyle.** Don't smoke, exercise regularly, maintain a healthy weight, and eat a diet with plenty of leafy, dark green vegetables. If you have diabetes, keep it under control.
- **Know your family's eye health history.** Having a family member with eye disease may put you at higher risk. Talk to your doctor to find out more.
- **When outside, try to wear sunglasses and a hat to shield your eyes from ultraviolet light (sunlight), especially if you are a farmer, a fisherman, or you spend a lot of time outdoors.**
- **Wear protective goggles when playing sports or doing yard work to guard your eyes against flying objects such as baseballs, wood chips, or debris.**

## Lenses After Cataract Surgery

After your eye's natural lens has been removed, it is usually replaced by an artificial lens, called an intraocular lens (IOL). An IOL is a clear, plastic lens that requires no care and becomes a permanent part of your eye. Light is focused clearly by the IOL onto the retina, improving your vision. You will not feel or see the new lens.

### IOL Types

**Monofocal**—This common IOL type has been used for several decades. Monofocals are set to provide best-corrected vision at near, intermediate, or far distances. Most people who choose monofocals have their IOLs set for distance vision and use reading glasses for near activities. On the other hand, a person whose IOLs were set to correct near vision would need glasses to see distant objects clearly. Some decide to have the IOL for one eye set for distance vision, and the other set for near vision, called "monovision."

**Multifocal**—These newer IOL types reduce or eliminate the need for glasses or contact lenses. In the multifocal type, a series of focal zones or rings is designed into the IOL. Depending on where incoming light focuses through the zones, the person may be able to see both near and distant objects clearly.

Discuss your lens options with your eye doctor to determine the IOL that best suits your vision needs and lifestyle.

—Source: American Academy of Ophthalmology (AAO)



Photos: Dr. Rachel Bishop

Dr. Rachel Bishop, chief of consult services at the National Eye Institute (NEI), National Institutes of Health (NIH).

## Research Update:

The NEI is conducting and supporting a number of studies focusing on factors associated with the development of age-related cataract. Researchers are examining:

- **The effect of sunlight exposure, which may be associated with an increased risk of cataract.**
- **Antioxidants and other vitamin supplements, which have shown varying results in delaying the progression of cataract.**
- **The role of genetics in cataract formation.**

# Comprehensive Dilated Eye Exam

A comprehensive dilated eye exam is a procedure in which an eye care professional examines your eyes to look for common vision problems and eye diseases, many of which have no early warning signs. Regular comprehensive eye exams can help you protect your sight and make sure that your eyes are healthy and you are seeing your best. This eye exam includes the following tests.

**Dilation:** Drops are placed in your eyes to dilate, or widen, the pupils. Your eye care professional uses a special magnifying lens to examine your retina to look for signs of damage and other eye problems, such as diabetic retinopathy or age-related macular degeneration. A dilated eye exam can also reveal cataracts and any damage to the optic nerve from glaucoma. After the examination, your close-up vision may remain blurred for several hours.

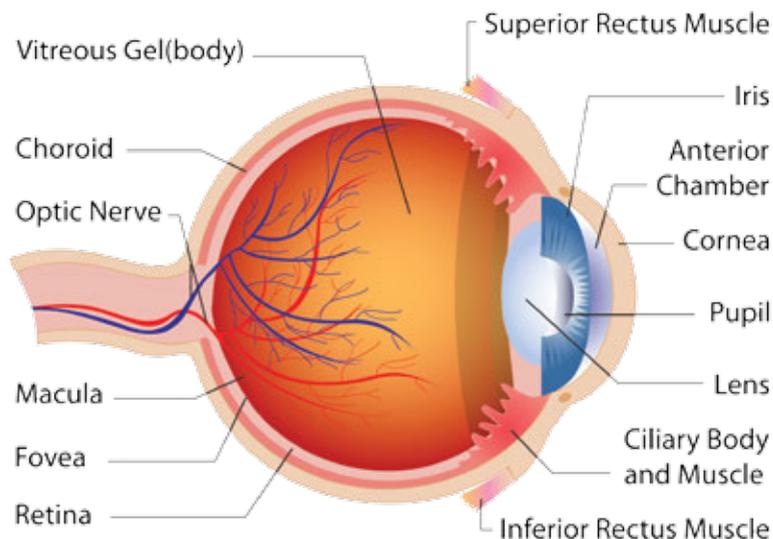
**Tonometry:** In this test, gentle pressure is applied to the outside of the eye to measure the pressure inside. The outside pressure may be produced by a small probe or by an air puff. Numbing drops may be applied to your eye first. Elevated pressure is a possible sign of glaucoma.

**Visual field test:** This test measures your side (peripheral) vision to determine if you have lost any—a sign of glaucoma.

**Visual acuity test:** This test measures how clearly you can see letters on an eye chart. The test is generally done at a distance of 20 feet, and a result of 20/20 indicates normal visual acuity. A result of 20/40 means that at 20 feet you can see what a person with normal vision can see at 40 feet.

## fastfacts

- 1 **Cataracts are the leading cause of blindness worldwide. Most cataracts occur naturally with aging.**
- 2 **People with diabetes are more likely to develop cataracts. So are smokers and people who spend a lot of time in the sun.**
- 3 **Surgery is the only treatment for cataracts—there are no approved medications at this time.**
- 4 **In about about 90 percent of cases, people who have cataract surgery have better vision afterward.**
- 5 **The most effective way to maintain your vision is through regular eye exams, a healthy lifestyle, and eye protection.**



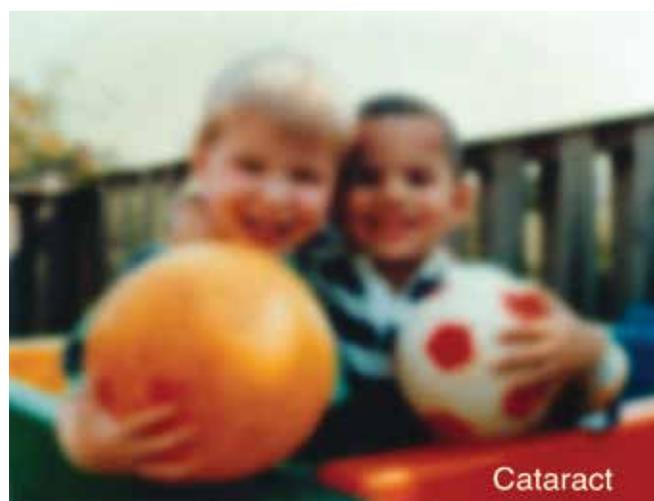
◀ In a normal eye, light passes through the transparent lens to the retina. The lens helps focus your eyes on what you see. It must be clear for the retina to receive a sharp image. The lens is made of mostly water and protein. The protein is arranged in a precise way that keeps the lens clear. As we age, some of the protein may clump together and start to cloud a small area of the lens. This is a cataract.

# Cataracts and Other Common Eye Diseases

Photos: National Eye Institute



▲ **Normal:** A scene as it might be viewed by a person with normal vision.



▲ **Cataract:** A scene as it might be viewed by a person with cataracts.



▲ **Diabetic Retinopathy:** A scene as it might be viewed by a person with diabetic eye disease.

## Diabetic Eye Disease

People with diabetes are at risk for diabetic retinopathy, cataract, and glaucoma. Diabetic eye disease refers to this group of eye problems that people may face as a complication of diabetes. There are no symptoms in the early stages of diabetic eye diseases.

### Treatment:

To prevent vision loss from diabetic eye disease, people with diabetes should control their levels of blood sugar, blood pressure, and blood cholesterol. Depending on the stage and type of diabetic eye disease, various treatments are used, including laser surgery, vitrectomy surgery (removal of blood from the center of the eye), and injections of drugs into the eye.

## Cataracts

Cataracts are a clouding of the lenses in your eyes, causing blurry vision. Unlike many eye diseases, they are usually not dangerous to the health of the eye and are curable with surgery. A cataract can occur in one or both eyes. It cannot spread from one eye to the other. By age 80, more than half of all Americans will have a cataract or have had cataract surgery.

### Common symptoms are:

- Blurry vision
- Colors that seem faded
- Glare
- Not being able to see well at night
- Double vision
- Frequent prescription changes in your eyewear

At first new glasses, brighter lighting, anti-glare sunglasses, or magnifying lenses can help with early symptoms. However, surgery is the only effective treatment. It involves removing the cloudy lens and replacing it with an artificial lens.



Age-related Macular Degeneration

▲ **Macular Degeneration:** A scene as it might be viewed by someone with age-related macular degeneration.



Glaucoma

▲ **Glaucoma:** A scene as it might be viewed by a person with glaucoma.

## Age-Related Macular Degeneration

Age-related macular degeneration (AMD) is a leading cause of vision loss in Americans 60 and older. It destroys the sharp, central vision needed to see objects clearly. Reading, driving, watching television, and routine daily tasks are affected. AMD causes cells in the macula—the part of the eye that allows you to see fine detail—to die. It does not cause pain.

There are three stages of AMD: early, intermediate, and late.

**In the early stages,** AMD has few symptoms, so it is important to have regular eye examinations.

**Intermediate AMD** may cause some vision loss, but most people will not experience any symptoms. It is important to have a dilated eye exam to detect intermediate AMD.

**Late-stage AMD** is comprised of two types: geographic atrophy (also called dry AMD), and neovascular AMD (also called wet AMD). Both cause vision loss. It is possible to have both geographic atrophy and neovascular AMD in the same eye, and either condition can appear first.

### Treatment:

Although currently there is no cure for AMD, regular eye exams can detect the disease and lead to early treatment, when it is most effective and often sight-saving. NEI-supported research shows that a specific combination of vitamins and minerals can help slow the progression to advanced AMD. Advanced AMD is treated with injections of drugs into the eye and lasers.

## Glaucoma

Glaucoma is a group of diseases that can damage the eye's optic nerve and result in vision loss and blindness. Open-angle glaucoma is the most common form of the disease. Often there are no symptoms in the early stages, but can be detected through a dilated eye exam.

### Treatment:

Glaucoma treatments include medicines, laser trabeculoplasty, conventional surgery, or a combination of any of these. While these treatments may save remaining vision, they do not improve sight already lost from glaucoma.

### Find out more

- ✓ **MedlinePlus.gov**  
[www.nlm.nih.gov/medlineplus/cataract.html](http://www.nlm.nih.gov/medlineplus/cataract.html)
- ✓ **National Eye Institute (NEI)**  
[www.nei.nih.gov/health/cataract/](http://www.nei.nih.gov/health/cataract/)
- ✓ **NIHSeniorhealth**  
<https://nihseniorhealth.gov/cataract/whatisacataract/01.html>
- ✓ **ClinicalTrials.gov**  
In the Search for Studies box, type "cataract."  
<https://clinicaltrials.gov/>
- ✓ **American Academy of Ophthalmology**  
Click on "Cataract."  
[www.aao.org](http://www.aao.org)



# Rheumatoid Arthritis

*When Your Immune System*  
**Attacks Your Body**

Photo: Thinkstock

Rheumatoid arthritis is a disease that affects the joints. It causes pain, swelling, and stiffness. If one knee or hand has rheumatoid arthritis, usually the other does, too. This disease often occurs in more than one joint and can affect any joint in the body. People with this disease may feel sick and tired, and they sometimes get fevers.

RA is an autoimmune disease, which means the arthritis results from your immune system attacking your body's own tissues.

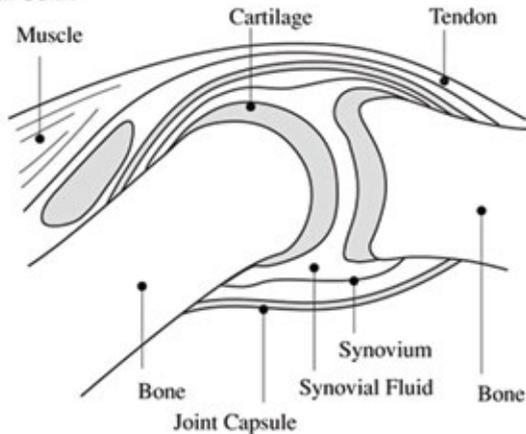
The course of rheumatoid arthritis can range from mild to severe. In most cases it is chronic, meaning it lasts a long time—often a lifetime. For many people, periods of relatively mild disease activity are punctuated by flares, or times of heightened disease activity. In others, symptoms are constant.

Scientists estimate that about 1.3 million people in the United States have rheumatoid arthritis.

## Who Gets Rheumatoid Arthritis?

The disease occurs in all racial and ethnic groups, but affects two to three times as many women as men. Rheumatoid arthritis is more commonly found in older individuals, although the disease typically begins in middle age. Children and young adults can also be affected.

### Normal Joint



### Joint Affected by Rheumatoid Arthritis

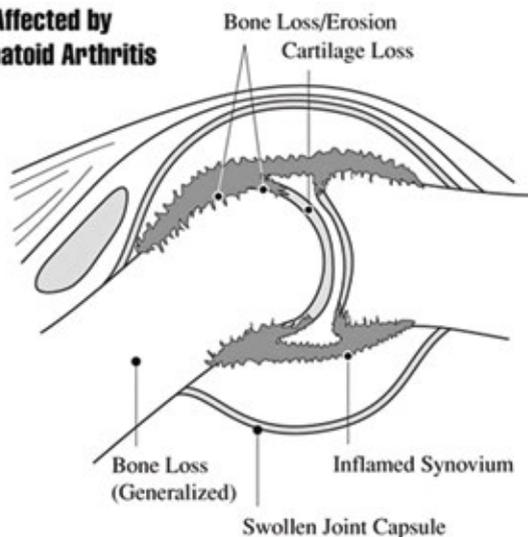


Photo: NIAMS

A joint (the place where two bones meet) is surrounded by a capsule that protects and supports it. The joint capsule is lined with a type of tissue called synovium, which produces synovial fluid that lubricates and nourishes joint tissues. In rheumatoid arthritis, the synovium becomes inflamed, causing warmth, redness, swelling, and pain. As the disease progresses, the inflamed synovium invades and damages the cartilage and bone of the joint. Surrounding muscles, ligaments, and tendons become weakened. Rheumatoid arthritis also can cause more generalized bone loss that may lead to osteoporosis (fragile bones that are prone to fracture). Source: NIAMS

## How Is Rheumatoid Arthritis Diagnosed?

People can go to a family doctor or rheumatologist to be diagnosed. A rheumatologist is a doctor who helps people with problems in the joints, bones, and muscles. Rheumatoid arthritis can be hard to diagnose because:

- There is no single test for the disease.
- The symptoms can be the same as other kinds of joint disease.
- The full symptoms can take time to develop.

To diagnose rheumatoid arthritis, doctors use medical history, physical exam, X-rays, and lab tests.

Rheumatoid arthritis is different from osteoarthritis, the common arthritis that often comes with older age. RA can affect body parts besides joints, such as your eyes, mouth, and lungs.

## fast facts

- 1 Rheumatoid arthritis (RA) is a chronic, systemic, autoimmune, inflammatory disease, characterized by pain on both sides of the body, swelling in multiple joints, and general malaise and fatigue.
- 2 RA affects about 1.3 million Americans, and there are 2.5 times as many women as there are men with RA, according to the Centers for Disease Control and Prevention (CDC).
- 3 No specific lab test is available to confirm a diagnosis of RA. Physicians diagnose RA based on the overall pattern of symptoms, medical history, physical exam, x-rays, and lab tests.
- 4 Doctors use a variety of approaches to treat RA—medications, lifestyle, and surgery. The goals are to relieve pain, reduce inflammation, stop joint damage, and improve the person's ability to function.

## Questions to Ask Your Healthcare Provider

1. What tests indicate I might have RA?
2. Are there medicines that can help treat RA?
3. Is joint-replacement surgery an option with RA?
4. What lifestyle changes can I make to help reduce the symptoms of rheumatoid arthritis?
5. May I exercise with RA?
6. Are there complementary and alternative medicines that might help my RA?



Photo: Thinkstock

## How Is Rheumatoid Arthritis Treated?

Doctors have many ways to treat this disease. The goals of treatment are to:

- Take away pain
- Reduce swelling
- Slow down or stop joint damage
- Help people feel better
- Help people stay active

Treatment can include patient education, self-management programs, and support groups that help people learn about:

- Treatments
- How to exercise and relax
- How to talk with their doctor
- Problem solving

## What Causes Rheumatoid Arthritis?

Doctors don't know the exact cause of rheumatoid arthritis. They know that with this arthritis, a person's immune system attacks his or her own body tissues. Researchers are learning many things about why and how this happens. Things that may cause rheumatoid arthritis are:

- Genes (passed from parent to child)
- Environment
- Hormones



## Accelerating Medicines Partnership (AMP—Part 2 of 4)

The NIH, pharmaceutical companies, and nonprofit organizations have together created the Accelerating Medicines Partnership (AMP) to develop new models for identifying and validating promising biological targets for new diagnostics and drug development. The partners have designed a project plan to address relevant challenges for rheumatoid arthritis.

*Read Part 1 on Lupus in MedlinePlus magazine, Spring 2014 issue: [www.nlm.nih.gov/medlineplus/magazine/](http://www.nlm.nih.gov/medlineplus/magazine/)*

## NIH-Supported Research

- NIH-supported researchers recently discovered that the presence of a specific type of gut bacteria correlates with rheumatoid arthritis in newly diagnosed, untreated people. The finding suggests a potential role for the bacteria in RA.
- In November 2012, the U.S. Food and Drug Administration approved a new oral medication (the first in a new class of drugs) for the treatment of rheumatoid arthritis. The drug, tofacitinib (Xeljanz), targets a protein that was discovered in the early 1990s by investigators at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).
- NIH scientists are studying genetic factors that predispose some people to developing rheumatoid arthritis, as well as factors connected with disease severity. Research in this area has led to several important genetic discoveries.
- Researchers continue to identify molecules that appear to play a role in rheumatoid arthritis and, thus, are potential targets for new treatments.



## What You Can Do: The Importance of Self-Care

Although healthcare professionals can prescribe or recommend treatments to help patients manage their rheumatoid arthritis, the real key to living well with the disease lies with the patients themselves. Research shows that people who take part in their own care report less pain and make fewer doctor visits. They also enjoy a better quality of life.

Self-management programs teach about rheumatoid arthritis and its treatments, exercise and relaxation approaches, communication between patients and health care providers, and problem solving. Research on these programs has shown that they help people:

- understand the disease
- reduce their pain while remaining active
- cope physically, emotionally, and mentally
- feel greater control over the disease and build a sense of confidence in the ability to function and lead full, active, and independent lives.



Photo: Kathy Lubbers

## Rheumatoid Arthritis: “You Are Not Alone.”

Members of the America 2 Anywhere 4 Arthritis (A2A4A) running group after finishing a marathon. Through their running, they have raised significant funds for the Arthritis Foundation. Kathy Lubbers is at far right.

One morning more than 26 years ago, Kathy Lubbers woke up and found that she could not bear to lift the sheet from her body because the pain was so great. Although she had been experiencing pain in both hands, nothing had prepared her for this.

With the help of her husband, she got to her doctor and then a rheumatologist. The diagnosis was lupus—an autoimmune disease with symptoms such as inflammation, swelling, and damage to joints, skin, kidneys, blood, the heart, and lungs.

It would be another 18 months of pain before a different doctor gave her the right diagnosis—rheumatoid arthritis (RA). Lubbers then began trying different medicines, including several common RA medications.

For a period of a dozen years, Lubbers dealt with significant pain. Her husband lifted her in and out of her car and the

bathtub. She had her desk in the bedroom, and she could take a couple of steps to do her work as a consultant in marketing communications and strategic planning—and then step slowly back to the bed.

Finally, about 10 years ago, she transitioned to a medication for moderate to severe RA, as well as psoriasis and psoriatic arthritis—generic name, entercept. It worked, and Lubbers has been thrilled with it ever since.

The reversal has been so great that Lubbers has finished six marathons. She and friends run together as a group called America 2 Anywhere 4 Arthritis. They have raised significant funds for the Arthritis Foundation. Lubbers served nine years on the National Arthritis Foundation Board.

For others with RA, Lubbers says, “Remember, you are not alone. Stay positive and connected to others.”

# RA Quiz

## 1. Rheumatoid arthritis is an inflammatory disease that affects the

- A. kidneys.
- B. joints.
- C. muscles.

## 2. In an autoimmune disease like rheumatoid arthritis, the immune system

- A. turns against parts of the body it is designed to protect.
- B. functions automatically.
- C. fails to fight off infections.

## 3. Rheumatoid arthritis generally affects

- A. one side of the body.
- B. both sides of the body.
- C. only the upper body.

## 4. Rheumatoid arthritis occurs more frequently in

- A. women.
- B. men.
- C. neither—it occurs as frequently in women as in men.

# RA Answers

## 1. B is the correct answer.

Rheumatoid arthritis is an inflammatory disease that affects the joints. It may also attack tissue in the skin, lungs, eyes, and blood vessels.

## 2. A is the correct answer.

In an autoimmune disease like rheumatoid arthritis, the immune system turns against parts of the body it is designed to protect.

## 3. B is the correct answer.

Rheumatoid arthritis generally affects both sides of the body. If one knee or hand is involved, the other one is, too.

## 4. A is the correct answer.

Rheumatoid arthritis occurs much more frequently in women than in men. About two to three times as many women as men have the disease.



Video: NIHSeniorHealth.gov

## Video: "Living with Rheumatoid Arthritis"

A 55-year old woman learns to successfully cope with rheumatoid arthritis.

<https://nihseniorhealth.gov/videolist.html#rheumatoidarthritis>

## To Find Out More

- ✓ MedlinePlus  
[www.nlm.nih.gov/medlineplus/rheumatoidarthritis.html](http://www.nlm.nih.gov/medlineplus/rheumatoidarthritis.html)
- ✓ National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)  
[www.niams.nih.gov](http://www.niams.nih.gov)
- ✓ National Institute of Allergy and Infectious Diseases (NIAID)  
[www.niaid.nih.gov/Pages/default.aspx](http://www.niaid.nih.gov/Pages/default.aspx)
- ✓ National Center for Complementary and Alternative Medicine  
<http://nccam.nih.gov>
- ✓ NIHSeniorHealth.gov—Rheumatoid Arthritis  
<http://nihseniorhealth.gov/rheumatoidarthritis/whatisrheumatoidarthritis/01.html>
- ✓ Arthritis Foundation  
[www.arthritis.org](http://www.arthritis.org)



# #BE BRAVE

*A Life-Saving Test*

***Good Morning America's Amy Robach*** got the shock of her life in November 2013 when she was diagnosed as the one of 1-in-8 women in America who will be affected by breast cancer in their lifetimes. She has confronted her diagnosis of breast cancer by speaking out in support of others facing the disease.

**You discovered your breast cancer in an unusually public way. Would you tell us about that?**

I was asked by *Good Morning America* producers to have the first-ever mammogram on live television to raise awareness for Breast Cancer Awareness month. I was very hesitant at first, because I was just 40, had no family history of the disease, and felt uncomfortable doing something so private, so publicly!

I was convinced when producers and my colleague, Robin Roberts, told me they were trying to reach women just like me – women who thought they couldn't have breast cancer. I'll never forget Robin saying to me "If you save one life because of early detection, it's completely worth the sacrifice." I just had no idea then that I would be saving my own life!

**What were your first thoughts when you received the diagnosis?**

I was in complete shock. I went back in for some follow-up images after the initial mammogram, never thinking just a few hours later I would have a cancer



Photo: Ida Mae Astute/ABC

▲ Amy Robach serves as the news anchor on ABC's top-rated *Good Morning America*.

diagnosis. No one is ever prepared to hear those words ... I was alone and in a state of disbelief. I've never been so scared, so devastated in my entire life.

**You've said that if it wasn't for your co-worker Robin Roberts, herself a breast cancer survivor, you may not have gotten your screening mammogram. What is your message to other women about the importance of screening? Especially younger working women?**

I've learned that if you're a woman, and you're getting older, you're at risk for breast cancer. More than 80 percent of breast cancer patients have zero family history. I had no knowledge of that statistic until I became a part of it. Mammograms aren't perfect, but they're what we've got, and a mammogram saved my life. I felt completely healthy,

I felt invincible ... all the while I had two malignant tumors in me, and the cancer had already spread to one of my lymph nodes. Women have to realize that ignorance is not bliss when it comes to cancer. Get screened. Every year. No excuses.

### Can you tell us about your course of treatment and how that has gone so far?

I had a bilateral mastectomy, where my surgeon found a second, hidden, malignant tumor, and further testing showed my left breast had a number of pre-cancerous cells developing. Because of my age and the fact that the cancer had spread to my sentinel lymph node, my oncologist felt the responsible next step was eight rounds of chemotherapy. After seven months of expanders in my breasts, I just had reconstructive surgery with implants. Now I begin 10 years of tamoxifen, starting at the end of June. The mental battle will always be with me, and I will never take my health for granted again. Not ever.

### What message do you have for others who have been diagnosed with breast cancer?

Know that you're not alone. There are nearly 2 million breast cancer survivors in this country, and we are thriving, excelling, living. Yes, it is a hellish journey through surgeries, chemotherapy, radiation, and drug therapy. But you will emerge a better person. I promise. You are stronger than you think, and you will find your inner warrior. Your family and friends will marvel at your strength, and they will weep with you on those days when you just don't want to get out of bed. It gets easier, and after this, there's nothing you can't do!

We know your family and friends have been very important to your success so far. What has been most helpful to you in the support you have received?

Support is everything. No one can do this alone. Every smile, every hug, every kind word, message, letter has had a tremendous impact on my will to keep going. I simply do not have the words to thank everyone who has been there for me in both little and big ways. Collectively, they have kept me in fighting mode and carried me through the toughest time in my life. I am eternally grateful and hope to pay it forward in every way possible. **Fight like a girl!!!!**



To count down her eight rounds of chemotherapy and share her progress with fans, Robach posted these photos on her Twitter account. Photos: @arobach

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**"There are nearly 2 million breast cancer survivors in this country, and we are thriving, excelling, living."  
—Amy Robach**

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# Breast Cancer Basics and You



Photo: Thinkstock

**A**ccording to the National Cancer Institute (NCI), there will be more than 232,670 new cases of female breast cancer in the United States in 2014. More than 40,000 women die of the disease each year. It occurs in both men and women, although male breast cancer is rare.

## The Breasts

Inside a woman's breast are 15 to 20 sections called lobes. Each lobe contains many smaller sections called lobules. These are groups of tiny glands that make breast milk. Breast milk flows through thin tubes called ducts to the nipple. Fat and other tissue fills the spaces between the lobules and ducts. The breasts also contain lymph vessels, which are connected to small, round masses of tissue called lymph nodes. Lymph nodes produce cells that help the body fight infection. Groups of lymph nodes are near the breast in the underarm, above the collarbone, and in the chest behind the breastbone.

## Cancer Cells

Cancer begins in cells, the building blocks of body tissues. Cells grow and divide to form new cells. When normal cells grow old or get damaged, they die, and new cells take their place. Sometimes new cells form when the body doesn't need them, and old or damaged cells don't die as they should. The extra cells often form a mass of tissue called a lump, growth, or tumor. Breast tumors can be benign (not cancer) or malignant (cancer).

## Benign tumors:

- are rarely a threat to life
- can be removed and usually don't grow back
- don't invade the tissues around them
- don't spread to other parts of the body

## Malignant tumors:

- may be a threat to life
- often can be removed but sometimes grow back
- can invade and damage nearby organs and tissues (such as the chest wall)
- can spread to other parts of the body

Breast cancer cells can break away from the original tumor and enter blood vessels or lymph vessels, which branch into all the tissues of the body. The cancer cells may spread to lymph nodes near the breast, or they may attach to other tissues, growing into new, damaging tumors.

## Risk Factors

No one knows what causes breast cancer. Risk factors for breast cancer include age, personal and family health history, genetic changes, prior radiation therapy, reproductive and menstrual history, race, breast density, overweight and obesity, physical inactivity, and alcohol consumption. You can avoid some risk factors, such as drinking alcohol. Having a risk factor does not mean that you will get breast cancer. Most women with risk factors never develop breast cancer.

## Symptoms

Early breast cancer usually doesn't cause symptoms. But as the tumor grows, it can change how the breast looks or feels, including:

- A lump or thickening in or near the breast or underarm area
- A change in the size or shape of the breast
- Dimpling or puckering in the skin of the breast. The skin may be ridged or pitted like an orange
- A nipple turned inward into the breast
- Fluid discharge from the nipple, especially if it's bloody
- Scaly, red, or swollen skin on the breast, nipple, or areola (the dark area of skin at the center of the breast)

See your healthcare provider about any of these symptoms that do not go away.

# Detection and Diagnosis

You should have regular clinical breast exams and mammograms to find breast cancer early, when treatment is more likely to work well.

## Clinical Breast Exam

During a clinical breast exam, your health care provider inspects your breasts, underarms, and collarbone area. She

- looks for differences in size or shape between the breasts
- checks your skin for a rash, dimpling, or other abnormal signs
- may squeeze your nipples to check for fluid
- uses the pads of her fingers to feel for lumps, pea-sized or larger
- checks the lymph nodes near the breast to see if they are enlarged

If there is a lump, your healthcare provider will feel its size, shape, and texture. She will also see if it moves easily. Lumps that are soft, smooth, round, and movable are likely to be benign. Hard, oddly shaped ones that feel firmly attached within the breast are more likely to be cancer, but you will need further tests to diagnose the problem.

## Mammogram

Mammograms are x-ray pictures of breast tissue. They can often show a lump before it can be felt. They also can reveal clusters of tiny specks of calcium. Lumps or specks can be from cancer, precancerous cells, or other conditions. If you have a lump or calcium deposits, you may need further tests to detect the presence of abnormal cells. You should get regular screening mammograms to detect breast cancer early .

## Other Imaging Tests

Ultrasound devices use inaudible sound waves to create images that show whether a breast lump is solid, filled with fluid (a cyst), or a mixture of both. Cysts usually are not cancer. Solid lumps may be. Magnetic resonance imaging (MRI) devices detail the difference between normal and diseased breast tissue.

## Biopsy

Biopsies remove small amounts of breast tissue for inspection. They are the only sure way to tell if you have cancer. A pathologist analyzes the tissue or fluid to determine the type of cancer.



Photo: iStockphoto.com

## Screening Mammography

In November 2009, the United States Preventive Services Task Force updated recommendations on breast cancer screening, suggesting that women ages 50 to 74 who are at average risk for getting the disease undergo a routine screening mammogram every two years.

The new recommendations do not advise routine mammography for average-risk women ages 40 to 49.

## Self-Examination

The updated 2009 recommendations also advise against teaching breast self-exam (BSE) because no clinical trials to date have shown that teaching of the technique reduces the number of deaths from breast cancer.

According to Dr. Stephen Taplin, senior scientist in NCI's Division of Cancer Control and Population Sciences' Applied Research Program (ARP), this recommendation "certainly does not mean that women shouldn't respond to lumps and bumps or other troublesome changes in their breasts that they discover on their own. Women should go to their healthcare provider when they have a concern."

## Testing Breast Tissue

Special tests on the diseased tissue may help determine treatment.

**Hormone receptor tests:** Some breast tumors need the hormones estrogen, progesterone, or both, to grow. If they are found, your healthcare provider may recommend hormone therapy.

**HER2/neu test:** HER2/neu is a protein found on some types of cancer cells. This test shows whether the tissue either has too much HER2/neu protein or too many copies of its gene. If the breast tumor has too much HER2/neu, then targeted therapy, which uses drugs to block the growth of breast cancer cells, may be an option.

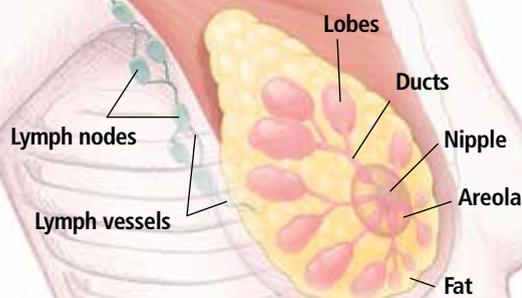


Illustration: Xkames

The lobes and ducts of the breast, and nearby lymph nodes (above) are areas that cancer can attack. The temporary inconvenience of a mammogram (opposite page) can save you from troublesome and costly treatment and surgery by catching breast cancer early, when it is easiest to treat.

## Staging

The extent (stage) of breast cancer needs to be determined to help choose the best treatment. The stage is based on the size of the cancer, whether it has invaded nearby tissues, or spread to other parts of the body. Staging may involve blood and other tests.

## Treatment

There are many options for treating breast cancer, including surgery, radiation therapy, hormone treatment, chemotherapy, and targeted therapy. A person may receive more than one type. What is best for one woman may not be best for another.

### Local Therapy

Surgery and radiation are types of local therapy, used to remove or destroy cancer in the breast.

### Systemic Therapy

Hormone therapy, chemotherapy, and targeted therapy are types of systemic therapy. They enter the bloodstream and destroy or control cancer throughout the body.

### Your Choices

The treatment that's right for you depends mainly on the stage of the cancer, the results of the hormone receptor tests, the result of the HER2/neu test, and your general health.

### Clinical Trials

You may want to talk with your doctor about taking part in a clinical trial, a research study of new treatment methods. Clinical trials are an important option at any stage of breast cancer.

If you are interested in a clinical trial, talk with your doctor. You may want to read the National Cancer Institute (NCI) booklet *Taking Part in Cancer Treatment Research Studies*. It describes how treatment studies are carried out and explains their possible benefits and risks (for details see page 21).

The NCI Web site includes a section on clinical trials at <http://www.cancer.gov/clinicaltrials>. It has general information about clinical trials, as well as detailed information about specific ongoing studies of breast cancer. Information specialists at 1-800-4-CANCER (1-800-422-6237) or at LiveHelp at <http://www.cancer.gov/help> can answer questions and provide information about clinical trials.

### Side Effects

Your doctor can describe your treatment choices, the expected results, and possible side effects. Because cancer therapy often damages healthy cells and tissues, side effects are common. Before treatment, ask your healthcare team how to prevent or reduce them, and how treatment may change your normal activities. Together, you and your healthcare team can develop a treatment plan that meets your medical and personal needs.

### Treatment Experts

Your doctor may refer you to a specialist, or you may ask for a referral. Specialists who treat breast cancer include surgeons, medical oncologists, and radiation oncologists. You may be referred to a plastic surgeon or reconstructive surgeon. Your healthcare team may also include an oncology nurse and a registered dietitian.

# Selected National Cancer Institute Breast Cancer Research Topics

- The Trial Assigning Individualized Options for Treatment (Rx), or TAILORx, is determining whether genes associated with risk of recurrence in women with early-stage breast cancer can be used to identify the most appropriate and effective treatments for these women.
- The Integrative Cancer Biology Program combines experimental and clinical research with mathematical modeling to gain new insights into cancer biology, prevention, diagnostics, and treatments. Multiple centers are developing breast cancer computational models.
- NCI and the National Institute of Environmental Health Sciences are jointly funding three Breast Cancer and Environment Research Centers (BCERCs) to conduct interdisciplinary research on the effects of early environmental exposures on breast development and breast cancer risk.
- The Breast Cancer Surveillance Consortium (BCSC) is a research resource for investigators assessing breast cancer screening practices and their relation to stage at diagnosis, survival, and breast cancer mortality. BCSC's Risk Calculator was developed to help health professionals estimate a woman's risk of developing invasive breast cancer.
- The Cancer Genome Atlas (TCGA) researchers are systematically identifying the major genomic changes involved in more than 20 cancers using state-of-the-art genomic analysis technologies. Recent findings suggest that there are genomic similarities between breast cancer and ovarian cancer, which may help to facilitate treatments for subtypes of both cancers.
- Nine breast cancer-specific Specialized Programs of Research Excellence (SPOREs) are moving results from the laboratory to the clinical setting. The SPOREs support research on the development of novel agents, technologies, and markers for better diagnosis, prognosis, screening, prevention, and treatment of breast cancer.

## To Find Out More

- ✓ MedlinePlus: Breast Cancer  
[www.nlm.nih.gov/medlineplus/breastcancer.html](http://www.nlm.nih.gov/medlineplus/breastcancer.html)
- ✓ National Cancer Institute, NIH, HHS  
Phone Number(s): (800) 322-8615;  
(301) 496-5583  
[www.cancer.gov/](http://www.cancer.gov/)
- ✓ American Cancer Society  
Phone Number(s): (800) 227-2345;  
(404) 329-7520  
[www.cancer.org/docroot/home/](http://www.cancer.org/docroot/home/)
- ✓ National Breast and Cervical Cancer Early Detection Program  
Phone number(s): (888) 232-6348  
[www.cdc.gov/cancer/nbccedp/](http://www.cdc.gov/cancer/nbccedp/)
- ✓ NCI book *Taking Part in Clinical Trials*  
[www.cancer.gov/clinicaltrials/Taking-Part-in-Cancer-Treatment-Research-Studies](http://www.cancer.gov/clinicaltrials/Taking-Part-in-Cancer-Treatment-Research-Studies)
- ✓ MedlinePlus tutorial  
[www.nlm.nih.gov/medlineplus/tutorials/breastcancer/htm/index.htm](http://www.nlm.nih.gov/medlineplus/tutorials/breastcancer/htm/index.htm)
- ✓ NIH Senior Health  
<http://nihseniorhealth.gov/breastcancer/breastcancerdefined/01.html>
- ✓ MedlinePlus tutorial: Breast Lumps—Biopsy  
[www.nlm.nih.gov/medlineplus/tutorials/breastlumpsbiopsy/htm/index.htm](http://www.nlm.nih.gov/medlineplus/tutorials/breastlumpsbiopsy/htm/index.htm)



The **Children's  
Inn** at NIH

“A place like home...” for all families!  
**The Children's Inn at NIH turns 25**



Photo: The Children's Inn

## What to Expect at The Children's Inn

The Children's Inn enhances opportunities for groundbreaking medical discoveries by providing a free “place like home” that reduces the burdens of illness through a supportive environment, including therapeutic, educational, and recreational programming.

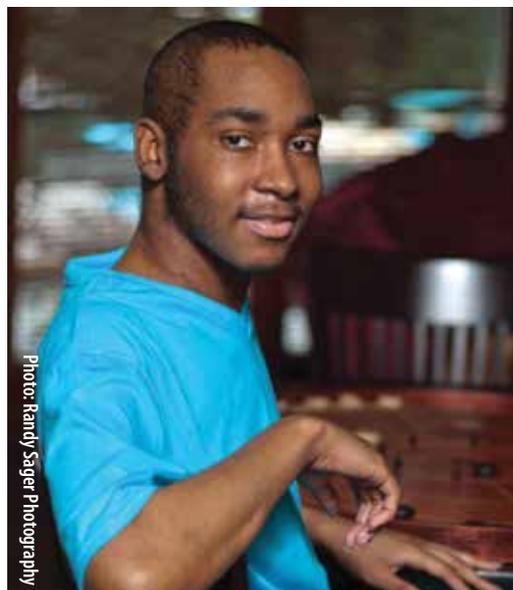


Photo: Randy Sager Photography

▲ Dalvin plays board games at The Inn's Woodmont House.

- No medical treatment, procedures, or appointments ever take place at The Inn. It is a safe haven.
- The Inn and its nearby transition facility, The Woodmont House, can accommodate up to 64 patient-families while their children are being treated at the NIH Clinical Center.
- The Inn has a playroom, kids' computer room, bistro, game room, learning center, business center, reflection space, teen lounge, arts and crafts studio, multipurpose room, exercise room, an outdoor sport court, and a park/playground.
- There are three large communal kitchens and dining rooms. The families make their own meals. Free shuttles go to the grocery store several times a week.
- As part of The Inn's popular “Family Dinner” program, community volunteers serve and share meals with Inn families every Sunday evening (and typically one or two other nights as well).
- Patients and their siblings are welcome to participate in any of The Inn's more than 1,000 yearly fun, educational, and therapeutic programs.
- Vi, The Inn's friendly therapy dog, is available to walk and play with Inn residents.
- The Inn has 26 full-time and 11 part-time staff members, and there is always a manager on duty. More than 200 volunteers help in every area of operations, too.

# The Children's Inn at NIH Anniversary Key Messages



- The Children's Inn at NIH is excited to celebrate its 25th Anniversary! President George H. W. Bush and his wife, Barbara, are serving as honorary chairpersons for the year of celebrations, kicking off on June 21, 2014, and continuing throughout the anniversary year of 2015. The Bushes presided over the ribbon cutting ceremony when The Inn became a reality in June 1990.
- Dr. Philip Pizzo, Chief of Pediatric Oncology at the NIH in the 1980s, observed that parents were congregating with other families in the waiting rooms of the Clinical Center and forming support networks, often reluctant to leave and go back to their respective hotels. It was his concept to create a place on the NIH campus where families could stay together, for free, to facilitate healing through mutual support including therapeutic, recreational, and educational programming.
- Establishment of The Inn took hard work, dedication and commitment, and the merging of public and private resources. Merck generously donated \$3.7 million for The Inn to be built; the NIH donated 2.5 acres of land; and a group of Congressional spouses formed Friends of The Children's Inn and raised money to furnish the facility. The Children's Inn at NIH opened on June 21, 1990, with 37 sleeping rooms.
- The Inn opened a major expansion in May 2004, adding a new wing with 22 additional sleeping rooms and many other communal and open spaces, such as a teen lounge, arts and crafts studio, multipurpose room, exercise room and a reflection space. Merck donated another \$3.7 million for the expansion project.

## fast facts

**1** The Children's Inn, located on the NIH campus in Bethesda, MD, is a unique private, non-profit, family-centered residence for children participating in groundbreaking medical research.

**2** Its mission is to respond to evolving family support needs, including pediatric research and clinical care.

**3** Children and their families stay for free. Before The Inn, families had to stay in area hotels, isolated and at considerable personal expense.

**4** The Inn operates "24/7" serving more than 12,500 patients from 50 states and more than 80 foreign countries since opening.



Photo: Mahan Byxell Associates

▲ Playground and Park at The Children's Inn at NIH

# The Children's Inn at NIH: Three Stories

## Kristal Nemeroff—The Patient

"I've been through a lot," says Kristal Nemeroff, 26, shrugging off her 25 broken leg bones, 10 major surgeries, and weeks and months of immobility in complete body casts over her lifetime. "You don't feel like you're in the hospital at The Children's Inn."

Kristal should know. She arrived first at the National Institutes of Health at eight months of age, before The Inn was even open, to enroll in a long-term research study of osteogenesis imperfecta (OI), or "brittle bone" disease. OI is a fairly rare genetic disorder that affects the protein collagen, found in bone, teeth, skin, tendons, and, parts of the eye.

As part of her study, Kristal has come to the NIH Clinical Center at least once a year for exhaustive rounds of experimental treatment and more routine examinations for mosts of her entire life. She and her family have come to consider The Children's Inn their "home away from home."

"Staying at The Inn helps make you feel not so different," she says. "We're all learning how to adapt to our conditions. You can learn so much about life just by spending a week at The Inn, meeting other kids from all over the world. We share handicaps, obstacles, challenges, life experiences, adversity. But the most amazing thing is that we're all living together under the same roof"

Now a registered nurse working as a school health office nurse at a Stroudsburg, PA, elementary school, Kristal credits "Nurse Kelly" and "Nurse Debbie," pediatric nurses at the NIH Clinical Center who were great to me" as her inspiration. "I found my place in nursing," she states. Kristal is currently studying to become a certified school nurse.

"I identify with others who must overcome adversity," she says. "It's very fulfilling as a nurse, helping others cope with their own adversities. I love being a school nurse and helping children be successful in the school environment."

▲ For much more information, including videos of the Inn and its children and their parents, visit The Inn's website at:

[www.childrensinn.org](http://www.childrensinn.org)



Photos: Kristal Nemeroff

▲ Kristal Nemeroff, age 2, (upper right) at the Children's Inn in May 1991. And a grown-up Kristal, 26, on a recent visit to the Inn.

**More than 1,500 families  
travel to The Inn each  
year looking for hope.**

## Dr. Brian Brooks— The Team Co-Leader

Photos: The National Eye Institute



▲ Dr. Brian Brooks uses a puppet during a young patient's eye exam to track eye movements.

As Chief of the Ophthalmic Genetics and Visual Function Branch at the NIH's National Eye Institute, Dr. Brian Brooks “works with tough cases, kids with rare inherited eye diseases that most don't have much experience with.”

## Luis and Maria Mendez—The Parents

The Mendez family lives near the beach in the city of Aguadilla, located on the west side of the island of Puerto Rico, where the climate is typically quite sunny. And that was their tip off about their three-month old daughter, Daniela Isabel.

“We noticed that she was closing her eyes a lot in the sun,” recounts her mother, Maria Isabel Medina. “So we told our pediatrician, and he advised us to go to an ophthalmologist, which we did. That's when he diagnosed Daniela with coloboma.

“Fortunately, it doesn't affect her that much. It's very rare and we don't know where it came from in our family tree. But I wanted to find out as much as possible about Daniela's condition.”

As any concerned parent in search of answers does these days, Maria got on the Internet. “First, I found out about her condition. Then I talked with another mom, and did some more research and came across Dr. Brooks and the NIH. We knew then we wanted to go to the best place and the best doctor to see about Daniela!”

After consulting with the their doctors at home and being referred to Dr. Brooks, the family came this past May for three days of intensive examination at the NIH Clinical Center. They stayed at The Children's Inn. “It was awesome,” says Maria, “Like a family. How many happy faces working for the children—and the children smiling, too.

“The families we met were amazing; all of us together. The volunteers gave us dinner all three nights. One even spoke Spanish. We felt very welcome and comfortable.”

He coordinates a multi-disciplinary team of researchers, geneticists, nurses, counselors, and patients' families—all of whom work in concert with The Children's Inn. “They do a great job at The Inn of nurturing families. It could be very sterile coming to a research hospital like ours. But The Inn makes it as pleasant as possible.”

Dr. Brooks and the team's current focus is on the genetics of a potentially blinding eye malformation called coloboma. “It is a rare condition—only one in 10,000 kids,” he explains. “We've seen 120 patients, more than anyone else. Because we specialize in rare conditions like this, we can give the family perspective on what to expect as the child grows up.

“Our sole function is research, so we can spend the time to answer their questions,” he points out. “The more information the family has, the more they feel empowered.”

Dr. Brooks understands the dilemma personally. At the age of two, his daughter was diagnosed with a rare cancer—but was successfully treated and now is a thriving nine-year old. “Going through that has made me a better doctor,” he believes. “We got a sense of the anxiety parents feel, the helplessness, of being out of control.”

## It's Never Too Late for Exercise

A large study finds that regular exercise can help older people maintain their mobility and prevent disability. Mobility—being able to walk without help—is important for an older person's independence and health.

Researchers studied people in their 70s and 80s who were inactive. Half followed a program of walking and exercises to improve strength, balance, and flexibility. The other half took health education classes and did stretching exercises.

The study showed a structured exercise program can reduce the risk of disability in older people—and is the first study to do so. NIH's National Institute on Aging was the primary sponsor. NIA Director Richard J. Hodes, M.D., calls the findings gratifying. "These are actionable results that can be applied today to make a difference for many frail older people and their families," he says.



Photo: Thinkstock

◀ These developing mouse nerve cells have a nucleus (yellow) surrounded by a cell body, with long extensions called axons and thin branching structures called dendrites. Electrical signals travel from the axon of one cell to the dendrites of another.



Photos: NIGMS, NIH-GOV

## Life: Magnified

A new exhibit gives people a unique look at life.

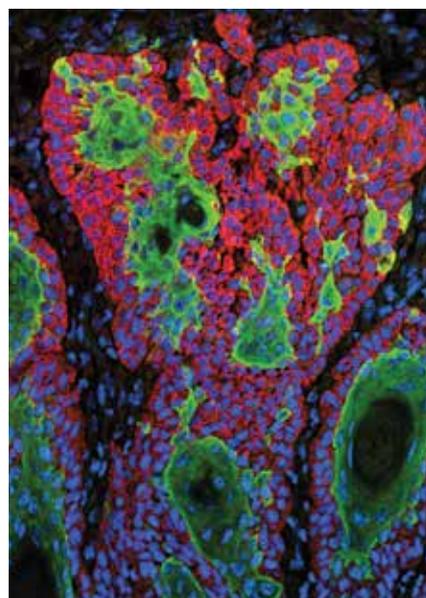
Life: Magnified is a collection of scientific images of blood, bacteria, viruses, and more, enlarged up to 50,000 times.

Scientists created the images for medical research. The colors come from chemical dyes and computer programs used to better see biology.

Life: Magnified is on display at Washington Dulles International Airport near Concourse C through November 2014. There's also an online version with images and longer captions. The images can be downloaded for free for educational, research, or news purposes. The gallery is available at <http://www.nigms.nih.gov/Education/life-magnified/Pages/default.aspx>.

Three organizations co-sponsored the exhibit: NIH's National Institute of General Medical Sciences, the American Society for Cell Biology, and the Metropolitan Washington Airports Authority Arts Program.

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▲ This image shows the uncontrolled growth of cells in squamous cell carcinoma, the second most common form of skin cancer. If caught early, squamous cell carcinoma is usually not life-threatening.

# Info to Know

## NIH Quickfinder

For more information or to contact any of the following NIH institutes, centers, and offices directly, please call or go online as noted below:

### 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 Alternative Medicine (NCCAM)**  
[www.nccam.nih.gov](http://www.nccam.nih.gov) 1-888-644-6226
- **National Center for Advancing Translational Research (NCATS)**  
[www.ncats.nih.gov](http://www.ncats.nih.gov) (301) 435-0888
- **NIH Clinical Center (CC)**  
[www.cc.nih.gov](http://www.cc.nih.gov) (301) 496-2563
- **Office of AIDS Research (OAR)**  
<http://www.oar.nih.gov> (301) 496-0357
- **Office of Behavioral and Social Sciences Research (OBSSR)**  
<http://obssr.od.nih.gov> (301) 402-1146
- **Office of Rare Diseases Research (ORDR)**  
<http://rarediseases.info.nih.gov>  
Genetic and Rare Disease Information Center  
1-888-205-2311
- **Office of Research on Women's Health (ORWH)**  
<http://orwh.od.nih.gov> (301) 402-1770

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Alcohol Use and Older Adults \* Alzheimer's Disease \* Osteoporosis  
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