



American Brain Tumor Association

## HEALTH INSURANCE

Whether or not you have health insurance, the health care system can be extremely confusing and difficult to navigate. In order to make informed decisions, it is important that you understand your health insurance benefits, your rights as a health care consumer, and the potential options if you want to acquire health insurance. To help, we have developed this resource to acquaint you with the different types of health insurance, common definitions related to your health insurance plan, sources for medical care if you are uninsured, health insurance legislation, the insurance appeal process, advocacy, pharmaceutical assistance, resources for children, and insurance coverage for clinical trials. Our hope is that this resource will clarify many health insurance issues, and provide you with the appropriate information needed to make informed medical decisions.

### TYPES OF HEALTH INSURANCE:

PUBLIC HEALTH INSURANCE: MEDICARE, MEDICAID, SOCIAL SECURITY DISABILITY INSURANCE (SSDI), STATE RISK POOLS, THE MILITARY HEALTH SYSTEM AND VETERAN'S HEALTH ADMINISTRATION PROGRAMS.

### MEDICARE

- Medicare is a federal health program administered by the Centers for Medicare & Medicaid Services (CMS).
- Medicare is available to individuals age 65 and older, to individuals with certain disabilities and receiving Social Security Disability Insurance (SSDI) after a 24 month wait period, and/or to individuals with ESRD (end stage renal disease).
- Medicare includes part A (hospital insurance), part B (medical insurance), part C (Medicare Advantage Plans), and part D (prescription drug coverage).
- State Health Insurance Assistance Programs (SHIP) in the 50 states and several U.S. territories are available for one-on-one assistance. Contact the office [www.medicare.gov](http://www.medicare.gov)

MEDICARE  
THE OFFICIAL GOVERNMENT SITE  
800-MEDICARE (633-4227)

[www.medicare.gov](http://www.medicare.gov)

This website provides comprehensive information about Medicare including eligibility, plan choices, appeals process, and provider information. The toll-free telephone line is available 24 hours/day, 7 days/week. The website and telephone line can also be accessed in Spanish.

MEDICAID

- Medicaid is a joint federal/state program that pays for health care services.
- Medicaid is available to certain low-income individuals and families who meet eligibility guidelines as determined by each state of residence.

CENTERS FOR MEDICARE AND MEDICAID SERVICES

[www.cms.hhs.gov/home/medicaid.asp](http://www.cms.hhs.gov/home/medicaid.asp)

This website provides general information about Medicaid. Contact your state department of human services for more specific information about Medicaid eligibility and the application process.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

- SSDI pays monthly benefits to individuals who are totally disabled (and certain family members) that have worked long enough and have paid Social Security taxes.
- After 24 months of receiving SSDI, beneficiaries become eligible for Medicare.
- Individuals with limited income/assets who are receiving SSDI may also qualify for Supplemental Security Income (SSI).

SOCIAL SECURITY ADMINISTRATION

800-772-1213

[www.ssa.gov](http://www.ssa.gov)

This website provides general information about SSDI, SSI, retirement benefits and the Ticket to Work program. Applications and appeals can be done through the website.

STATE RISK POOLS

- Are created by state legislatures for individuals who have pre-existing medical conditions that make them “high-risk” or “medically uninsurable.”

- Generally, there are no exclusions for coverage.
- Costs may be high and there may be waiting periods, however, state risk pools can make insurance available to those who would otherwise not be able to obtain coverage.
- Not all states have risk pools.
- Eligibility requirements vary from state to state. Contact your State Department of Insurance to locate a risk pool in your state of residence.

NATIONAL ASSOCIATION OF INSURANCE  
COMMISSIONERS (NAIC)  
866-470-6242 (NAIC)

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

NAIC provides links and information on state department of insurance websites which can provide information on state risk pools.

NATIONAL ASSOCIATION OF STATE COMPREHENSIVE  
HEALTH INSURANCE PLANS (NASCHIP)

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

NASCHIP provides educational opportunities and information for state high risk insurance pools. View the NASCHIP website to locate states which have high risk pools.

MILITARY HEALTH SYSTEM

- The health program for active duty service members, their families, survivors, retirees and former spouses is called TRICARE.
- To be eligible for benefits, you must be registered in DEERS- Defense Enrollment Eligibility Reporting System.
- TRICARE brings together health care resources from the uniformed services and the civilian health care system.
- Offers several health and dental plans.

MILITARY HEALTH SYSTEM

[www.health.mil](http://www.health.mil)

The mission of the Military Health System is to provide optimal health services in support of the nation's military mission.

## VETERAN'S HEALTH ADMINISTRATION PROGRAMS

- Those eligible for veteran's health benefits include- Army, Navy, Air Force, Marines, Coast Guard, Reservists and National Guard members who were called to active duty.
- Provides a Medical Benefits Package which includes preventive care services, ambulatory (outpatient) diagnostic and treatment services, hospital (inpatient) diagnostic and treatment services, medications and supplies.
- Offers special health benefits which includes, but not limited to Agent Orange treatment, beneficiary travel reimbursement, dental care, extended care, home health and nursing home care.

## VETERANS' HEALTH ADMINISTRATION (VHA)

877-222-8387

[www.va.gov/health](http://www.va.gov/health)

The mission of the VHA is to serve the needs of America's veterans by providing primary care, specialized care, related medical and social support services. Contact the VHA directly to learn more about eligibility and available programs.

## PRIVATE HEALTH INSURANCE: INDEMNITY PLANS AND MANAGED CARE PLANS

### INDEMNITY PLANS

- Also known as fee-for-service or traditional health insurance.
- Usually indemnity plans offer more flexibility in choosing doctors and hospitals.
- Typically, there is a deductible, the amount of money you must pay before the medical plan starts paying a portion of the bill.
- Indemnity insurance usually pays a portion of the bill usually 80%. The policy holder will then be responsible for the other 20%. This is known as co-insurance.

### MANAGED CARE PLANS

- Have agreements with certain physicians, hospitals and health care providers to provide a range of services.
- Include PPO's, HMO's and POS's.

- PPO's have arrangements with physicians, hospitals and other providers of care. PPO physicians can make referrals, but plan members can also refer themselves to other physicians, including one outside of the plan.
- HMO's provide a list of physicians to choose from to select a primary care physician. The primary care physician coordinates all care and needs to be visited or contacted in order to receive a referral to another physician or specialist.
- POS's primary care physicians in a POS plan usually make referrals to other providers in the plan. Members can refer themselves outside of the plan and can still receive some coverage.

## AMERICA'S HEALTH INSURANCE PLANS (AHIP)

202-778-3200

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

AHIP is a national association of health insurers which provides consumer information on a number of different health insurance plans. The AHIP website also offers resource guides on health insurance and managed care.

## GROUP INSURANCE VS. INDIVIDUAL HEALTH INSURANCE

### GROUP INSURANCE

- Group health plans typically are offered by employers and may be less expensive.
- Can also be available through unions, professional organizations, alumni associations or other possible sources.

### INDIVIDUAL INSURANCE

- Individual coverage is available through an insurance company for those who are self-employed or do not have group health insurance available through their employer.
- Individual coverage can be more expensive since the policy holder is responsible for paying the entire premium.

## OUT-OF-POCKET COSTS DEFINITIONS FOR HEALTH INSURANCE

- Premium- the amount you pay for your insurance- your monthly bill for coverage.

- Deductible- the amount you must pay each year before your medical plan starts paying a portion of the bill.
- Co-pay- the fixed dollar amount that you pay at the time of service.
- Co-insurance- the portion of the expense you pay. For example, your plan may cover 70% and you will be responsible for the other 30%.

## SOURCES OF MEDICAL CARE FOR THOSE WHO DO NOT HAVE HEALTH INSURANCE

### HILL-BURTON FACILITIES

- A small number of hospitals and health care facilities are required to provide low-cost or no-cost medical care to those in need.
- Eligibility is determined by family size and income.
- Funding and sites are limited.
- There are about 200 health care facilities nationwide.

### HILL-BURTON FREE AND REDUCED COST HEALTHCARE HEALTH RESOURCES AND SERVICES ADMINISTRATION 800-638-0742

[www.hrsa.gov/hillburton](http://www.hrsa.gov/hillburton)

In 1946, hospitals, nursing homes and other health facilities were provided grants and loans for constructions and modernization. In return, these facilities agreed to provide health care services to individuals who are unable to pay. For a listing of Hill-Burton obligated facilities, visit the website or call the toll-free telephone number.

### FEDERALLY-FUNDED HEALTH CENTERS

- Provide health care/dental care to individuals of all ages.
- Are available to those without health insurance.
- Payment is based on income- you pay what you can afford.

## HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

888-275-4772

[www.findahealthcenter.hrsa.gov](http://www.findahealthcenter.hrsa.gov)

Search for local centers via the website or the toll-free telephone number. Information specialists are available in English and Spanish.

## LEGISLATION

### COBRA (CONSOLIDATED OMNIBUS BUDGET RECONCILIATION ACT OF 1986)

- Group health plans with 20 or more employees are required to offer continuation of group health insurance coverage for individuals and their dependents.
- Employees qualify for COBRA due to voluntary or involuntary termination or reduction in the number of hours worked. COBRA coverage is available for 18 months after an individual leaves employment or up to 36 months in some circumstances.
- If you become disabled within 60 days of starting COBRA and apply for Social Security Disability Insurance (SSDI), you need to inform your COBRA Plan Administrator within 60 days of being notified of SSDI eligibility. In that event, COBRA can be extended for an additional 11 months. This expansion of COBRA to a total of 29 months will allow you to have continuous coverage until you become eligible for Medicare, which begins 24 months after you become eligible for Social Security Disability.
- Group health coverage for COBRA participants is usually more expensive than health coverage for active employees. This is because the employer typically pays for part of the health insurance premium for active employees. COBRA participants must pay the full health insurance premium.
- Although COBRA coverage can be costly, it can be less expensive than individual health coverage.
- Under the American Recovery and Reinvestment Act of 2009, a 65% reduction in COBRA premiums is available to certain assistance eligible individuals for up to nine months.

UNITED STATES DEPARTMENT OF LABOR  
866-487-2365

[www.dol.gov/dol/topic/health-plans/cobra.htm](http://www.dol.gov/dol/topic/health-plans/cobra.htm)

Provides information on COBRA coverage and the new COBRA subsidy available through the American Recovery and Reinvestment Act of 2009.

## HIPAA (HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996)

- Limits exclusions for pre-existing medical conditions in group health plans to a maximum of 12 months (18 months for late enrollees).
- A pre-existing medical condition is one in which medical advice; diagnosis, care or treatment was recommended or received during the 6 month period prior to an individual's enrollment date.
- HIPAA limits exclusions for pre-existing medical conditions if you have had continuous coverage without a break in insurance coverage for 63 days or more.
- Individuals with a history of prior health care coverage (63 days or less) will be able to reduce the exclusion period by using creditable coverage. Creditable coverage can be used to offset a pre-existing condition exclusion period.
- Creditable coverage includes participation in a group health plan, COBRA continuation coverage, Medicare, Medicaid and coverage through an individual health insurance policy.
- Also prohibits employers who offer group plans from denying or dropping coverage based on an employee's medical status.
- Prohibits discrimination in enrollment and in charged premiums charged to employees and their dependents based on health status-related factors.

EMPLOYMENT BENEFITS SECURITY ADMINISTRATION  
(EBSA)

UNITED STATES DEPARTMENT OF LABOR

866-444-3272 (EBSA)

[www.dol.gov/ebsa](http://www.dol.gov/ebsa)

[www.dol.gov/dol/topic/health-plans/cobra.htm](http://www.dol.gov/dol/topic/health-plans/cobra.htm)

[www.dol.gov/ebsa/publications/yhphipaa.html](http://www.dol.gov/ebsa/publications/yhphipaa.html)

EBSA has benefit advisors available to answer questions and provide assistance about health benefits laws. Contact EBSA directly for more information about COBRA and HIPAA.

## APPEALING AN INSURANCE DENIAL

If your insurance provider will not pay for a certain treatment that your physician believes is necessary, appealing the insurance denial may be a logical next step. Here are some steps to help you through this process:

1. Make sure you understand your health insurance benefits by reading/reviewing your health insurance policy handbook and/or by talking with your benefits manager or human resources representative.
2. Request a copy of the insurance denial and try to understand the specific reason why your insurance company is denying you of this treatment option.
3. Obtain your medical records, supporting documentation from your physician and peer-reviewed articles demonstrating that the treatment is medically indicated and beneficial.
4. Contact your insurance company and speak to a customer service representative or supervisor to file an internal appeal.
5. If you do not make progress over the telephone, write an appeal letter to the insurance company. Talk with your nurse, social worker or patient advocate to find out exactly (word for word) what should be written in the letter. Make sure to include all supportive documentation from your physician and peer-reviewed journal articles that cite evidence for the treatment/procedure.

## ADVOCACY AND INFORMATION

### CANCER LEGAL RESOURCE CENTER (CLRC)

866-843-2572

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

The CLRC is a joint program of the Disability Rights Legal Center and the Loyola Law School. The CLRC provides free and confidential information and resources on cancer-related legal issues. Volunteer attorneys and other professionals are available to provide in depth information and counsel to CLRC callers.

### CENTER FOR MEDICARE ADVOCACY, INC.

860-456-7790 (National Office)

202-293-5760 (Washington DC Office)

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

The Center for Medicare Advocacy provides education, advocacy and legal assistance to help individuals obtain Medicare and necessary health care. The Center is staffed by attorneys, nurses; legal assistants and information specialists which can help answer questions and provide assistance in appealing Medicare denials.

### DIGNITY RESOURCES

877-563-2100

[www.dignityresources.com](http://www.dignityresources.com)

Dignity Resources is a non-profit organization that is dedicated to helping individuals understand their assets and the financial options available by providing confidential, personal consultations via email or telephone. Information is available on COBRA and HIPAA through the website.

### MEDICARE RIGHTS CENTER (MRC)

800-333-4114

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

The MRC provides information and assistance to individuals with Medicare through a toll-free telephone hotline and educational publications. Medicare counselors are available to discuss rights and protections, denials or appeals, complaints about care and treatment and Medicare bills.

NATIONAL COALITION OF CANCER SURVIVORSHIP  
(NCCS)

877-622-7937

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

NCCS is a survivor led cancer advocacy organization which offers a variety of publications and tools for cancer survivors. Contact NCCS directly for their publication, *What Cancer Survivors Need to Know about Health Insurance* or their set of CD's, *Cancer Survival Toolbox* which includes a module for the underinsured or uninsured called, "Paying for Care." Publications are available in English and Spanish and English PDF's can be downloaded through the website.

NATIONAL ORGANIZATION OF SOCIAL SECURITY  
CLAIMANTS' REPRESENTATIVES (NOSSCR)

800-431-2804

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

NOSSCR provides services, information and support to those who are claiming Social Security Disability benefits or need representation. Contact NOSSCR directly for a referral to lawyers who specialize in SSDI. The NOSSCR website provides a helpful section on frequently asked questions about SSDI.

PATIENT ADVOCATE FOUNDATION (PAF)

800-532-5274

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

The Patient Advocate Foundation has a legal resource network where attorneys offer pro bono counsel. Also, the PAF can help to mediate disputes with insurance companies by acting as a liaison. PAF also offers publications on managed care and health insurance appeals.

PHARMACEUTICAL ASSISTANCE/CO-PAY ASSISTANCE  
PROGRAMS

PATIENT ADVOCATE FOUNDATION

866-512-3861

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

Their Co-Pay Relief Program offers co-payment assistance to patients with brain cancer. Program accepts calls beginning the first business day of each month until funds are depleted. Providers can also apply on behalf of their patients online.

GENERIC PRESCRIPTION PROGRAMS

- Are available at many major stores such as Wal-mart, Sam's Club, Neighborhood Market, Target, K-mart, Walgreen's, and Wegman's.

- These programs vary by retailer. For example: some stores offer \$4 generics for a 30 day supply or \$10- \$15 generics for a 90 day supply.
- Contact your local retailer to inquire further about available generic prescription programs in your local area.

#### PRESCRIPTION ASSISTANCE PROGRAMS (PAPS)

- PAP's provide free or discounted medications to the uninsured, underinsured, or those with limited income.
- PAP's are usually sponsored through the pharmaceutical's manufacturer.
- Each program has specific eligibility criteria.
- Online not-for-profit organizations are available to help locate PAP's.

#### NEEDY MEDS

[www.needymeds.com](http://www.needymeds.com)

Needy Meds is a non-profit organization with the mission of helping people who cannot afford medicine or health care costs. The Needy Meds website provides a comprehensive database to search for available prescription assistance programs for both brand name and generic prescriptions. Application forms are also available for certain prescription assistance programs. Needy Meds also provides information about disease-based assistance programs, discount drug cards and government programs.

#### PARTNERSHIP FOR PRESCRIPTION ASSISTANCE (PPA)

888-477-2669

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

PPA provides access to both public and private patient drug assistance programs by providing online links to programs in each state. This website also permits patients to search for prescription assistance programs by prescription name for which they may be eligible.

RX ASSIST  
PATIENT ASSISTANCE PROGRAM CENTER  
401-729-3284

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

Rx Assist is a pharmaceutical access information center created by Volunteers in Health Care (VIH) a national resource center for safety net organizations. Rx Assist provides a comprehensive database of prescription assistance programs with application forms available at the website. Information is also available on low-cost prescriptions, co-pay assistance and Medicare Part D.

TOGETHER RX ACCESS PROGRAM  
800-444-4106

[www.togetherrxaccess.com](http://www.togetherrxaccess.com)

Offers savings on brand name and generic medications for children and adults, who are not covered through Medicare and who do not have public or private prescription drug coverage. To qualify applicants must be under age 65, be a legal resident of the United States or Puerto Rico and meet income guidelines.

#### MEDICARE PRESCRIPTION DRUG COVERAGE

- In January 2006, Medicare Part D, prescription drug coverage, became available to Medicare beneficiaries.
- Part D covers both generic and brand name prescription drugs.
- You will pay a monthly premium, coinsurance and co-pays for prescription drugs which vary by plan.
- If you have limited income and finances, you may qualify for Extra Help. Extra Help will help pay for premiums, annual deductible and co-payments.

ACCESS TO BENEFITS COALITION (ABC)  
202-479-6670

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

ABC provides assistance/information about Medicare Part D Extra Help and other available prescription savings plans to Medicare beneficiaries with limited means.

MEDICARE  
THE OFFICIAL GOVERNMENT SITE  
800-MEDICARE (633-42273)

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

Visit the Medicare website to compare prescription drug plans, enroll in Part D and add/update prescription drug/pharmacy information.

MY MEDICARE MATTERS

National Council on Aging

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

This website provides information on how to choose or switch Medicare Part D Plans.

FOR CHILDREN

CHILDHOOD BRAIN TUMOR FOUNDATION (CBTF)  
877-217-4166

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

CBTF offers an ombudsman program to provide advocacy assistance to parents related to health insurance issues.

FAMILY VOICES (FV)

888-835-5669

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

Family Voices works with families of special needs children to advocate for health care services, provides information on appealing insurance claims, and can put families in touch with health care programs in all states. Contact the FV program in your state for more information.

SCHIP-THE STATE CHILDREN'S HEALTH INSURANCE  
PROGRAM

877-KIDS-NOW (877-543-7669)

[www.insurekidsnow.gov](http://www.insurekidsnow.gov)

The State Children's Health Insurance Program (SCHIP) is a combined federal and state program that provides health insurance for children whose family's income is too high to qualify for Medicaid, but too low to afford private insurance. It is directed at children 18 years of age or younger, who currently have no coverage and whose parent(s) are working. There are SCHIP plans in all 50 states and the District of Columbia.

ST. JUDE CHILDREN'S RESEARCH HOSPITAL  
866-278-5833

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

St. Jude Children's Research Hospital is a health care charity that accepts patients for treatment without regard to family's ability to pay. The child must be referred by a physician and meet protocol eligibility guidelines for a research study.

## INSURANCE COVERAGE FOR CLINICAL TRIALS

- A clinical trial is a research study which investigates new treatments for brain tumors.
- Out-of-pocket costs to a patient in a clinical trial can vary depending on the trial.
- Some insurance companies may not cover an early phase of a clinical trial if the treatment is considered "experimental."
- If you are denied coverage on the basis that the trial is considered "experimental," you can ask your doctor to provide documentation if he/she believes the treatment is medically necessary, citing peer-reviewed studies showing it to be effective in treating brain tumors.
- If your insurance policy does cover a particular clinical trial, it may require that you pay for certain "patient costs" viewed as routine or not specific to the trial itself. Some states have passed legislation requiring health plans to pay the cost of routine medical care you receive as a participant in a clinical trial.

AMERICAN BRAIN TUMOR ASSOCIATION (ABTA)  
800-886-2282

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

ABTA offers a listing of physicians involved in clinical trials. Call us to request this listing.

MEDICARE  
THE OFFICIAL GOVERNMENT SITE  
800-MEDICARE (633-42273)

[www.medicare.gov](http://www.medicare.gov)

Medicare beneficiaries have the option of joining certain clinical trials and will cover some of the patient care costs. Contact Medicare directly to request the Medicare publication, *Medicare and Clinical Trials*.

NATIONAL CANCER INSTITUTE (NCI)

800-422-6237

<http://www.cancer.gov/clinicaltrials/developments/page9>

[www.cancer.gov/clinicaltrials/findtrials](http://www.cancer.gov/clinicaltrials/findtrials)

National Cancer Institute offers information on health care coverage for clinical trials. US veterans and Department of Defense TRICARE beneficiaries can participate in NCI-sponsored clinical trials as part of their health benefits. For more information, visit

<http://www.cancer.gov/clinicaltrials/digestpage/VA-DOD>

This information is not intended as a substitute for professional medical advice and does not provide advice on treatments or conditions for individual patients. All health and treatment decisions must be made in consultation with your physician (s), utilizing your specific medical information. The American Brain Tumor Association does not endorse any of the organizations listed or guarantee that individuals will qualify for the services they provide. Please contact each organization for their specific guidelines.

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