Take an active role in your health: Tools that empower patients

by Cynthia Johnson

The start of a new year leads many of us to contemplate what’s working well and what we’d like to change moving forward. Popular New Year’s resolutions include exercising regularly, losing weight, and renouncing unhealthy habits such as smoking and drinking.

If patients want to make these health-related objectives stick, perhaps they should also resolve to take an active role in their healthcare and use reputable tools such as those developed by the Agency for Healthcare Research and Quality (AHRQ) and Ipswich-based EBSCO Publishing to guide them through 2011.

“Getting enough rest, exercising, and eating well are the basic foundation for being healthy,” says Cynthia Brown, MD, deputy editor for DynaMed®, an evidence-based clinical reference tool by EBSCO. “Supplementing that with accurate information on how to take care of yourself is important. As patients, we need to take responsibility for our own health and not just dump our bodies in the laps of our physicians.”

The arrival of consumer-directed healthcare plans that oblige patients to cover more out-of-pocket expenses is also prompting them to scrutinize the decisions they make regarding their care and where they spend their healthcare dollars.

“The financial impact would cause one to ask questions if for no other reason than to ensure that you’re getting the services you’re paying for,” says Howard Holland, acting director of AHRQ’s Office of Communication and Knowledge Transfer. “There’s a lot at stake for everyone in the healthcare system these days.”

‘Questions Are the Answer’

In 2007, AHRQ kicked off a campaign called “Questions Are the Answer” (www.ahrq.gov/questionsaretheanswer). It challenges patients to become more engaged in their health by asking providers questions to help them understand their condition and evaluate options.

The campaign’s website contains a list of the 10 best questions every patient should ask their healthcare provider, such as “Why do I need this treatment?” It also houses a tool that lets
Active role
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patients build their own list of personalized questions to take with them to a healthcare encounter. Users can build questions around prescriptions, medical tests, surgery, long-term care, and other topics based on their unique set of circumstances.

“That is a heavily trafficked area of our website,” says Farah Englert, associate director for marketing and implementation in AHRQ’s Office of Communication and Knowledge Transfer. “People are really interested in the tool.”

The questions serve to encourage a dialogue between patients and healthcare providers to foster shared decision-making. By doing so, patients can develop strong relationships with their clinicians to ensure that they receive safe, quality care.

“If you’re anxious in the examining room, you’re not going to hear things and you’re going to forget to ask the questions that you meant to ask,” says Brown. “This is why writing down questions before the visit is so important.”

Using a donated media model by the Ad Council, the campaign reaches patients through television, radio, print, and Internet advertisements, as well as outdoor ads in the form of posters and billboards. AHRQ developed the materials after conducting research and focus tests with consumers and physicians to ensure that the messages would resonate with both parties.

The television advertisements are perhaps the most impressive. One such ad depicts a woman in a restaurant inundating her waiter with a volley of questions related to her meal selection. However, when the same woman is in her physician’s exam room, she has nothing to ask of her doctor.

In the past, AHRQ has also run successful commercials encouraging patients, specifically men, to have regular coloscopies and prostate screenings.
“The movement from AHRQ is about patients being better informed and more enabled to participate in their care and assume responsibility for their own health instead of taking a passive role and just doing as you’re told,” says Brown. “Ask those questions and challenge yourself and your healthcare provider to be as healthy as possible.”

Providing patients with current, evidence-based information

EBSCO (www.ebscohost.com/pointOfCare) has two tools that subscribing physicians can offer to help empower patients in 2011: Health Library and Patient Education Reference Center (PERC). Both compliment the DynaMed reference that healthcare providers use as a point-of-care resource.

Health Library offers evidence-based health and wellness information, whereas PERC consists of a collection of current, evidence-based patient education information that clinicians can print and distribute at the point of care.

According to Brown, 50% of the healthcare dollars spent in this country are on alternative and complementary

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These questions are the answer

The Agency for Healthcare Research and Quality developed the following list of the 10 best questions that every patient should ask their healthcare providers:

1. What is the test for?
2. How many times have you done this procedure?
3. When will I get the results?
4. Why do I need this treatment?
5. Are there any alternatives?
6. What are the possible complications?
7. Which hospital is best for my needs?
8. How do you spell the name of that drug?
9. Are there any side effects?
10. Will this medication interact with medicines that I’m already taking?

To learn more about the “Questions Are the Answer” campaign, visit www.ahrq.gov/questionsaretheanswer.
AHRQ and DynaMed are both developing tools to help physicians make the most out of healthcare interactions with patients. According to Brown, if patients medicine, which makes getting current, evidence-based information about them all the more critical.

For example, the Institute of Medicine’s Food and Nutrition Board recently published a consensus report that concluded that the majority of Americans and Canadians are receiving adequate amounts of calcium and vitamin D. It also found emerging evidence that suggests that too much of these nutrients may in fact be harmful. EBSCO examines such findings on a daily basis and puts the information into the hands of consumers and their physicians.

“We don’t want patients harming themselves,” says Brown. “The over-the-counter preparations, vitamin preparations, and supplement preparations are not FDA controlled and can have a lot of ingredients in them that may be harmful. It’s important to know what you’re doing to yourself to make sure that the things that you think are harmless actually are.”

One difficulty lies in patients failing to ask their providers about these alternative and complementary therapies. Patients often experience anxiety when they are in an examination room. This anxiety often causes them to forget to ask the questions they need to have answered. It can also cause them to become distracted and hear only a small percentage of what the doctor is saying.

Brown says physicians can provide patients with a PERC handout that patients can take home and read at their leisure. The handout reduces anxiety and arms patients with information presented at the proper educational level so they don’t have to turn to unreliable sources on the Internet for answers.

Arming physicians with information

AHRQ and DynaMed are both developing tools to help physicians make the most out of healthcare interactions with patients. According to Brown, if patients

Making and keeping New Year’s resolutions

In 2007, professor Richard Wiseman of the University of Hertfordshire in the United Kingdom tracked the lives of more than 700 people as they attempted to achieve their New Year’s resolutions. His research found that only 12% of participants achieved their resolution.

As a result, Wiseman identified the following 10 tips for keeping a New Year’s resolution:

1. Create sub-goals that are concrete, measurable, and time-based
2. Tell your friends and family about your goals to create a support system
3. Remind yourself of the benefits associated with achieving your resolution
4. Expect that you may revert to your old habits, but treat any failure as a temporary setback
5. Making only one resolution will increase your chance of succeeding
6. Don’t wait until New Year’s Eve to make a resolution; give it thoughtful consideration in the days before the new year
7. Avoid previous resolutions that could set you up for frustration and disappointment
8. Think about what you really want rather than choosing popular resolutions
9. Treat yourself to small rewards along the way to your goal
10. Keep a handwritten journal to document your progress

To learn more about Wiseman, visit http://59seconds.wordpress.com.
are going to ask their physicians questions about their health, physicians must have the proper armamentarium to answer those questions accurately using evidence-based sources of information.

However, having the right answers isn’t all it takes. Primary care providers are feeling the current strain in the healthcare industry. Brown points to the shortage of physicians as one example, saying that they’re expected to do more with less. She predicts that the electronic medical records (EMR) that are part of healthcare reform will help contribute to solving this dilemma. DynaMed can link its patient information handouts to these systems so that physicians can print them for patients while they are using an EMR.

Along with the physician shortage, the time that a doctor can spend with a patient is also on the decline. “Clinicians are just as frustrated as patients are with the fact that they have limited time for their appointments,” says Englert. “I think there’s a desire on both sides to maximize or get the most that they can get out of that precious appointment time.”

AHRQ is developing a physician-targeted campaign that it plans to launch in mid-2011. The campaign will help physicians understand the importance of shared decision-making and teach them how to create an environment that allows shared decision-making to happen within today’s changing healthcare environment.

“I won’t say it’s always been the case, but physicians have perhaps been taking the approach that they know what’s best for the patient,” says Holland. He describes an antiquated model in which patients visit a doctor and leave without asking questions about the prescription, treatment, or remedy that they receive.

The physician version of the AHRQ site will help physicians determine how best to work with patients who bring Web articles and other data that they’ve collected with them to an appointment. Doctors will be able to use the AHRQ print and Web-based materials in their offices to help explain complex medical issues to their patients.

Reaching at-risk audiences

Now that the AHRQ campaign is under way, the next goal the agency is working toward is developing information to reach at-risk audiences. Although the tool is currently available in English and Spanish, AHRQ plans to create specialized advertising directed at groups such as Hispanics and African-Americans rather than trying to reach them with the more general messages. The hope is that developing these messages will influence how these specific groups interact with their providers.

“This strategy is in line with the National Healthcare Quality Report and National Healthcare Disparities Report that AHRQ produces each year. Both reports show that there continue to be gaps in the care that different populations get and that there is a need to develop more culturally appropriate messages.”

—Farah Englert

“An educated patient is our best patient,” says Brown. “I think the movement for patients to take ownership of their health is what is really needed in this country—to not take a backseat and a passive role, but to participate in being healthy and well.”
Imaging self-referrals don’t reduce sick days, costs

A controversial practice in which physicians self-refer patients for imaging tests with the doctor’s own equipment does not result in shorter length of illness. Rather than reducing costs, the cost per episode of care generally averages 4%–10% higher when the physician self-refers a patient, according to a report on self-referral imaging published in the December issue of Health Affairs.

The authors of the report say their results refute claims by some physician groups that self-referral, which can allow same-day service as the visit with the physician, results in a quicker diagnosis, keeps the cost of care lower, and speeds patient recovery. In fact, the authors suggest that the practice leads to more testing and radiation exposure.

EHR certification final rule up for review

The Office of the National Coordinator for Health Information Technology has sent a final rule to establish a permanent certification program for electronic health record (EHR) technology to the Office for Management and Budget (OMB). According to a HealthLeaders Media article, review by the OMB is required to publish a final rule.

The rule, “Establishment of the Permanent Certification Program for Health Information Technology,” outlines the certification program, which is used to provide assurance that an EHR technology or module will have the capabilities necessary to meet meaningful use standards. Using certified EHR technology is required for providers who are hoping to qualify for the meaningful use incentive dollars under the HITECH legislation.

CCHIT program to help hospitals pass EHR certification

The Certification Commission for Health Information Technology (CCHIT) is launching a new electronic health record (EHR) certification program for hospitals. According to an InformationWeek article, the program is for hospitals that have uncertified legacy software, customized commercial products, or self-developed EHR systems.

The program contains three phases, all of which are designed to give applicants the greatest possible chance of passing the test. Applicants can only undergo the final inspection if they have gone through the first two phases of the program.

VA pilots digital medical record retrieval

The Department of Veterans Affairs (VA) has announced that it will work with a private contractor to speed claims decisions and significantly reduce the average time needed to obtain medical records from private physicians.

According to an InformationWeek article, the department noted that one of the pilot projects in the VA Claims Transformation Plan can significantly improve the efficiency of the claims processing system as well as help the department meet its goal of processing all claims within 125 days and with 98% accuracy by 2015.
Plastic surgeon sues patients over negative reviews on Yelp and Citysearch

Three women who used Yelp and Citysearch® to review the plastic surgeon they say botched their breast surgeries are being sued by the very same surgeon. According to an ABC News article, Dr. Jay Pensler, a Chicago-based cosmetic surgeon, is suing each of the women for $100,000 in compensatory and punitive damages.

Pensler filed three separate complaints with the Circuit Court of Cook County, IL, claiming that the women attempted to ruin the professional reputation of a well-respected plastic surgeon through false and defamatory statements. In separate comments, the women referred to the surgeon as “dangerous,” “ruthless,” a “liar,” and “horrible.”

Accountability Office (GAO) report titled, Health Care Delivery: Features of Integrated Systems Support, Patient Care Strategies, and Access to Care, but Systems Face Challenges.

The GAO examined 15 private and public integrated delivery systems that are aligned across primary, specialty, and acute care. The report offers a look at how chief medical officers and other systems officials are using digitized medical records, as well as their evaluation of the impact that EHRs have on patient care, including care coordination, disease management, and use of care protocols.

Key ingredient to effective cancer treatments

About 50% of cancer patients have tumors that are resistant to radiation because of low levels of oxygen, a state known as hypoxia. According to an MIT Technology Review article, a startup in San Francisco is developing proteins that could carry oxygen to tumors more effectively, increasing the odds that radiation therapy will help these patients.

$18M fiber-optic network to open in Nebraska

The Rural Nebraska Healthcare Network, a consortium of nine hospitals and clinics in western Nebraska, has broken ground on a new $18 million fiber-optic medical network. According to a HealthLeaders Media article, the

Institute names top 10 healthcare technology hazards for 2011

The ECRI Institute, an independent group that evaluates medical devices and procedures, has issued its latest list of the 10 most perilous technologies in healthcare that health providers should keep an eye out for in 2011.

According to a HealthLeaders Media article, the goal of the program is to increase awareness of these hazards and to stimulate action within healthcare facilities to minimize dangers.

The technologies that made the top 10 list are:
1. Radiation overdose and other dose errors during radiation therapy
2. Alarm hazards
3. Cross contamination from flexible endoscopes
4. The high radiation dose of CT scans
5. Data loss, system incompatibilities, and other health information technology complications
6. Tubing misconnections
7. Oversedation during use of PCA infusion pumps
8. Needlesticks and other sharps injuries
9. Surgical fires
10. Defibrillator failures in emergency resuscitation attempts
Ultrasound gets more portable

A startup company, Mobisante, awaiting clearance from the FDA hopes to begin selling a portable ultrasound device this year. According to an MIT Technology Review article, two years ago, computer engineers at Washington University in St. Louis created a prototype that took ultrasound imaging to a new level of mobility and connectivity by connecting an ultrasound probe to a smartphone.

The device would be useful for emergency responders who could scan an injured person to detect internal bleeding or other trauma and then send an image to the hospital so physicians could be better prepared for the patient’s arrival. A nurse practitioner visiting a pregnant woman’s home could also ask a specialist stationed elsewhere to weigh in on anomalies in a scan.

Depending on the components included, the device could cost $5,000–$10,000 initially and drop in half within the next three years.

EHR online safety system launched

A new online safety reporting system to help doctors and other clinicians tackle issues related to the implementation of electronic health records (EHR) has been launched by the iHealth Alliance, a nonprofit organization. According to an InformationWeek article, the organization collaborates with federal agencies, the PDR Network, and other healthcare stakeholders.

At a press conference to launch the website, EHRevent.org, speakers indicated that they clearly expect difficult issues to arise as healthcare delivery organizations move away from a paper-based system and accelerate their adoption of EHRs. However, they noted that information collected from the site should help healthcare providers with software problems, inadequate user training, security, and data-related issues.

Insurance companies and the FDA plan to use the information collected on the website to develop educational literature regarding patient safety and EHRs.

AEDs in hospitals fail to improve survival odds

Using automated external defibrillators (AED) in hospitals on patients with sudden cardiac arrest is ineffective and potentially harmful when compared with traditional defibrillators, according to a November 2010 study in the Journal of the American Medical Association.

The study examined data from the National Registry of Cardiopulmonary Resuscitation, according to a HealthLeaders Media article.

AEDs diagnose sudden cardiac arrest, judge whether defibrillation is needed, and deliver an electrical shock to restore the heart’s normal rhythm. For cardiac arrest patients who respond to a defibrillation shock, there was no difference in rates of survival between those treated by an AED or a conventional defibrillator. In some circumstances, the use of AEDs in the hospital was associated with higher death rates.

Although AEDs have improved survival in out-of-hospital settings such as schools, airports, and sporting events, data on their effectiveness in hospitals—where they are increasingly used—are limited.
Web ratings are flawed

Web-savvy consumers often use online rating services to review restaurants, hairdressers, and carpenters. More than 30 online services now grade physicians, which are proving to be much more controversial, according to a Chicago Tribune article.

Critics say that most sites have too few reviewers per doctor to offer statistically significant information. Rating proponents say that consumer reviews can help identify competent practitioners and pressure physicians to improve.

Robot nurse washes human

A robot known as “Cody” successfully wiped away blue candy from a test user’s legs and arms without being forceful, say researchers from Atlanta’s Georgia Institute of Technology.

According to an MIT Technology Review article, the elderly and people with disabilities often have trouble with daily activities, such as maintaining personal hygiene. Robots like Cody may one day be able to help them maintain an independent lifestyle for longer in their homes or help ease some of the burden of hospital or assisted-living workers.

AMA releases social media guidelines for physicians

The AMA adopted a social media use policy to help physicians protect patient privacy and physicians’ personal and professional reputations. According to a HealthLeaders Media article, the new policy encourages physicians to:

» Use privacy settings to safeguard personal information on social networking sites
» Monitor their Internet presence to ensure that the personal and professional information on their sites and content posted about them by others is accurate and appropriate
» Maintain appropriate boundaries of the patient-physician relationship when interacting with patients online
» Consider separating personal and professional content online
» Recognize that online actions and content posted can negatively affect their reputations among patients and colleagues
HEALTHCARE GUIDE TO THE INTERNET

Focus: Brain tumor resources

According to the American Brain Tumor Association (ABTA), physicians were expected to diagnose an estimated 62,000 new cases of primary brain tumors in 2010. However, it is difficult for physicians to diagnose patients with brain tumors since symptoms, such as headaches, personality changes, and seizures, often mimic those of other diseases.

The ABTA site (www.abta.org) is a great place to begin learning more about the disease. You’ll find information about treatment options, statistics, quality of life studies, online support tools, and much more. Don’t forget to check out the site’s educational diagrams and videos.

The National Brain Tumor Society site (www.braintumor.org) also houses a great wealth of information. For example, the site has an online community that lets users exchange thoughts with like-minded individuals. Other features include an ask-the-expert tool, online publications, and information for the newly diagnosed.

Several brain tumor resources are described and reviewed in the following pages, as listed in the index below, using the five-star system to rate each on content, interface, and style.

**OUR SITE-RATING SYSTEM**

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American Brain Tumor Association

www.abta.org

Ratings: Content: ***** Interface: ***** Style: *****

The ABTA works to provide funding to researchers working toward breakthroughs in brain tumor diagnosis, treatment, and care in order to find a cure. It also provides information and support for patients, families, and caregivers who are living with the disease.

You can navigate this website using the top-level navigation links. You can also access featured content on the site’s home page, such as news articles, event information, and videos.

Key features of this site include:

- Information about the various types of brain tumors, including childhood brain tumors and pituitary tumors
- Treatment options for patients
- A description of how doctors diagnose tumors
- A list of symptoms associated with brain tumors
- A diagram of the parts of the brain
- Information for newly diagnosed patients and their families
- Facts and statistics
- A list of potential causes and risk factors for developing brain tumors
- Quality of life studies
- Information about the association
- Links to social networking tools such as Facebook and Twitter
- Online support tools, including a pen pal program
- News regarding brain tumor research
- Clinical trials information
- Information aimed at children with brain tumors (click the Kids link in the upper right-hand corner)
- Information aimed at healthcare professionals (click the Healthcare Professionals link in the upper right-hand corner)

Unique elements: The site contains diagrams and videos that you can access from the home page. Topics include The Talking Brain Tumor, The Major Parts of the Brain, The Brain Stem, and many others.
The site contains information regarding brain tumors in adults and children.

Key features of this site include:

- Detailed medical guides or easy-to-understand overview documents
- A definition of brain tumors
- Brain tumor statistics
- Information regarding the risk factors for the disease, such as radiation exposure, family history, and immune system disorders
- Information regarding researchers’ knowledge about what causes the disease, such as chemical changes that occur in normal brain cells
- A list of symptoms associated with brain tumors, such as headache, nausea, vomiting, blurred vision, balance problems, personality changes, and drowsiness
- Information about how physicians diagnose brain tumors through medical history, imaging tests, and MRI and CT scans, among other tests
- How brain tumors are staged
- Information regarding treatment options, including surgery, radiation therapy, chemotherapy, targeted therapy, and clinical trials
- Questions to ask your doctor if you are concerned about brain tumors
- Information about life after treatment, including topics such as quality of life, recovering from treatment effects, emotional health, and lifestyle changes
- News articles
- A glossary of terms
- Links to additional resources

Unique elements: The site contains a Treatment Decision Tool that lets users learn more about treatment for their brain tumors.
specific form of cancer. To access this tool, select the type of cancer you want to learn more about, then click the Visit Treatment Decision Tool link.

Comments: The site is available in English and Spanish.

Cost: Free. Certain areas may require registration, which is free.

RSS XML link: www.cancer.org/rss?idService=GET_INTHENENEWS_FEED

Keywords: cancer, brain tumor, brain cancer, glioma, meningioma, American Cancer Society, ACS.

» Treatment options for patients
» Fact sheets
» Answers to FAQs
» Information about the foundation
» News articles
» Event information
» Patient stories
» Links to social networking tools such as Facebook, YouTube, and Twitter

Unique elements: The About the BSF section contains a multimedia page that contains videos, including spotlights of patients and supporters.

Comments: The site contains a glossary of terms, which you can find in the About Primary Brain Tumors section.

Cost: Free. Users can sign up for the foundation’s e-mail list by clicking the link at the top of the home page.

RSS XML link: Visit www.brainsciencefoundation.org/matriarch/rsschannellist.asp for a complete list.

Keywords: cancer, brain tumor, brain cancer, glioma, meningioma, primary brain tumors, Brain Science Foundation, BSF, Brigham and Women’s Hospital.

Brain Science Foundation
www.brainsciencefoundation.org

Ratings: Content: ***** Interface: **** Style: ****

The Brain Science Foundation (BSF) is a nonprofit organization working to find a cure for meningioma and other primary brain tumors. It also works to advance the understanding of brain function and how it relates to these tumors. The foundation supports the work and goals of the Institute for the Neurosciences at Brigham and Women’s Hospital in Boston.

You can navigate this website using the top-level navigation links. Some of these links expand to reveal additional drop-down options. You can also access featured content on the site’s home page, such as news articles and videos.

Key features of this site include:

» Information about the types of primary brain tumors
» Symptoms associated with these types of tumors
» How physicians diagnose primary brain tumors in patients

The Brain Tumor Foundation
www.brainintumorfoundation.org

Ratings: Content: **** Interface: **** Style: ****

The Brain Tumor Foundation (BTF) treats patients by addressing their social, financial, and emotional needs. It offers support, guidance, and education through its programs and resources, including support groups, medical referrals, peer matching programs, and educational materials.
You can navigate this website using the top-level navigation links. You can also access featured content on the site’s home page, such as news articles and links to popular content.

Key features of this site include:
» Information about the foundation
» Epidemiology content
» Answers to FAQs about brain tumors
» Publications, such as newsletters and brochures
» A list of symptoms associated with brain tumors, such as seizures, personality changes, and neurological deficit
» Information about treatment options, such as radiation therapy, radiosurgery, and surgery
» A list of the types of brain tumors, including brain stem glioma, chordoma, and pituitary tumors
» Mailing lists
» Online forums
» News articles
» Event information

Unique elements: The site contains a support group called the BRAINTMR List. Users can subscribe to the list by clicking Online Support Groups, then selecting BRAINTMR List.

Comments: The organization runs more than a dozen online supports groups and distributes over 300,000 e-mails every week.

Cost: Free.

RSS XML link: None.

Keywords: cancer, brain tumor, brain cancer, glioma, meningioma, support groups, Brain Trust.

The Healing Exchange Brain Trust
www.braintrust.org

Ratings: Content: **** Interface: *** Style: ***

The Healing Exchange Brain Trust provides support services for people affected by brain tumors and related conditions, including patients and families, healthcare professionals, and researchers. The organization is a grassroots nonprofit founded by two brain tumor survivors, a neurosurgeon and a nurse.

You can navigate this website using the top-level navigation links. You can also access featured content on the site’s home page, such as links to the trust’s social networking pages.

Key features of this site include:
» Information about the trust
» A list of recommended books

Unique elements: The site contains a support group called the BRAINTMR List. Users can subscribe to the list by clicking Online Support Groups, then selecting BRAINTMR List.

Comments: The organization runs more than a dozen online supports groups and distributes over 300,000 e-mails every week.

Cost: Free.

RSS XML link: None.

Keywords: cancer, brain tumor, brain cancer, glioma, meningioma, support groups, Brain Trust.

National Brain Tumor Society
www.braintumor.org

Ratings: Content: ***** Interface: ***** Style: *****

The National Brain Tumor Society (NBTS) provides education and information to those affected by brain tumors to help them make informed decisions and develop strong support systems. The society also invests in research projects that look for new therapeutic targets and improve existing treatments that may lead to a cure.

You can navigate this free website using the top-level navigation links. You can also access featured content
Established in 1937, the National Cancer Institute (NCI) is part of the National Institutes of Health (NIH) and the U.S. Department of Health and Human Services. NCI’s main responsibilities include coordinating the National Cancer Program, conducting and supporting cancer-related research, training physicians and scientists, and disseminating information about cancer.

You can navigate this site using the top-level navigation links. The site also has a list of Quick Links on the left-hand side of the page that will display frequently requested content. In addition, you can click on links on the site’s home page to access featured content, such as information regarding types of cancer and cancer topics. To access information regarding brain tumors, click All Cancer Types, then select from any of the brain tumor topics listed.

Key features of this site include:
» A description of the anatomy of the brain
» A list of symptoms associated with brain tumors
» Descriptions of the types of brain tumors
» Information about how physicians diagnose patients
» Survivorship information
» An ask the expert tool
» Answers to FAQs
» Online publications
» Information regarding treatment options
» Clinical trials resources
» Information for the newly diagnosed patient
» Links to support groups and information
» Patient stories
» Information for healthcare professionals
» Links to social networking tools

Unique elements: The site contains an online community where users can exchange their thoughts with like-minded individuals. You’ll find this community in the Patients, Family & Friends section.

Comments: The site contains a helpful glossary of terms, also in the Patients, Family & Friends section.

Cost: Free. Users can sign up to receive an e-newsletter from the association. Under Tumor & Treatment Info, select Brain Tumor E-News. Users can also sign up with the ABTA to get access to personalized areas of the website for free.

Unique elements: The site contains links along the right-hand side of the page to related topics such as a link to the Neuro-Oncology Branch.
Comments: The site is available in English and Spanish.
Cost: Free.
Keywords: cancer, brain tumor, brain cancer, glioma, meningioma, National Institutes of Health, NIH, National Cancer Institute, NCI.

National Institute of Neurological Disorders and Stroke
www.ninds.nih.gov

Ratings: Content: **** Interface: **** Style: ****

As one of the National Institutes of Health (NIH), the National Institute of Neurological Disorders and Stroke (NINDS) works to reduce the burden of neurological diseases. It conducts research, provides grants and fellowships, and collects and disseminates information.

From the home page, you can navigate this site using the left-hand navigation menu. You can also click on links on the site’s home page to access featured content, such as research information and clinical trial opportunities. To locate the brain tumor information available on the site, select Disorders A–Z, click B, then select Brain and Spinal Tumors.

Key features of this site include:
» Information about the disorder
» Treatment options associated with the condition, including surgery, radiation, steroids, and chemotherapy
» The prognosis for patients who suffer from brain and spinal cord tumors
» Research progress in the field of brain tumors
» Clinical trials resources

Unique elements: The site contains a publication called Brain and Spinal Tumors: Hope Through Research. You can access it from a link at the top of the page.

Comments: The site contains information in English and Spanish.

Cost: Free.

Keywords: cancer, brain tumor, brain cancer, glioma, meningioma, National Institutes of Health, NIH, National Institute of Neurological Disorders and Stroke, NINDS.

Neuro-Oncology Branch
Home.ccr.cancer.gov/nob/default.asp

Ratings: Content: **** Interface: **** Style: ***

The Neuro-Oncology Branch is a trans-institute program of the National Cancer Institute (NCI) and the National Institute of Neurological Disorders and Stroke (NINDS). The branch works to develop an integrated clinical, translational, and basic research program to develop experimental therapeutics for children and adults with tumors of the central nervous system.

You can navigate this site using the top-level navigation links. Some of these links expand to reveal additional menu options. You can also click on links on the site’s home page to access featured content, such as clinical trials information and visitor information.

Key features of this site include:
» Information regarding patient consultations at the Brain Tumor Clinic

Links to additional resources
Organizations with an interest in the condition
News articles
Research literature
Unique elements: The site contains information for patients who are seeking a second opinion and would like the clinic to review their case.

Comments: The branch provides services to both adults and children with brain tumors.

Cost: Free.

RSS XML link: None.

Keywords: cancer, brain tumor, brain cancer, glioma, meningioma, National Cancer Institute, NCI, National Institute of Neurological Disorders and Stroke, NINDS, Neuro-Oncology Branch.

**RadiologyInfo.org**

www.radiologyinfo.org

Ratings: Content: **** Interface: **** Style: ****

RadiologyInfo.org is the public information website developed jointly and funded by the Radiological Society of North America (RSNA) and the American College of Radiology (ACR). It was established to educate and inform the public about radiologic procedures and the role of radiologists in healthcare.

You can navigate this website using the top-level navigation links. Some of these links expand to reveal additional drop-down options. You can also access featured content on the site’s home page, such as patient safety information. To access the brain tumor information on the site, select Procedures A–Z, then click Brain Tumors.

Key features of this site include:

- An overview of brain tumors
- Information about the treatment options that are available to patients
- A description of what happens during radiation therapy for brain tumors
- A list of the possible side effects of radiation therapy
- Complications and risks associated with radiation therapy
- Research progress regarding brain tumor treatments
- Links to additional resources

Unique elements: The Images/Videos section of the site allows users to search for images and videos of procedures and tests.

Comments: The site contains a glossary of terms in the About Primary Brain Tumors section.

Cost: Free.

RSS XML link: None.

Keywords: cancer, brain tumor, brain cancer, glioma, meningioma, National Cancer Institute, NCI, National Institute of Neurological Disorders and Stroke, NINDS, Neuro-Oncology Branch.
Focus: Glaucoma resources

January is National Glaucoma Awareness Month. Glaucoma is the leading cause of preventable blindness, and everyone is at risk. According to the Glaucoma Research Foundation (www.glaucoma.org), more than 4 million Americans and nearly 70 million people worldwide have the disease. Experts estimate that half of them are unaware that they have the disease.

In addition to offering basic information about the disease, the Glaucoma Foundation site (www.glaucomafoundation.org) contains instructive videos that you can access from the home page. It also contains a helpful guide for patients and their families.

The Glaucoma Research Foundation site (www.glaucoma.org) is also worth visiting. It offers educational booklets, facts, tips for managing the disease, information about assistive technologies, and a list of questions patients can ask their physicians.

A number of glaucoma resources are described and reviewed in the following pages, as listed in the index below, using the five-star system to rate each on content, interface, and style.

American Glaucoma Society
www.glaucomaweb.org
Ratings: Content: **** Interface: *** Style: ***

The American Glaucoma Society (AGS) works to promote excellence in the care of patients with glaucoma and to preserve or enhance vision by supporting glaucoma specialists and scientists.

You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as news articles and event information.

Key features of this site include:
» A link to a directory of pharmaceutical assistance programs
» Meeting information
» Research award information
» A description of the society’s Patient Care Improvement Project
» Statements by the society
» A list of the myths associated with glaucoma and headaches
» An archive of ask-the-expert questions
» Information from the society about eye exam frequency
» Position statements, such as one on the use of marijuana to treat glaucoma
» Answers to FAQs
» Links to additional resources
» Information about the society

Unique elements: The site contains an archive of answers to ask-the-expert questions.
Comments: The site contains a physician locator tool.
Cost: The majority of information on the site is free, with certain areas, such as the Physician Members Only section, reserved for members only. To learn more about membership, click the Become a Member link at the top right-hand side of the site.
RSS XML link: None.
Keywords: glaucoma, eye diseases, optic nerve damage, intraocular pressure, vision loss, blindness, ophthalmology, optometry, American Glaucoma Society, AGS.

American Health Assistance Foundation
www.ahaf.org
Ratings: Content: ***** Interface: **** Style: *****
The American Health Assistance Foundation (AHAF) is a nonprofit organization that funds research that looks for cures for age-related diseases such as glaucoma. The organization provides the public with information about risk factors, preventive lifestyles, available treatments, and coping strategies.
You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as treatment information and resources. To access the glaucoma information on the site, click National Glaucoma Research.
Key features of this site include:
- A description of the disease
- Risk factors associated with the disease and risk reduction advice
- Symptoms associated with glaucoma
- Information about how physicians screen patients for the disease and how they diagnose them
- Common treatments for the disease as well as information about potential treatments that may be used in the future
- Clinical trials resources
- Advice for those living with glaucoma, such as how to cope with everyday life, using low-vision aids, senior housing, and other useful topics
- An ask the expert feature that contains answers to some FAQs
- News articles
- Publications and newsletters
- Medical illustrations
- A recommended reading list
- Event information

Unique elements: The site contains video presentations that help users learn more about the disease. To access them from the Glaucoma section, select Resources, then click Video. Titles include “Glaucoma Risk Factors” and “Glaucoma Symptoms.”
Comments: The site is available in English and Spanish.
Cost: Free. Users can register with the organization to receive e-mails about the foundation and its programs. Click the Register link in the upper right-hand side of the site.
RSS XML link: http://feeds.feedburner.com/GlaucomaQuestionsAndAnswers
Keywords: glaucoma, eye diseases, optic nerve damage, intraocular pressure, vision loss, blindness, ophthalmology, optometry, American Glaucoma Society, AGS.

American Optometric Association
www.aoa.org
Ratings: Content: ***** Interface: **** Style: *****
The American Optometric Association (AOA) represents doctors of optometry, optometry students, and paraoptometric assistants and technicians. It is a federation of state, student, and armed forces optometric associations. The AOA works to provide the public with quality vision and eye care.
You can navigate this site using the top-level navigation links that prompt you to identify your role—doctors, paraoptometrics, and students & educators. Each of these selections
EyeSmart
www.geteyesmart.org

Ratings: Content: ***** Interface: **** Style: *****

EyeSmart is a public awareness campaign that provides information to the public to help them take charge of their eye health. It emphasizes the need for patients to know their risk factors for eye diseases, infections, and injuries. The site also provides information about how ophthalmologists can help prevent, diagnose, and treat eye conditions. The campaign is sponsored by the American Academy of Ophthalmology (AAO).

You can navigate this site using the top-level navigation tabs. You can also click on links on the site’s home page to access featured content, such as eye care resources and brochures. To access the glaucoma information on the site, select Diseases & Conditions, then click Glaucoma on the right-hand side of the page.

Key features of this site include:
» Answers to FAQs about glaucoma
» A description of the disease, including the various types of glaucoma
» Information about how doctors diagnose patients with the disease through testing such as tonometry, pachymetry, and visual field testing
» A breakdown of possible medical and surgical treatment options
» Risk factors associated with glaucoma, such as age, race, family history, and medical conditions
» Clinical practice guidelines

Unique elements: The site contains a number of glaucoma videos on topics such as how fluid circulates, ocular hypertension, surgery, and many others.

Comments: The site also contains a glossary of all eye and vision conditions. The site is available in English and Spanish.

Cost: The majority of information on the site is free, with certain areas reserved for members only. To learn more about membership, click Join AOA in the upper-right corner of the site.

RSS XML link: None.
A list of risk factors associated with the disease, such as age, family history, ancestry, past eye injury, and elevated eye pressure

How physicians diagnose patients with the disease during an eye exam and related testing

A list of potential treatment options such as medication and surgery

Links to additional resources

Unique elements: There are many helpful videos embedded within the glaucoma section.

Comments: The site is available in English and Spanish.

Cost: Free.

RSS XML link: None.

Keywords: glaucoma, eye diseases, optic nerve damage, intraocular pressure, vision loss, blindness, ophthalmology, optometry, American Academy of Ophthalmology, AAO, EyeSmart.

Glaucoma Foundation

www.glaucomafoundation.org

Ratings: Content: ***** Interface: **** Style: *****

The Glaucoma Foundation (TGF) funds research and educates the public about eye disease and the importance of early detection to prevent blindness. Founded in 1994, the nonprofit organization works to eradicate blindness from glaucoma through research and education.

You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as news articles and event information.

Key features of this site include:

- Answers to FAQs
- A description of glaucoma, including its various types
- Information about the eye and how it works
- A description of how physicians diagnose patients with glaucoma, including eye exam information and tests
- Links to additional resources
- A list of factors that put certain patients at greater risk for developing the disease
- Newsletters
- A guide for patients and families
- Grant information
- Information about the foundation
- Links to social networking tools

Unique elements: The site contains educational videos, which you can access from the home page.

Comments: The site allows visually impaired users to enlarge and contrast the text on the site.

Cost: Free.

RSS XML link: None.

Keywords: glaucoma, eye diseases, optic nerve damage, intraocular pressure, vision loss, blindness, ophthalmology, optometry, The Glaucoma Foundation, TGF.

Glaucoma Research Foundation

www.glaucoma.org

Ratings: **** Content: **** Interface: **** Style: ****

The Glaucoma Research Foundation (GRF) funds research and provides educational materials about glaucoma. The foundation’s mission is “to prevent vision loss from glaucoma by investing in innovative research, education, and support with the ultimate goal of finding a cure.”

You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as research milestones and coping strategies.
The Glaucoma Research Society of Canada (GRSC) is a national registered charity that works to fund research into the causes, diagnosis, prevention, and treatment of glaucoma. The society supports new ideas with seed money. It reviews research proposals and awards research grants on an annual basis.

You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as grant information.

Key features of this site include:
- Educational booklets
- A description of eye anatomy
- Information about the types of glaucoma
- Facts about glaucoma
- Information about glaucoma and the brain (researchers now view it as a disease of the brain rather than simply an eye disease)
- Symptoms associated with glaucoma
- Answers to FAQs
- Tips for managing the disease, including creating a medication schedule
- Links to additional resources
- Technologies used by patients with glaucoma
- Information about glaucoma treatments, such as medication, surgery, and alternative medicine
- A list of questions patients should ask their doctors
- Research updates
- News articles

Unique elements: The home page contains a link to the site’s information for the newly diagnosed.

Comments: The site allows users to adjust the site’s viewing options to accommodate their vision needs.

Cost: Free.

RSS XML link: http://feeds.feedburner.com/GRFMainFeed

Keywords: glaucoma, eye diseases, optic nerve damage, intraocular pressure, vision loss, blindness, ophthalmology, optometry, Glaucoma Research Foundation, GRF.

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Glaucoma Research Society of Canada
www.glaucomaresearch.ca
Ratings: Content: **** Interface: *** Style: ****

The Glaucoma Research Society of Canada (GRSC) is a national registered charity that works to fund research into the causes, diagnosis, prevention, and treatment of glaucoma. The society supports new ideas with seed money. It reviews research proposals and awards research grants on an annual basis.

You can navigate this site using the top-level navigation links. You can also click on links on the site’s home page to access featured content, such as grant information.

Key features of this site include:
- Details about current and past research projects
- Information about the research grant process
- Access to the society’s newsletter
- Glaucoma facts
- Information about the disease
- Symptoms associated with glaucoma
- A description of the importance of intraocular pressure
- A glossary of terms

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January 2011

A publication called Glaucoma—A Patient’s Guide to the Disease

Information about available treatment options since there is currently no cure for glaucoma

Answers to FAQs

News articles and event information

Links to additional information

**Unique elements:** Users can take the site’s “Eye Q Test” to find out how much they know about glaucoma. You’ll find the test in the About Glaucoma section.

**Comments:** The site is available in English and French.

**Cost:** Free.

**RSS XML link:** None.

**Keywords:** glaucoma, eye diseases, optic nerve damage, intraocular pressure, vision loss, blindness, ophthalmology, optometry, Glaucoma Research Society of Canada, GRSC.

**National Eye Institute**


**Ratings:** Content: **** Interface: **** Style: ****

As part of the National Institutes of Health (NIH), the National Eye Institute conducts and supports research, training, health information dissemination, and other programs related to blinding eye diseases, visual disorders, mechanisms of visual function, preservation of sight, and the health problems and requirements of the blind.

You can navigate this site using the left-hand navigation links. You can also click on links on the site’s home page to access featured content, such as news articles and event information. To access the glaucoma information on the site, select Health Information, then click Glaucoma.

**Key features of this site include:**

» Facts about glaucoma

» A PDF titled “Glaucoma: What you should know”

» News articles

» Highlights from ongoing and completed research projects

» A diagram of the eye

» Tips for talking to your doctor

» How to find an eye care professional

» Glaucoma photos and images, including an image that shows how someone with glaucoma might view a scene

» Links to additional resources

**Unique elements:** The site contains a quiz that tests how much you know about glaucoma.

**Comments:** The site contains information in Spanish and English. Users can change the text size on the site to accommodate their vision needs.

**Cost:** Free.


**Keywords:** glaucoma, eye diseases, optic nerve damage, intraocular pressure, vision loss, blindness, ophthalmology, optometry, Glaucoma Research Society of Canada, GRSC.

**NIH Senior Health**

[nihseniorhealth.gov](http://nihseniorhealth.gov)

**Ratings:** Content: ***** Interface: ***** Style: ****

The NIH Senior Health site was developed by the National Institute on Aging and the National Library of Medicine as part of the National Institutes of Health. The website features health and wellness information for older adults.

You can navigate this site using the links on the home page. To access the glaucoma information, select G, then click Glaucoma.

**Key features of this site include:**

» A definition of glaucoma

» A list of the potential causes and risk factors associated with the disease

» Symptoms associated with glaucoma
You can navigate this site using the left-hand navigation links. You can also click on links on the site’s home page to access featured content, such as eye safety information. To access the glaucoma information on the site, click Eye Problems, then use the drop-down menu to select Glaucoma.

Key features of this site include:

» Glaucoma news
» A Guide for People with Glaucoma
» An interactive guide that shows patients how to take glaucoma eye drops
» A description of the disease
» Factors that put patients at risk for glaucoma
» Information about how glaucoma damages eyes
» Information about available treatment options
» Advice for living with glaucoma
» Links to financial assistance and vision care resources

Unique elements: The site contains a glaucoma forum where users can exchange information with like-minded individuals.

Comments: The site contains an adult vision risk assessment.

Cost: Free. Users can sign up to receive e-mail updates from the site using the sign-up fields on the site’s home page.

RSS XML link: None.

Keywords: glaucoma, eye diseases, optic nerve damage, intraocular pressure, vision loss, blindness, ophthalmology, optometry, Prevent Blindness America.
SITE OF THE MONTH

Children’s Brain Tumor Foundation
www.cbtf.org

Founded in 1998 and based in New York City, the Children’s Brain Tumor Foundation is a nonprofit organization that works to improve the treatment, quality of life, and long-term outlook for children with brain and spinal cord tumors through research, support, education, and advocacy. The foundation assists both families and survivors.

If you are looking for a brain tumor primer or would like content aimed at parents of the newly diagnosed, visit the About section and click on the link to access the foundation’s free publication, *A Resource Guide for Parents of Children with Brain and Spinal Cord Tumors*. It is currently in its fourth edition. The foundation authored the resource guide to help parents navigate medical procedures, interruptions in school and social life, and the uncertainty that the future may hold.

You can navigate this free website using the top-level navigation links. Some of the links expand to reveal additional menu options. You can also access featured content on the site’s home page, such as news articles, educational resources, and event information.

Key features of this site include:

» Information about the foundation, including its involvement in advocacy efforts, its board of directors, and its staff
» A blog containing topics such as event information, fundraising opportunities, and survivorship
» Information regarding the stages of childhood brain tumors—in treatment; after treatment and survivorship; and loss, grief, and bereavement
» A description of the various treatment options available
» Resources for those looking for emotional support
» Information about the types of childhood brain and spinal tumors, including astrocytoma, ependymomas, gliomas, and optic nerve gliomas
» Advice regarding how to create an educational setting for children with brain and spinal tumors
» Employment information
» Information regarding how brain tumors affect relationships and families
» Brain tumor facts
» Links to additional resources
» Research news and reports
» Publications by the foundation

In addition to these resources, the site’s Find Connections & Support section is home to an online community called Jenna’s Corner. Here, users can connect with others who share similar experiences. It is a way for parents, survivors, siblings, professionals, and others to gain information, peer support, and guidance.

If you appreciate the content on this site, you can sign up to receive an e-newsletter from the association. You’ll find the link to the mailing list within the Support Us section.

RSS XML link: www.cbtf.org/feed

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