Caregiving and Decision-Making With Older Adults

How you can help

TV’s Dr. Nancy Snyderman talks about her parents and their decisions.

Women and P.A.D.
Is serious artery disease causing your leg pain?

SPECIAL SECTION
HIV/AIDS
Much accomplished
Much to do

SUMMER 2009
The Friends of the National Library of Medicine (FNLM) is delighted to bring you another issue of NIH MedlinePlus magazine. As always, we want to offer you and your family good, helpful health information that is based on the very best medical research conducted by and for the National Institutes of Health (NIH).

This issue focuses on several topics in which NIH-funded research continues to make significant improvements to the health and well being of all Americans. Starting on page 10, our special section will bring you up to date on the latest research results about HIV and AIDS. It also offers a sobering look at the continuing growth of HIV among certain segments of the American population, especially those facing health disparities.

Other sections offer useful tips about maintaining a healthy weight, helping our seniors and their caregivers make the best lifestyle choices, and how women can prevent and treat peripheral arterial disease (P.A.D.).

We are also pleased to present highlights from FNLM’s conference on electronic health records and the Annual Awards Dinner honoring the best medical researchers in the world. We hope you enjoy this issue!

Sincerely,
Donald West King, M.D., Chairman
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Dr. Francis Collins

Dr. Francis Collins, M.D., Ph.D., is the new Director of the National Institutes of Health (NIH), part of the U.S. Department of Health and Human Services. President Barack Obama nominated Dr. Collins, who served as Director of the National Human Genome Research Institute (NHGRI) at NIH from 1993-2008. In August, the U.S. Senate confirmed his appointment by a unanimous vote.

Announcing his choice, the President said, “Dr. Collins is one of the top scientists in the world, and his groundbreaking work has changed the very ways we consider our health and examine disease.” The President recalled that, with Dr. Collins at the helm, the Human Genome Project met its milestones ahead of schedule and under budget. The project concluded successfully in April 2003 with the complete map of the human genome, the instruction book for peoples’ DNA.

Dr. Collins is also known for discovering a number of important genes, including those responsible for cystic fibrosis, neurofibromatosis, Huntington’s disease, a familial endocrine cancer syndrome, and, most recently, genes for adult onset (type 2) diabetes and the gene that causes Hutchinson-Gilford progeria (rapid aging) syndrome.

Following Dr. Collins’ confirmation, HHS Secretary Kathleen Sebelius said, “Dr. Collins is one of our generation’s great scientific leaders. He will be an outstanding leader. Today is an exciting day for NIH and for science in this country.”

Collins received a B.S. in chemistry from the University of Virginia, a Ph.D. in physical chemistry from Yale University, and an M.D. with Honors from the University of North Carolina. Prior to coming to NIH, he spent nine years on the faculty of the University of Michigan, where he was an investigator at the Howard Hughes Medical Institute. He has been elected to the Institute of Medicine and the National Academy of Sciences, and was awarded the Presidential Medal of Freedom in November 2007.

Dr. Collins has recently completed a book on personalized medicine, The Language of Life: DNA and the Revolution in Personalized Medicine, to be published in early 2010 by HarperCollins.
Caregiving and Decision-Making For Seniors

How You Can Help

Every day millions of Americans deal with how best to care for their aging parents or other loved ones. The challenges, from ensuring basic health and safety to assisting in detailed planning for the future, are magnified when children and other caregivers live far from those they are trying to assist. NIH’s National Institute on Aging (NIA) has publications and online resources (www.nia.nih.gov) to help older adults, their loved ones, and caregivers manage the transitions and needs of later life. In the following pages, we summarize some of the key resources and suggestions for effective care and decision-making for seniors.

—The Editors
For Dr. Nancy Snyderman’s Parents, Staying Close to Family Is Key

As Chief Medical Editor for NBC News and host of the popular MSNBC show, Dr. Nancy, Dr. Nancy Snyderman offers health-care and medical advice every day. When it came to the next chapter in her own parents’ life, the discussion was a family affair.

Parents seem to be encapsulated in time, always remaining the same. Yet, as we grow older, so do they. Eventually, there comes a time when we have to be there for them, as they were once there for us. I grew up in Fort Wayne, Ind., and have always tried to stay true to my Midwestern roots and visit often.

After my siblings and I moved away, I always thought my parents would revel in their newfound freedom as empty nesters. Yet, as they grew older, they soon realized aging comes with its sorrows as well as its benefits. Friends passed on, and family moved farther away from our childhood home. Fort Wayne had quickly become foreign to them. They were looking for a town closer to family to call home.

My husband, Doug, and I offered our assistance, and so began their trip east. But moving past a certain age can be challenging both mentally and physically. As most people know, moving is more than physically transferring your belongings. The process of finding new doctors, new friends, and even a new favorite take-out restaurant can be a journey, but at least we are there to help.

Watching my children grow closer to my parents has been a blessing, and having us nearby is a great comfort to them. However, all of us have to be careful to respect one another’s boundaries. We live in homes with doors and telephones; it’s important not to overuse either. Communication is important in any relationship, and with family, it’s vital. I am so thankful to have my parents nearby, and to be involved in this new chapter in their lives.
I want to stay in my home of 30 years as long as I can. What resources are there, and how can my children help?

It’s possible to help an older person stay in his or her home, with a little planning and regular upkeep. Many services necessary for continued, independent living at home are available locally. For specific information, contact the Area Agency on Aging; municipal, county, and state offices on aging; social services organizations; nearby senior centers; and civic, tribal, and religious organizations. They are there to help.

Personal care: If bathing or dressing is getting harder to do, a nearby relative or friend may be willing to help. Or, a trained home health aide can be hired for an hour each day to meet this need.

Homemaking: Need help cleaning the house, grocery shopping, or doing the laundry? Try a residential cleaning service. Or maybe a friend or neighbor has a housekeeper to suggest. Increasingly, grocery stores and drug stores offer telephone ordering and home delivery service. Some drycleaners will pick up and deliver, too.

Meals: Tired of cooking every day or eating alone? Share the cooking with a friend, or host a potluck dinner with a group of friends. Many senior centers, churches, synagogues, and mosques serve meals for all, and eating out gives a chance to visit with others. If getting out is too difficult, a community program like Meals on Wheels will bring hot meals into your home.

Money management: Are the bills piling up because it’s too tiring or confusing to keep track? Here’s where a trusted relative can prove invaluable. If that’s not possible, there are trained volunteers to call on, or financial counselors or geriatric care managers to hire. Just make sure the helper comes from a trustworthy source, like the local Area Agency on Aging.

Health Care: Organizing and tracking medications can be very stressful. However, there are simple devices to help sort them and even prompt when to take them. If an older person is just out of the hospital and needs temporary at-home help, Medicare often pays for a home health aide. A concerned son, daughter, or other relative can help clarify available options.

How Can I Help My Mom Stay in Her Home?

As people age, they often start having trouble with shopping, cooking, taking care of the house, their personal grooming. If that is the case with your parents, an aunt, uncle, or someone else, consider the following actions to help them—and you—make the right decisions:

- Talk with them about getting help.
- Offer to gather information about locally available services, like Meals on Wheels or volunteer transport.
- Discuss with others in the family how they can help.
- Ask friends in similar situations what has—and has not—worked well for them.

Then, meet with those needing help to share what you have learned. Armed with as much specific, helpful information as possible, together you can develop a plan of action for continued independent home living.
Assisted Living

*Mom and dad are finding it harder to live by themselves at home. I think they need a place where they can have at least some assistance day-to-day.*

Quite often, adults reach a point when they should no longer live on their own but don’t need round-the-clock nursing care. Assisted living facilities provide an alternative. Assisted living is for adults who need help with everyday tasks of dressing, bathing, eating, or using the bathroom. But they don’t need full-time nursing care. Often they are part of retirement communities or are near nursing homes, so a person can move easily if their needs change.

Although assisted living costs less than nursing home care, according to the U.S. Administration on Aging, it is still fairly expensive. Older people or their families usually foot the bill. Health and long-term care insurance policies may cover some of the costs. Medicare does not cover the costs of assisted living.

Licensing requirements for assisted living facilities vary by state. There are as many as 26 different names for assisted living, among them: residential care, board and care, congregate care, and personal care.

What Services Are Provided?

Residents of assisted living facilities usually have their own units or apartments. In addition to having a support staff and providing meals, most assisted living facilities offer at least some of the following services:
- Health care management and monitoring
- Help with bathing, dressing, and eating
- Meals (some or all)
- Housekeeping and laundry
- Medication reminders and/or help with medications
- Recreational activities
- Security
- Transportation

How to Choose a Facility

A good match between a facility and a resident’s needs depends as much on the philosophy and services of the assisted living facility as it does on the quality of care. The Administration on Aging, a part of the U.S. Department of Health and Human Services (HHS), offers these suggestions to help you get started in your search for a safe, comfortable, and appropriate assisted living facility:
- Think ahead. What will the resident’s future needs be and how will the facility meet those needs?
- Is the facility close to family and friends? Are there any shopping centers or other businesses nearby (within walking distance)?
- Does the facility have limits on admitting or allowing residents to remain if they have mental impairments or severe physical disabilities?
- Does the facility provide a written statement of its philosophy of care?
- Visit each facility more than once, sometimes unannounced.
- Visit at meal times, sample the food, and observe the quality of mealtime and the service.
- Observe interactions among residents and staff.
- Check to see if the facility offers social, recreational, and spiritual activities.
- Talk to residents.
- Learn what types of training staff receive and how frequently.
- Review state licensing reports.
Long Distance Caregiving

My father lives by himself almost a thousand miles from my home. What can I do from such a distance to help him?

Caregiving is often a long-term task. What begins with an occasional phone call to share family news can become daily contact to manage the demands, small and large, of another person’s life. The monthly trip to check on Mom becomes the major project transitioning her to an assisted living or managed care facility close to your home.

Although mid-life, working women with their own major family responsibilities remain our primary caregivers, more and more men are becoming caregivers. However, anyone anywhere can give care—regardless of gender, income, age, social status, and employment. No matter how great the distance, being helpful is what counts.

Here are some tips from an NIA booklet called So Far Away: Twenty Questions for Long-Distance Caregivers:
1. Seek out help from people in the community: the next-door neighbor, an old friend, the doctor. Call them. Tell them what is going on. Make sure they know how to reach you.
2. If there is already an on-site caregiver, identify options to help them if a crisis occurs. Making prior arrangements can make things easier when a crisis occurs.
3. Get a directory of senior resources and services from the local library or senior center, and check for updates on these resources. This helps everyone know what’s out there and begin “plugging into networks.”
4. Pull together a list of the person’s prescriptions and over-the-counter medicines, including doses and schedules. This is essential for emergencies. Update the list regularly.
5. Discuss an advance directive that states your parents’ health-care treatment preferences. If he or she does not have one, talk about setting it up. If there is, make sure you have a copy and know where the original is kept. You might want to make sure the person’s doctor has a copy for the medical record.

Personal Transitions

Juanita S. Kuhn

Staying Positive and Moving Forward

For Juanita Kuhn, moving to an independent living facility is just the latest adventure in her life.

At 91, Juanita Kuhn still holds one of the oldest and unlikeliest records in sports: the slowest elapsed time between San Francisco’s Golden Gate and Hawaii’s Diamond Head — 23 days, 23 hours, 55 minutes, 4 seconds — set during the 1939 TransPacific Yacht Race. After 32 years in her own Washington, D.C., apartment, she is moving to an independent living facility in upstate New York to be near her family.

On Old Age: I’ve always been an adventurer. But being brave at my age isn’t easy. I never thought I’d reach 91. I wonder about my...continued on page 8
friend, Miklos, who's 95. He got out of the shower, looked at his body in the mirror and was horrified. That's one of the shockers, when you realize you're older than you think you are…

**On Transitions:** I've made many transitions over my life but I was stronger physically and emotionally. I dread leaving my apartment and going into a place where I don't know people; of having to make polite conversation. Making friends is hard. I hope they have someone to introduce me, show me the ropes.

**On Family:** My children are my greatest satisfaction—and my grandchildren, at least the grown up ones. I'm not sure what to do with the little ones. I hope I'll be part of their lives. Hearing, “Granny, how are you?” gives me a boost.

**On Friends:** Keep in touch, as much as possible. I think of those with nobody; it's very unfortunate if they have no relatives.

**On Getting Along:** Don't complain. Be pleasant to be included. And don't turn on the TV!
When 97-year-old Alice Anguria was asked what she would tell someone who is thinking about transitioning from their own home to an assisted living facility, her answer was quick and thoughtful: “If you can’t live in your own home, this is a wonderful place to be.”

Alice’s transition to a Worcester, Mass., assisted living facility about three years ago was prompted by a desire to continue to live close to her sister Grace. Three years younger than Alice, Grace had suffered a stroke and required care that only a long-term care facility could provide.

Prior to moving into the assisted living facility, Alice and Grace had lived together more than 80 years in the Worcester home in which they were born, before moving into a nearby apartment to simplify their lives. Fortunately, relatives found Alice and Grace a home that included both long-term care and assisted facilities. They were able to stay together, and Alice was able to visit her sister daily until she died in November 2008.

Alice has already made friends at her new home. Frequent luncheon partners and home residents Beatrice Camara and Helen Abounader call Alice a “most remarkable woman.” “She doesn’t use a walker and has a positive mental attitude,” they both echoed.

“I keep busy,” says Alice. “We have lots of activities. We are starting a ‘happy hour’ next week so residents can meet each other. And every day I exercise, go to Mass, eat meals with my friends, take choir and music classes, and try to read the news daily. And, I never miss the Red Sox, the Patriots, or any other Boston sports event. Everyone tries to help everyone else here.”

Asked about the food, Alice weighs her words carefully, “You can’t expect it to be like home, but I like the food here. It is pretty good.”
HIV and AIDS are a global catastrophe. While advances in testing and treatment can now often turn these killers into chronic diseases, they continue to take a staggering toll on our nation and the world. There are ways for you to protect yourself and your loved ones from HIV/AIDS.

The AIDS Memorial Quilt

In 1987, a total of 1,920 AIDS quilt panels were first displayed in the nation’s capital, near the Washington Monument. Today, the Quilt includes more than 47,000 panels, representing over 91,000 people, and it continues to grow.

—Courtesy The NAMES Project Foundation
For the past three decades, Dr. Anthony S. Fauci, Director of the National Institute of Allergy and Infectious Diseases (NIAID), has overseen extensive research efforts to prevent, diagnose, and treat infectious diseases, such as HIV/AIDS and other sexually transmitted infections, influenza, tuberculosis, malaria, and illness from potential agents of bioterrorism. A native of Brooklyn, N.Y., Dr. Fauci received his M.D. degree from Cornell University Medical College in 1966. In 1980, he was appointed Chief of the NIAID Laboratory of Immunoregulation, a position he still holds. He spoke with NIH MedlinePlus magazine coordinator Christopher Klose about the continuing challenge of HIV/AIDS.

Is HIV/AIDS much of a threat anymore?

Dr. Fauci: Unfortunately, many people think it is no longer a problem. But HIV/AIDS remains a substantial global health threat. In the U.S., alone, there have been almost 1 million cases so far and over half a million deaths. There are 1.1 million people living with HIV in the U.S., and 21 percent do not know that they are infected. Every year we continue to see about 56,000 new infections here and 2.7 million worldwide. Globally, 33 million people are living with HIV, 90 percent of them in the developing world—with 67 percent concentrated in sub-Saharan and southern Africa.

What benefits have there been from the research over the years?

Dr. Fauci: About 11 percent of NIH’s annual budget—approximately $3 billion—goes to AIDS research. We have developed an extraordinary understanding of how the HIV virus destroys the body’s immune system. In addition, therapy has been one of the major success stories. We now have more than 30 federally approved drugs for HIV that, when used in combination, have literally transformed the lives of HIV-infected people. Conservatively, an estimated 3 million years of life have been saved in this country from 1996 through 2005. And I do not mean people alive in bed, but out working as productive members of society. The payback from research by the NIH and others has been extraordinary.

Hasn’t the HIV research also been helpful in understanding and treating other diseases?

Dr. Fauci: Right. What we know about regulation of the immune system in general comes a lot from the study of HIV/AIDS. That helps us with autoimmune and hypersensitivity diseases, and how the body defends against other infections, and against cancers.
For example?
Dr. Fauci: Understanding the precise steps in the replication cycle of HIV has allowed for better diagnosis and treatment, as well as for targeted drug development. We have always been able to target for different infections and cancers, but targeting a drug to block a particular component of the HIV virus, which we’ve done, has opened the way to do the same for cancer therapy, and for infectious diseases ranging from influenza and tuberculosis to malaria.

Is your ultimate goal a vaccine for HIV/AIDS?
Dr. Fauci: Yes. Developing an HIV vaccine is one of the most challenging scientific problems we tackle. The fundamental principle in vaccines is to mimic natural infection in order to trigger the immune system to mount a successful defense, since the immune response to natural infection almost invariably results in the control and elimination of infection. In this manner, we have developed vaccines against a number of microbial killers — smallpox, measles, polio.

But with HIV, the body is incapable of mounting a successful, natural immune response. Out of the tens of millions who have been infected, there is not a single documented case of anyone’s immune system having completely eradicated the HIV virus from the body. So we have to induce the body to do better than it does naturally.

You’re up against a very smart cookie. What is it going to take to protect us?
Dr. Fauci: Ultimately, it comes down to research. Research is discovery; its goal is to answer the unanswered questions. In addition, the technology is extraordinary. So the challenge is to apply fundamental, bright, new ideas in the backdrop of this rapidly emerging technology.

How do you handle all the information?
Dr. Fauci: If you do not have an orderly way to handle the explosion of information about the biological sciences—we call it bioinformatics—it can almost overwhelm you. Fortunately, the National Library of Medicine has pioneered a number of very user-friendly, helpful tools.

What’s a good example of a useful information tool?
Dr. Fauci: There is GenBank, for one, which is an annotated database collection of all publicly available DNA sequences. I used to have to go to the library and work my way through volumes of books. Now, I sit at my computer, press a button, and ten seconds later I have what I need. It’s amazing.

How do you inspire the new generation of researchers to take on HIV and other challenges?
Dr. Fauci: You make it clear that biomedical research, discovering the unknown, is very exciting. And that they are doing something extremely
important: for people's health, the health of the community, the health of the world. That actually making a difference; helping society, is very gratifying.

On the other hand, what do you say to those in the minority communities who are most at risk of HIV/AIDS?

Dr. Fauci: There has to be more open, freer communication about the risk of HIV, and who is at risk and what they can and should be doing to help protect themselves. The numbers are really startling. For instance, although African Americans comprise 12 percent of the population, they account for 45 percent of all new HIV infections nationwide, and 65 percent of all new infections among women. A substantial portion of newly infected African Americans are bisexual and homosexual men.

Unfortunately, there is not much acceptance of being gay in the African American community. People are forced underground. They do not have access to the testing, counseling, and preventive methods proven to help protect against HIV, like the use of condoms. Also, in the natural course of a relationship, many young African American women are unwittingly exposed to HIV because their partners do not know they themselves are infected.

That is why we have to target those people at highest risk, and why the messages of awareness and self-protection must be delivered by community leaders who are respected and understood by the community, not some guy in a suit who shows up in the inner city one day and says, “Just say, 'No.'”

Prevention

Because there is no cure or vaccine to prevent HIV, the only way people can prevent infection from the virus is to avoid high-risk behaviors putting them at risk of infection, such as having unprotected sex or sharing needles.

NIAID urges everyone ages 13 to 64 to get tested for HIV as part of their routine health care. Catching HIV in its early stages can make a lifesaving difference.
In the United States, the groups that AIDS affects have changed since the beginning of the epidemic. The percentage of new AIDS cases among whites has decreased, but the percentages among African Americans and Hispanics have increased, according to the Centers for Disease Control and Prevention (CDC). (See interview with Dr. Anthony Fauci, starting on page 11.)

“There is a grossly disproportionate impact of the epidemic upon those who are already marginalized—the poor, the disenfranchised, and racial, ethnic, and sexual minorities,” says Victoria Cargill, M.D., Director of Clinical Studies and Director of Minority Research at the NIH Office of AIDS Research (OAR).

Of adults and adolescents diagnosed with AIDS during 2007 (the most recent CDC data):
- 48% were black
- 28% were white
- 21% were Hispanic
- 1% were Asian
- Less than 1% each was Native American/Alaska Native, and Native Hawaiian/other Pacific Islander.
- In 2007, an estimated 26,111 AIDS cases were diagnosed in U.S. minority races and ethnicities. That accounted for 71 percent of all AIDS cases diagnosed that year in the U.S.

“The HIV epidemic in many of our cities has rates of infection that rival some third-world nations,” says Dr. Cargill. “We need only look at Washington, D.C., to see that. Sadly, while it may have some of the worst numbers, it is not alone.”

In addition to her NIH work, Dr. Cargill sees the challenges first-hand at a clinic she runs in the District of Columbia. In addition to being HIV-positive, patients are often fighting other health challenges, as well as cultural and economic hardships. “Many of our patients are obese, HIV-infected, and have developed diabetes,” she says.

These other issues make the HIV challenges even harder. Dr. Cargill encourages her patients to work with her and to be partners in recovering their own health. She is now starting an incentives program that she hopes will give her patients the tools they need to change their behaviors and live healthier lives.

“There is a clear gap between knowledge and behavior,” she adds, “and when survival is added to the equation, that widens the gap. The exchange of sex for money, drugs, shelter, and safety is not a new transaction. HIV infection has just made the transaction more fraught with danger—and fatality.”

HIV: Getting Tested Is the First Step
“Being tested for HIV infection is so important, but it isn’t the end of the line,” says Dr. Cargill. “It is just the beginning of the journey.”

Once a person is tested for HIV, there is an immediate fork in the road, she adds. “You’re either HIV-infected (tested positive) or
HIV-uninfected (tested negative). Both groups need our attention,” she says. “If the person tests positive, there is a critical need to not only engage the person in medical care, but to also get them to examine their social and sexual networks to look for other infections. They also need to start making behavior changes that are a central part of treatment, reducing transmission risk to others, and remaining an active participant in HIV care.

“If the person is HIV-negative, then it’s critical to review the behaviors that might place him or her at risk. You have to go beyond that and explore the thinking that allows people to conclude that an HIV-negative result means whatever they have been doing up to that point is OK. That’s false. It just may mean that they have not encountered an HIV infected partner yet.”

For those at high risk of HIV infection, testing must be paired with behavior changes that take them out of the high-risk category, emphasizes Dr. Cargill.

NIH Research to Results

The NIH is working to find new and effective ways to prevent HIV. Research is focused on:
- Behavioral strategies designed to increase condom usage, delay sexual activity among young people, and reduce sexually transmitted infections, which can make people more susceptible to HIV infection.
- Using HIV medicines that can treat HIV as a way to prevent infection among high-risk groups.
- Microbicides—gels, creams, or foams—that women could use to protect themselves against HIV.
- Developing a safe, effective vaccine against HIV infection.
- Drug abuse intervention and treatment programs to prevent HIV transmission among injection drug users.

To Find Out More

For information and resources, search for “HIV” on these Web sites:
- National Library of Medicine: www.medlineplus.gov
- National Institute of Allergy and Infectious Diseases: www.niaid.gov
- AIDSInfo: www.aidsinfo.nih.gov/
- NIH Office of AIDS Research: www.oar.nih.gov/

NIH and Pregnancy

Are there ways to help HIV-infected women keep from passing HIV to their newborns? The answer is usually yes.

Today, HIV-infected women receive a combination of highly active AIDS drugs throughout pregnancy. HIV infection of newborns has shrunk to less than 2 percent of births by HIV-positive women in the United States. This is done through a combination of drug therapy, universal prenatal HIV counseling and testing, cesarean delivery, and avoidance of breastfeeding.

“We now have a series of guidelines to prevent the perinatal (around the time of birth) transmission of HIV infection, and a sizable number of agents to prevent HIV transmission—not just relying on a single agent,” says Dr. Victoria Cargill of the NIH Office of AIDS Research.
Imagine a gathering of more than 400,000 people, with many of their complete personal health records immediately available at the hospital right next door. That’s what happened on May 24 this year at the Indy 500, the world’s largest single-day sporting event, held in Indianapolis, Ind.

For the first time at any type of mass gathering, many of the people’s electronic health records were instantly, securely available to medical personnel at the world-famous Indy 500 motor race. That was especially true for all of those from Indiana—the state with the most electronically wired health records in the nation. The Indianapolis Motor Speedway’s Clarian Emergency Medical Center had access to those records, thanks to the Indiana Network for Patient Care (INPC).

INPC is an electronic data-sharing system that allows physicians and emergency medical personnel access to individual patient records. It is made up of 15 hospitals, including all five major hospitals in the city of Indianapolis, and more than 100 clinics. Currently, it provides access to about 1.5 billion pieces of secure health data for most of the residents of the state of Indiana. The data include admission and discharge notes, lab test results, and other critical information.

The INPC was developed by Dr. Clement J. McDonald when he was at the Regenstrief Institute, a health-care research organization. The institute has close ties to the Indiana University School of Medicine and the Health and Hospital Corporation of Marion County, Ind. Funding for the INPC came from the
Health Records—

What’s In a Name?

Health records are undergoing many changes, and the variety of names can be confusing.

With a personal health record (PHR), you control who can see or use the information in it. You may have a personal health record on paper, or you may have it in electronic form. An electronic personal health record is often stored on a Web site. Other people, such as your doctor, may be able to add information to it.

With an electronic health record (EHR) or electronic medical record (EMR), your doctor (or hospital) controls the information. Your electronic health records may be stored at a doctor’s office, a hospital, an insurance company, or an employer.

Electronic Health Records—Are They Secure?

Many people wonder whether their health information is kept private and secure in an electronic health record system.

In an electronic health record, your information is protected from being viewed without your consent or authorization because of the security technology used by the companies that offer them, according to the Department of Health and Human Services (HHS).

Some of the organizations that provide electronic health records include health plans and providers. Health plans and most health-care providers are required to give you a Notice of Privacy Practices, which tells you how they keep any of your personal information private and safe, including when it is maintained in an electronic system. If you don’t remember seeing the privacy notice, you should ask the health plan or provider for a copy, or check the Web site of your provider.

For information related to protection of patient records, filing a privacy complaint, or other questions, visit the HHS site: www.hhs.gov/ocr/privacy/

National Institutes of Health and the National Library of Medicine, where Dr. McDonald is currently Director of the Lister Hill National Center for Biomedical Communications.

“Nowhere else in the nation has this capability,” says John T. Finnell, M.D., Regenstrief Institute researcher and associate professor of emergency medicine at the IU School of Medicine. “Throughout May, leading up to The 500, we treat as many as 2,000 patients at the Clarian Center, caring for everything from blisters to heart attacks. The heart doctor can see what’s been going on with a patient almost as soon he or she arrives.”

Geoffrey L. Billows, M.D., medical director of the Indianapolis Motor Speedway, adds, “The technology also gives us a record of the care provided for future reference by the patient’s primary physicians or other health consultants.”

Based on this year’s success, the plan is to offer the INPC procedures for the 2012 Super Bowl, which Indianapolis will host.

A Sample Health Record

You’ve probably seen the records and charts your doctor keeps on your health many times. You may have records with several doctors, or at one or more hospitals where you’ve been treated. You can create a simple version for yourself: a single, easily accessible list of your basic information. Keeping such a list is a good idea—for yourself, your loved ones, and caregivers.

It’s as easy as 1, 2, 3 … Start with your:

1. Name, birth date, blood type
2. Emergency contact(s)
3. Primary caregiver/phone number
4. Medicines, dosages, and how long taken
5. Allergies/allergic reactions
6. Date of last physical
7. Dates/results of tests and screenings
8. Major illnesses/surgeries and their dates
9. Chronic diseases
10. Family illness history
Health-care spending in the United States has been skyrocketing in recent years and is fast approaching 20 percent of the nation’s Gross Domestic Product. One suggestion for saving money is to implement electronic personal health records.

With this in mind, the Friends of the National Library of Medicine (FNLM) and the National Library of Medicine (NLM) hosted a conference on the subject. Some of the nation’s leading health-care experts spoke at the conference, discussing how electronic health records (EHRs) could be used to save money, improve individual care, and make our national health-care system more efficient. Titled “Personal Electronic Health Records: From Biomedical Research to People’s Health,” the conference was in May at the National Institutes of Health (NIH) campus in Bethesda, Md.

“We believe electronic health records will become as integral to medicine as the stethoscope,” says Dr. David Blumenthal, national coordinator for health information technology. He is leading the Department of Health and Human Services’ (HHS) effort to modernize the health-care system through the adoption of health information technology.

Says NLM Director Donald A.B. Lindberg, M.D., “For more than 30 years, the National Library of Medicine has funded research and development related to electronic health records, including the Indianapolis Patient Care Network (see related story, “Electronic Health Records Place 1st at Indy 500.”). Given the wide variation in U.S. health-care delivery, one size is unlikely to fit all, so it is encouraging that a variety of models is being pursued.”

As the following survey of expert opinions indicates, optimism ran high at the May conference about the gains stemming from widespread adoption of electronic health records:

“…increasingly useful”: “As we have seen information technology extremely useful in almost every other aspect of society, we will see it increasingly useful in health care.” — Alfred Spector, Vice President, Research and Special Initiatives, Google

“…great decision support tools”: “These are great decision support tools, and physicians and clinicians could be greatly empowered by having more information in a timely manner.” — Andrew Balas, Dean, College of Health Sciences, Old Dominion University and FNLM Board Member

“…enables patients to understand”: “The new technology of personalized health records enables patients to understand their conditions and participate with their health-care providers in the decisions affecting their care.” — Daniel Masys, Chair, Department of Biomedical Informatics, and Professor of Medicine, Vanderbilt University Medical Center

“…people will see two benefits”: “People will see two benefits. First, the doctor will know more—what medications you’re allergic to, your history, the latest lab results, imaging, and so on—so we can provide good care on the spot. Second, we’ll be able to aggregate the information and learn, for example, if people taking a particular drug are having any adverse consequences we hadn’t known about before.” — David Cutler, Otto Eckstein Professor of Applied Economics, Harvard University

“…quality and safety”: “The University of Pittsburgh Medical Center is implementing an electronic health record for our patients for quality and safety.” — G. Daniel Martich, MD, Professor of Critical Care Medicine, Vice President of eRecord, University of Pittsburgh Medical Center

“…helps doctors communicate”: “The biggest effect is to have helped doctors communicate with other doctors, with nurses, and more recently patients. Getting the information in a central point where everybody can have it has had a big effect. You can search outside databases and do studies to understand what treatments work best. That gets published and used by everybody.” — George Hripcsak, MD, MS, Chair, Department of Biomedical Informatics, Columbia University

“…more informed decisions”: “As patients, we can alert our providers to any issues or questions, but also help make more informed decisions in our own interest. The cure is informed by the best evidence, your past history, not best guess.” — John Perlin, Chief Medical Officer and President, Clinical Services, Hospital Corporation of America

More on the Health Records Conference Online at fnlm.org

Videos, interviews, quotes, PowerPoints, and links from the conference are online at the Friends’ Web site, www.fnlm.org.
On May 5th, the 2009 FNLM Annual Awards Dinner celebrated advances in public health and medicine, along with the individuals and organizations dedicated to this cause. The dinner was dedicated to the memory of FNLM’s long-time chairman, the Honorable Paul G. Rogers, a member of Congress for 22 years and one of America’s greatest health advocates and a passionate supporter of the Friends.

1 Vincent T. DeVita, Jr., M.D. (right), the Amy and Joseph Perella Professor of Medicine at Yale University School of Medicine, received a Distinguished Medical Science Award for his global leadership in cancer research and the development of combination chemotherapy programs that have revolutionized cancer treatment. To his left is Donald A.B. Lindberg, M.D., Director of the National Library of Medicine.

2 NIH researchers John T. Schiller, Ph.D. (at podium) and Douglas R. Lowy, M.D. (at right) received Distinguished Medical Science Awards for their leadership in cancer research and the development of a vaccine to protect against two of the deadliest forms of the human papillomavirus (HPV).

3 The Michael E. DeBakey Library Services Outreach Award was presented to Greysi Reyna, MLS, Assistant Director, Mario E. Ramirez, M.D. Medical Library, University of Texas Health Science Center, for her many years of dedication to improving access to health information to the health-care professionals and the underserved populations in the Rio Grande Valley.

4 The Paul G. Rogers Public Service Award was presented to Mary Woolley, President of Research!America, for her many years of advocacy on behalf of health and medical research.

5 Rebecca Rogers, widow of the Honorable Paul G. Rogers, was presented a special award from the NIH Board of Regents and the FNLM Board of Trustees, in appreciation for his outstanding service to his country and to the NIH.
September is National P.A.D. Month. A new campaign has begun to alert women to the dangers of peripheral arterial disease. P.A.D. can increase heart disease—the No. 1 killer of women.

What Most Women Don’t Know About P.A.D.

“I used to go on long hikes with my husband, but now my legs get tired so quickly, I can’t go any more.”
—Susan, 54 years old

“I don’t know what’s happened to me. I have an awful pain in my right calf after just 10 minutes of walking. It feels like someone put a clamp on my leg.”
—Caroline, 60 years old

“When I walk, I get an aching pain—like a charley horse—in my left leg. When I go shopping, the pain gets so bad I can only walk for about five or six minutes before I have to sit down and rest. I must be getting old.”
—Barbara, 65 years old

Do the comments at left sound familiar? How many times have you heard family members or friends complain about leg pain and chalk it off to “old age?”

Peripheral arterial disease, or P.A.D., may be the cause of their leg pain. But, according to a recent survey by the P.A.D. Coalition, an alliance of health organizations, only 28 percent of American women have even heard of this serious condition. This is alarming, since P.A.D. is a common and dangerous disease that affects about nine million Americans, half of whom are women. That’s 1 in 20 over age 50 and 1 in 5 over age 70.

To call attention to this little-known threat, the P.A.D. Coalition and WomenHeart, the National Coalition for Women with Heart Disease, developed the educational campaign. The campaign is in support of “Stay in Circulation: Take Steps to Learn About P.A.D.,” a nationwide effort sponsored by the NIH’s National Heart, Lung, and Blood Institute and more than 80 health organizations, vascular health societies, and government agencies.

P.A.D. occurs when fatty deposits clog arteries in the legs, reducing blood flow and causing leg pain when walking. Left untreated, P.A.D. can lead to disability,

**FAST FACTS**

- **P.A.D. occurs when arteries in the legs become clogged with fatty deposits.**
- **Signs of P.A.D. include:**
  - Cramps, tiredness, or pain in your leg muscles that occurs when you walk but goes away with rest.
  - Foot or toe pain at rest that often disturbs your sleep.
  - Skin wounds or ulcers on your feet or toes that are slow to heal.
Risk Factors for P.A.D.

Some conditions and habits raise your chance of developing P.A.D. Your risk increases if you:

- Are over 50.
- Smoke or used to smoke. Those who smoke or have a history of smoking have up to four times greater risk of developing P.A.D.
- Have diabetes. One in every three people over the age of 50 with diabetes is likely to have P.A.D.
- Have high blood pressure. Also called hypertension, high blood pressure raises the risk of developing plaque in the arteries.
- Have high blood cholesterol. Excess cholesterol and fat in the blood contribute to the formation of plaque in the arteries, reducing or blocking blood flow to the heart, brain, or limbs.
- Have a personal history of vascular disease, heart attack, or stroke. If you have heart disease, you have a one in three chance of also having P.A.D.
- Are African American. African Americans are more than twice as likely to have P.A.D. as their white counterparts.

amputation (losing a foot or leg), and poor quality of life. Having P.A.D. also means an increased risk of heart attack or stroke. Blocked arteries found in people with P.A.D. can be a red flag that other arteries, including those in the heart and brain, may also be blocked. In the short term, having P.A.D. markedly increases your risk for heart attack, stroke, amputation, and death. In the long term, people with P.A.D. have a two- to six-fold increased risk of a heart attack or a stroke.

“Symptoms of P.A.D. should not be mistaken for inevitable consequences of aging,” says NHLBI Director Elizabeth G. Nabel, M.D.

“Early detection and treatment of P.A.D. are important for staying in circulation and continuing to enjoy life to the fullest.”

Heart disease is the No. 1 killer of American women. While many women now know about the risk factors for heart disease—high blood pressure, not exercising, high cholesterol, high blood fats, and high blood sugar—most women are not aware that if you have P.A.D., you are at increased risk for heart disease and stroke. In fact, P.A.D. is caused by the very same conditions and lifestyle behaviors that cause heart disease and stroke.

To Find Out More

For more information about P.A.D. and to download free education materials, visit:

- MedlinePlus
- Stay in Circulation
  [www.aboutpad.org](http://www.aboutpad.org)
- P.A.D. Coalition
  [www.padcoalition.org](http://www.padcoalition.org)
- WomenHeart, the National Coalition for Women with Heart Disease
  [www.womenheart.org](http://www.womenheart.org)
Does this sound familiar? You have only a few minutes with your health-care provider. You say what’s on your mind. But, later, you remember something you forgot to ask. Or, maybe you listen to what she says, and then forget parts of what she told you. Or, you realize that although you thought you understood what she was telling you at the time, there are some words and directions that now confuse you.

Today, patients take an active role in their health care. How well you and your health-care provider talk to each other is one of the most important parts of getting good health care. Unfortunately, it isn’t always easy. It takes time and effort on your part. Here are some tips for making the most of your visit.

Straight talk with your health-care provider is important. You and your medical team can then both make better decisions for your good health. Here’s how.
Today, patients take an active role in their health care. Speaking clearly with your health-care provider about what’s wrong and how to cure it is one of the most important aspects of getting good care.

Make a List

Come prepared for your visit. Make a list of the things that you want to discuss, such as:

- Any symptoms that are bothering you. Have they changed since your last visit?
- Medicines you take. Be sure to include vitamins and any complementary and alternative therapies you use, such as herbs or supplements.
- Any allergies you may have, especially to medications.
- A description of symptoms, when they started, and what makes them better.

Be sure to understand your diagnosis and prescribed treatments. Ask your health-care provider to write down his or her instructions to you. If you still don’t understand, ask where to go for more information.

Ask Questions

If you don’t understand your health-care provider, ask questions until you do understand. Write down what he or she says. Go with a trusted friend or relative, and let your health professional know if you want that person to hear what is said. Helpful questions for clear understanding:

- About My Disease or Disorder
  - What is my diagnosis?
  - What caused my condition?
  - Can it be treated?
  - How will it affect my health now and in the future?
  - Should I watch for any particular symptoms and notify you if they occur?
  - Should I make any lifestyle changes?

- Treatment
  - What is the treatment for my condition?
  - When will the treatment start, and how long will it last?
  - What are the benefits of this treatment, and how successful will it be?
  - What are the risks and side effects associated with this treatment?
  - Are there foods, drugs, or activities I should avoid while I’m on this treatment?
  - If treatment includes taking a medication, what should I do if I miss a dose?
  - Are other treatments available?

- Medical Tests
  - What kinds of tests will I have?
  - What do you expect to find out from these tests?
  - When will I know the results?
  - Do I have to do anything special to prepare for any of the tests?
  - Are there any side effects or risks?
  - Will I need more tests later?

Look it up

Sometimes, it can seem as if you and your health-care provider are speaking different languages. Health professionals often use technical terms instead of more common names for conditions. For example, a doctor might say you have a contusion. You would call it a bruise.

You can use the Merriam-Webster Medical Dictionary at www.MedlinePlus.gov to look up words. Just go to www.nlm.nih.gov/medlineplus/mplusdictionary.html and enter the word you’re looking for. On that same page, you can also find lists of word parts and what they mean, some common abbreviations, and even a tutorial, “Understanding Medical Words.”

- Understanding Medical Words: www.nlm.nih.gov/medlineplus/medicalwords.html
- Word Parts and What They Mean: www.nlm.nih.gov/medlineplus/appendixa.html
- Some Common Abbreviations: www.nlm.nih.gov/medlineplus/appendixb.html

To Find Out More

Talking to Your Doctor
www.nei.nih.gov/health/talktodoc.asp

Questions are the Answer
www.ahrq.gov/questionsaretheanswer/index.html

Talking with your Doctor
nihseniorhealth.gov/talkingwithyourdoctor/toc.html
Healthy Weight: You Can Do It, Too

Russell Morgan changed the way he eats and exercises, and reduced his weight by 60 pounds—with healthy habits he can keep for a lifetime. You can, too.

By Christopher Klose

Over a recent eight-month period, public health expert Russell Morgan, 66, of Chevy Chase, Md., dropped 60 pounds from his five-foot, nine-inch frame, going from 250 to 190 pounds. He spoke with NIH MedlinePlus magazine about how he did it, and what he does to maintain his weight.

What motivated you to lose weight?
Russell Morgan: One evening at dinner with friends, I suddenly noticed my pants were too tight. And I was sweating and couldn’t enjoy the food. My body was sending me a message: Get rid of the weight. That was a transformative moment.

How did you feel?
Russell Morgan: Finally, I was in the mood to change. That was key. Nothing’s going to sell you on losing weight if you don’t want to. Beyond wanting, however, you have to have the time, which I did. Most people don’t.

Did you follow a process?
Russell Morgan: Yes, on my doctor’s advice, I entered a weight management clinic at a local medical school. It included physician counseling and support group therapy managed by psychologists and psychiatrists to understand the behavioral factors influencing obesity and people’s eating.

FAST FACTS

- About two-thirds of U.S. adults are overweight, and almost one-third are obese, according to the Centers for Disease Control and Prevention (CDC).
- Overweight and obesity are known risk factors for diabetes, coronary heart disease, high blood cholesterol, stroke, high blood pressure, gallbladder disease, osteoarthritis (degeneration of cartilage and bone of joints), sleep apnea and other breathing problems, and some forms of cancer (breast, colorectal, endometrial, and kidney).
- There are healthy ways to reduce your weight, increase your exercise, and improve your eating habits. They all start by talking with your health-care provider.
- Restaurant food portions have mushroomed in size over the past 20 years; we’re eating out more often, and eating more when we do.
habits. I began a nutritious, low-calorie liquid protein diet, weighed myself daily, and kept a journal of everything I ate. And I began to exercise regularly, beginning with walking with family and friends. As I approached my target weight, guided by the clinic’s dietitian, I began transitioning back to regular foods. With my weight down, my own doctor took me off the high blood pressure medicine I’d been on for years.

Were you pleased with your progress?
Russell Morgan: Yes, as a scientist, I had confidence in the system and it was helpful to learn what to expect. I wanted to understand the underlying biology and psychology of my obesity. Self-understanding is a very important key to weight control.

What about your family?
Russell Morgan: You want them on “your” side, of course. They were very supportive, but skeptical; then surprised when I became compulsive about losing weight. Tracking lost pounds became a stimulus in itself. Best thing of all, I don’t snore any more; my wife couldn’t be happier!

What’s your advice about obesity?
Russell Morgan: One thing about obesity, it’s a chronic disease. But it’s a disease you can do something about yourself. Losing the weight is easy. Maintaining your new profile is hard. Self-awareness and discipline are critical. But the reward is terrific. Everyone notices the difference, which makes you very proud of what you’ve accomplished.

Russell Morgan, who reduced his weight by 60 pounds, now eats a nutritious, low-calorie diet (without being “on a diet”) and gets regular exercise.
Healthy Weight Loss Starts With a Plan You Can Stick To

Talk with your doctor or other health-care provider about controlling your weight before you decide on a weight-loss program. Health-care providers don’t always address issues such as healthy eating, physical activity, and weight management during general office visits. It’s important for you to start the discussion in order to get the information you need. Even if you feel uncomfortable talking about your weight with your health-care provider, remember that he or she is there to help you improve your health. Here are some tips:

- Tell your health-care provider that you would like to talk about your weight. Share your concerns about any medical conditions you have or medicines you are taking.
- Write down your questions in advance. Bring pen and paper to take notes.
- Bring a friend or family member along for support if this will make you feel more comfortable.
- Make sure you understand what your health-care provider is saying. Do not be afraid to ask questions if there is something you do not understand.
- Ask for other sources of information, like brochures or Web sites.
- If you want more support, ask for a referral to a registered dietitian, support group, or commercial weight-loss program you can try.
- Call your health-care provider after your visit if you have more questions or need help.

Responsible, Safe Weight Loss

If your health-care provider says you should lose weight, and you want to find a weight-loss program, look for one that is based on regular physical activity and an eating plan that is balanced, healthy, and easy to follow. Weight-loss programs should encourage healthy behaviors and that you can stick with every day.

The Truth About Portion Distortion

Over the past 20 years, the portions of food served in restaurants and fast-food eateries have ballooned—as have the waistlines of many Americans. Take this quiz from the National Heart, Lung, and Blood Institute to find out just how many more calories this adds.

1. A bagel 20 years ago was three inches in diameter and had 140 calories. How many calories are in today’s typical bagel?
2. A cheeseburger 20 years ago had 333 calories. How many calories are in today’s cheeseburger?
3. A plate of spaghetti and meatballs 20 years ago had 500 calories. How many are there today?
4. A 6.5 ounce portion of soda had 85 calories. How many calories are in today’s 20-ounce portion?
5. Twenty years ago, a serving of French fries was 2.4 ounces and had 210 calories. How many calories are in today’s 6.9 ounce serving?
6. A turkey sandwich 20 years ago had two slices of bread and 320 calories. How many calories are in today’s 10-inch turkey sandwich?
7. A standard cup of coffee 20 years ago was 8 ounces and had 45 calories with whole milk and sugar added. How many calories are in today’s 16-ounce mocha coffee with steamed whole milk and mocha syrup?
8. A blueberry muffin 20 years ago was 1.5 ounces and had 210 calories. How many muffins are in today’s 5 ounce muffin?
9. Twenty years ago, two slices of pepperoni pizza had 500 calories. How many calories are in today’s large pizza slices?
10. A chicken Caesar salad was 1 ½ cups and had 390 calories 20 years ago. How many calories are in today’s 3 cup chicken Caesar salad?
When it comes to reaching and keeping your healthy weight, the National Heart, Lung, and Blood Institute (NHLBI) and the National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK) both offer information and programs based on NIH research to help Americans achieve their healthiest weight.

- NIDDK’s Weight-control Information Network (WIN) program provides the public, health professionals, the media, and Congress with up-to-date, science-based information on weight control, obesity, physical activity, and related nutritional issues.

- To help African American women reach and keep healthy weight, WIN has a section called “Sisters Together: Move More, Eat Better,” a national campaign designed to encourage Black women 18 and over to maintain a healthy weight by becoming more physically active and eating healthier foods.

- NHLBI’s We Can!, or “Ways to Enhance Children’s Activity & Nutrition,” is a national program designed for families and communities to help children maintain healthy weight. It focuses on improved food choices, increased physical activity, and reduced television, computer, and videogame screen time.

- The NIH also recommends the DASH diet (Dietary Approaches to Stop Hypertension). More than the traditional low-salt or low-sodium diet to reduce blood pressure, DASH is based on an eating plan rich in fruits and vegetables, and low-fat or non-fat dairy.

To Find Out More

- Weight control

- WIN: Weight-control Information Network
  win.niddk.nih.gov

- We Can! national program on children’s weight, exercise, and diet
  wecan.nhlbi.nih.gov

- DASH diet (Dietary Approaches to Stop Hypertension)
  dashdiet.org/
Heart-Safe Exercise

In the largest study of its kind to date, researchers have found that exercise is safe for people with heart failure, improves quality of life — and may even reduce the risk of death or hospitalization. This is good news for the 5 million Americans whose hearts cannot pump enough blood through the body due to coronary heart disease, diabetes, high blood pressure, or other causes. Funded by the National Heart, Lung, and Blood Institute, the study included walking and riding a stationary bicycle for exercise. People with heart failure should talk with their doctors prior to sustained physical activity.

Obesity, Allergy Connection?

Obese children and teens are more likely than children of normal weight to suffer from allergies, particularly food allergies. Analyzing data on more than 4,000 children between the ages of 2 and 19, researchers found the obese to be about 26 percent more likely to have allergies. The results do not prove that obesity causes allergies — more investigation is needed. The study was funded by the National Institute of Environmental Health Sciences and the National Institute of Allergy and Infectious Diseases.

Check Out Health-Helpful Web Sites

MedlinePlus.gov and other NIH Web sites contain plenty of information for people wanting to take care of themselves and their loved ones.

- A new, four-minute video looks closely at depression and why getting treatment is so important. Depression is a serious medical illness that affects 20 million Americans. Produced by the National Institute of Mental Health for individuals, community groups and health-care providers, the video can be seen at www.nimh.nih.gov/health/topics/depression/index.shtml.

- Caring for an older friend or family member? Then “Medicare Basics for Caregivers,” an instructional program on the federal health insurance program for those 65 and older and younger people with disabilities, may be very helpful. Go to www.nihseniorhealth.gov.

- If you need health information in other than English, check out the “multiple languages” collection on www.medlineplus.gov. It has material in more than 40 languages, plus their English translations, to help people with limited English skills communicate with their health-care providers.

Correction

The first question in the Migraine 101 quiz in the Spring 2009 issue should have read: “A migraine headache usually begins with a visual disturbance called an aura (spots, dots, or even zigzag lines).” The answer should have been: “False. In most cases of migraine, there is no aura.”
# 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  1-888-FIND-NLM
  - National Cancer Institute (NCI) www.cancer.gov  1-800-4-CANCER (1-800-422-6237)
  - National Eye Institute (NEI) www.nei.nih.gov (301) 496-5248
  - National Heart, Lung, and Blood Institute (NHLBI) www.nhlbi.nih.gov (301) 592-8573
  - National Human Genome Research Institute (NHGRI) www.genome.gov (301) 402-0911
  - National Institute on Aging (NIA) Alzheimer's information 1-800-222-2225
  - National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) www.niddk.nih.gov (301) 480-4098
  - National Institute of Neurological Disorders and Stroke (NINDS) www.ninds.nih.gov 1-800-352-9424
  - National Institute of Nursing Research (NINR) www.ninr.nih.gov (301) 496-0207
  - National Institute of Drug Abuse (NIDA) www.nida.nih.gov (301) 443-1124
  - National Institute of Environmental Health Sciences (NIEHS) www.niehs.nih.gov (919) 541-3345
  - National Institute of General Medical Sciences (NIGMS) www.nigms.nih.gov (301) 496-7301
  - National Institute of Mental Health (NIMH) www.nimh.nih.gov 1-866-615-6464
  - National Institute of Neurological Disorders and Stroke (NINDS) www.ninds.nih.gov 1-800-352-9424
  - National Institute of Nursing Research (NINR) www.ninr.nih.gov (301) 496-0207
  - National Institute on Drug Abuse (NIDA) www.nida.nih.gov (301) 443-1124

## Centers & Offices

- **Center for Information Technology (CIT)** www.cit.nih.gov (301) 594-6248
- **Center for Scientific Review (CSR)** wwwcsr.nih.gov (301) 435-1115
- **Fogarty International Center (FIC)** www.fic.nih.gov
- **National Center for Complementary and Alternative Medicine (NCCAM)** www.nccam.nih.gov 1-888-644-6226
- **National Center on Minority Health and Health Disparities (NCMHD)** www.ncmhd.nih.gov (301) 402-1366
- **National Center for Research Resources (NCRR)** www.ncrr.nih.gov (301) 435-0888
- **NIH Clinical Center (CC)** www.cc.nih.gov (301) 496-2563
- **Office of Research on Women’s Health (ORWH)** http://orwh.od.nih.gov (301) 402-1770

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**NIH MedlinePlus Advisory Group**

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- **Kate Egan**, National Institute of Mental Health
- **Marian Emr**, National Institute of Neurological Disorders and Stroke
- **Martha Fishel**, National Library of Medicine (ex-officio)
- **Susan Johnson**, National Institute of Dental and Craniofacial Research
- **Mary Beth Kester**, National Institute of Biomedical Imaging and Bioengineering
- **Kathy Kranzfelder**, National Institute of Diabetes and Digestive and Kidney Diseases
- **Carol Krause**, National Institute on Drug Abuse
- **Jo-Ann Kriebel**, National Institute of Alcohol Abuse and Alcoholism
- **Lonnie Lisle**, National Institute on Deafness and Other Communications Disorders
- **Ann London**, National Institute of Allergy and Infectious Diseases
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- **Diane Striar**, National Heart, Lung, and Blood Institute
- **Chris Thomsen**, National Center for Complementary and Alternative Medicine
- **Larry Thompson**, National Human Genome Research Institute
- **Anne Thurn, Ph.D.**, Office of Dietary Supplements
- **Marcia Vital**, National Institute of Arthritis and Musculoskeletal and Skin Diseases
Do you have trouble understanding some of the words that your doctor or other health-care provider uses? Now you can learn about them with a free, colorful, and easy-to-use set of lessons on the Internet. There are quizzes to help you mark your progress, with topics like these:

- **Word Roots:** The “root” of a medical word is often a body part, like “derm” (skin) in dermatitis.
- **Beginnings and Endings:** hyper- (above normal); hypo- (below normal)
- **Abbreviations:** MRI (Magnetic Resonance Imaging), a test that uses images of your body
- **Medical Dictionary:** A direct link to the MedlinePlus.gov medical dictionary