

HEALTH INSURANCE FOR PRIMARY IMMUNE DEFICIENCY: *TAKING CONTROL*



As we are all aware, having a chronic condition, like a primary immune deficiency, can be financially taxing. If therapy is not administered on a regular basis, the cost of complications and subsequent hospitalizations is burdensome.

HEALTH INSURANCE FOR PRIMARY IMMUNE DEFICIENCY: *TAKING CONTROL*

As we are all aware, having a chronic condition, like a primary immunodeficiency, can be financially taxing. If therapy is not administered on a regular basis, the cost of complications and subsequent hospitalizations is burdensome.

Most individuals with primary immune deficiency rely on private third party payers to assist them with these expenses, but often are frustrated when faced with the overwhelming task of paperwork, phone calls, and other issues, simply to justify the use of a therapy prescribed by their physician.

In addition, looking for health insurance and understanding the maze of issues involved can be an overwhelming process that can often lead to feelings of isolation and helplessness. The purpose of this chapter, while not designed to solve each and every health insurance problem, is to prepare you with some of the information you will need to be your own best advocate.

Most of the information that follows is practical. We begin by describing the various payers, what they cover and whom they serve. Next, you will learn about what to look for when changing insurance coverage, a very important issue when a chronic condition is involved! We will also review The Health Insurance Portability and Accountability Act of 1996 (HIPAA), one of the most important federal laws enacted within the past decade regarding protection for you and your family's health insurance coverage when faced with life events. You will read about other features that you should have a general working knowledge of, like COBRA, a name for extended benefits.

Other hands-on information follows with how to prepare yourself to face your insurer confidently with questions about your coverage. And last, but not least, as in

every profession these days, health insurance has its own "language." We will arm you with a glossary of terms so that you will feel confidently "bilingual."

When it comes to your health coverage, never hesitate to ask lots of questions and search for as many resources as possible. Your well-being and that of your family relies on it!

WHO ARE THE "PAYER PLAYERS?"

In order to best prepare for working with your health insurer, you must understand who the various "payer players" are in the scheme of things.

MEDICARE

Medicare is a federal health insurance program which provides coverage for people over the age of 65, blind, disabled individuals, and people with permanent kidney failure or end-stage renal disease. The Medicare program is administered by the Health Care Financing Administration (HCFA) and pays only for medical services and procedures that have been determined as "reasonable and necessary". Medicare is divided into two parts - Parts A and B. Part A covers inpatient hospital services and certain follow-up care. This includes the cost of lab tests, x-rays, nursing services, meals, semi-private rooms, medical supplies, medications, necessary appliances, and operating and recovery rooms.

Medicare Part B covers physicians services and other medical expenses. Unfortunately, neither prescription drugs nor home infusion of IGIV is covered. Beneficiaries must pay a monthly premium and a small deductible each year for all approved services covered under Part B.

For most of these services, Medicare pays 80% of the bill and the beneficiary pays the 20% co-payment. You must first have Part A before receiving Part B. If you apply for Social Security disability, you will receive Medicare benefits after being on disability for two years.

In many states, people covered under Medicare have the option of choosing between managed care and indemnity plans.

MEDICAID

Medicaid is a welfare program sponsored by both the federal and state governments, which is administered by the individual states. Coverage varies from state to state although each of the state programs adheres to certain federal guidelines.

Medicaid enrollment criteria also vary from state to state, but coverage is usually available only to those who are not eligible for any other type of health insurance, and meet poverty guidelines. Each state has a predetermined income level that an individual or family must meet in order to qualify for Medicaid benefits. The local office of the State Department of Social Services is responsible for reviewing applications and managing eligibility requirements. Some states require Medicaid beneficiaries to join managed care plans.

Medicaid programs may require prior authorization for certain forms of treatment or prescription drugs. This means that your physician must contact Medicaid to obtain approval for reimbursement of the treatment before you receive it.

STATE ASSISTANCE PROGRAMS

Your state may have a special assistance program for particular chronic conditions. Most of these programs are funded by state and local budgets and are designed to meet the needs of adults and/or children who are not eligible for any other medical coverage.

They may also serve as a secondary or supplemental coverage to Medicaid. The level of coverage available will change

according to such variables as state needs and available funding. These programs may be identified under such names as Children with Special Health Care Needs, Crippled Children's Services, or Children's Medical Services.

Coverage for children with a Primary Immune Deficiency may be severely restricted or not available at all. It is best to check with your local sources at information for eligibility information before considering this as a coverage option. SSI or Supplemental Security Income makes monthly payments to aged, disabled, and blind people with limited income and resources.

Disabled children as well as adults may qualify for SSI payments. Eligibility and benefits vary by state, but more information can be obtained by contacting your local Social Security Office listed in the White Pages of the phone book.

STATE CHILDREN'S HEALTH INSURANCE PROGRAM (SCHIP)

As part of the Balanced Budget Act of 1997, Title XXI (or SCHIP) of the Social Security Act was passed in late 1997. The State Children's Health Insurance Program gives grants to states to provide health insurance coverage to uninsured children up to 200% of the federal poverty level (FPL). States may provide this coverage by expanding Medicaid or by expanding and creating a separate state children's health insurance program. The program's primary purpose is designed to help children in working families with incomes too high to qualify for Medicaid but too low to afford private family coverage. Although benefits vary from state to state, children generally are eligible for regular check-ups, immunizations, eyeglasses, doctor visits, prescription drug coverage, and hospital care. Based on income levels states can impose premiums, deductibles, or fees for some services. Since coverage and benefits do vary from state to state, it's important that families investigate the options available in their respective state. For more information

regarding eligibility and coverage you can call 1-877-Kids-NOW (1-877-543-7669).

THIRD PARTY INSURERS

Third party insurers offer various types of plans; for example, fee-for-service plans or 80/20 plans are normally obtained through your employer. The services covered by the policy will vary depending on your employer, so read the summary of benefits carefully, especially the exclusionary language.

The beneficiary is free to choose his or her own provider. A premium is paid for coverage by the beneficiary, the employer, or the cost is shared. The beneficiary is usually responsible for an annual deductible before the insurance coverage becomes effective. Once the deductible is met, the plan pays a portion of the bill - normally 80%. The beneficiary is then responsible for the remaining 20%, which is called a co-payment. These co-payments, premiums, deductibles, and co-insurance amounts are considered out-of-pocket expenses. Consumers may also incur out-of-pocket expenses for some products or services not covered by their health care plan, such as over-the-counter drugs.

PREPAID/MANAGED CARE

These plans cover medical services provided by "participating" physicians. Premiums are paid in advance for most covered services, depending on the nature of the problem. Group practice health maintenance organizations or HMOs cover you only if you go to HMO affiliated health care providers (doctors, labs, hospitals) for all your health needs.

You may go to one central facility for your care, or you may visit an HMO-affiliated physician at his or her office. When you join an HMO you must choose a primary care physician (PCP) who is responsible for controlling a large portion of dollars spent in a managed care organization. Your PCP will be the person who orders lab tests, CT scans, MRI scans, and dozens of other tests when diagnosing illnesses. It is also

the primary care physician who will determine whether a patient's condition requires the care of a specialist. As a healthcare consumer, you must make sure that you are comfortable with your PCP, and that he or she understands you or your child's illness, and the medical care associated with that illness. Remember that most PCP's are general practitioners, family practitioners, and internal medicine physicians, not specialists.

There are also preferred provider organizations or PPOs. These plans are similar to HMOs in that members pay a set amount each month for health care services. A group of physicians or other types of health care providers contract with the PPO, to provide services to members. These plans offer greater flexibility of choice of provider. Under most situations, a PPO offers a financial incentive, in the form of the percentage of co-payment, for the patient to use a participating provider. The co-payment may be set at 90/10, for example. If, however, the patient sees a provider outside the network, the co-payment for the patient may increase to 70/30.

YOU, THE CONSUMER

It is important to consider specific issues when deciding on a health insurance policy. You should compare:

- The lifetime maximum
- Any pre-existing condition waiting period
- Out-of-pocket cost including premium cost sharing, deductible, and co-payment
- Inadequate or no coverage

Your lifetime maximum will differ according to the health coverage you have. Most LTMs will range from \$250,000 to \$1 million. Once you have exhausted your LTM, you no longer have health coverage,

so it is wise to keep a running total of the major expenses that affect it: hospitalizations, surgeries, annual cost of drug therapy, etc. Also, know the difference between elective and required procedures and plan accordingly, as these costs most likely will go against your lifetime maximum.

The pre-existing condition waiting period is an amendment to your coverage that states that if you have a chronic condition, or are, for example pregnant, you're subject to a waiting period before your benefits cover you for that "condition".

Look for a pre-existing condition waiting period clause in the summary of benefits booklet.

Out-of-pocket costs are those co-payments, deductibles, or premium cost sharing expenses you may incur to meet your financial obligation under the plan. These were reviewed under the previous payer section. Language in your health policy can differ. It can be explicit or vague, so knowing what to look for is important. You must always check the exclusionary language in your summary of benefits booklet. Finally, if you are considering signing up with an HMO, but you are concerned because you may have to change to a different doctor, check with others who are members to ask about their level of satisfaction.

Ask such questions as: How are chronic conditions like primary immune deficiency covered within the plan? What about referrals to specialists? What are the procedures? Do they have restrictions on prescription drugs?

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996 (HIPAA)

As we had mentioned earlier in the introduction, probably one of the most important and encompassing federal laws affecting the health insurance industry was the passage of HIPAA.

We all are susceptible to a variety of

events in life, which may affect your health insurance coverage. Situations such as the onset of a chronic illness or disabling disease, to changing jobs or a business closing can have adverse consequences when locating or attempting to keep your health insurance coverage. HIPAA protects health insurance coverage for worker's families when they change or lose their jobs. Due to the fact that the HIPAA law is very complex and contains many more provisions than indicated in this writing, we recommend that for further information on how HIPAA can affect you or your family, contact your employer's benefits administrator or your State Insurance Commissioners office.

KEY Provisions:

- Group Health Insurance - Employees can credit time spent under their previous employer's plan satisfying a pre-existing exclusion towards the new employer's plan, as long as they do not have more than a 63 day break between coverage.
- Moving from Group Health to an Individual Health Plan - If you are no longer eligible for Group coverage, you are able to obtain coverage with an Individual health plan, which includes HMO's if:
 - You have an aggregate 18 months or more of previous coverage under a group health, government or church plan;
 - You have had no lapse in coverage longer than 63 days;
 - You are not eligible under another group plan, Medicare or Medicaid;
 - You do not have any other health insurance coverage;
 - You have elected and exhausted any eligible COBRA coverage;
 - You were not terminated from your most recent prior coverage due to non-payment of premiums or fraud.

Be aware that your state law may pro-

vide for greater protection than HIPAA, but not less than the minimum requirement mandated by the HIPAA law.

COBRA

COBRA or the Consolidated Omnibus Budget Reconciliation Act was enacted into Federal law in 1985. Should you leave your job for any reason other than gross misconduct, your employer is required under the law to offer you continuing health benefits for a period of time - the same benefits you were receiving while you were employed.

Small employers (less than 20 employees) church groups, and the federal government are exempt from COBRA legislation. Federal employees however, are not without help. Those employees should contact the personnel office servicing their agency for more information on temporary extensions of health benefits.

You are responsible for paying the premium, which is usually kept at 102% of what your employer was paying on your behalf. (The 2% is for administrative fees). For job termination or a reduction in hours, COBRA's duration is normally 18 months. In the case of a divorce, separation or death of a spouse, COBRA may be available for up to 36 months. If you are deemed disabled by Social Security within 60 days of your termination of employment or reduction in hours of employment, you are able to extend the COBRA continuation period from 18 months to 29 months. This extension is granted under the HIPAA federal legislation we spoke about earlier. The extended period of time offered is designed to protect you until you become eligible for Medicare, since there is a 29 month waiting period before you can receive Medicare benefits.

When these situations, known as "qualifying events," occur, it is your responsibility, as the employee, to notify the human resources department of your employer (that person or group responsible for medical insurance) within 60 days or you lose the option.

For further information on COBRA coverage and your rights under COBRA law, you should contact the human resource department or the benefits manager within your organization or call your local department of labor.

HIGH RISK POOLS

High-risk pools provide coverage for individuals whose medical conditions have prevented them from obtaining private health insurance and those who may not qualify for government or state assistance. At this writing, high-risk insurance pools are now available in 29 states. While the operation of plans varies considerably from state to state, there is a basic pattern.

The state generally forms an association of all health insurance companies doing business in the state. One organization is selected to administer the plan under the guidelines for benefits, premiums, deductibles, etc., as set forth under state law. Individual policies are available through the risk pool and are subject to the very same restrictions as private, third party insurance.

So do not be surprised if you see co-payments, deductibles, lifetime maximums, and pre-existing condition waiting periods. Coverage usually includes physician and inpatient hospital services, home health care, skilled nursing care and prescription drugs. If high-risk insurance is available in your state, be sure to inquire about eligibility requirements and the specific benefits which are covered. There can be waiting lists for enrollment in these programs in some states.

WORDS TO THE WISE

As you've repeatedly just read, it is very important for you to be your own best

advocate when dealing with your health plan. First, read your policy and then ask your personnel department, the IDF, and any other resource you can find lots of questions. Try to keep current information concerning the new rules affecting your policy.

Review your medical bills to check for mistakes. (Billing errors occur more often than you would think!) Keep important information such as your policy number, your ID number, insurer's address and phone number, and doctor's address and phone number in one place to refer to whenever you communicate with your insurer. If there's a possibility you might reach your lifetime maximum, please explore the alternatives before your maximum runs out.

Many employers offer open enrollment once a year when you may change your coverage to another plan offered by your employer. Ask your employer if and when an open enrollment period is offered. If you have difficulty getting benefits through your employer, consider coverage through associations, schools, professional groups, farm groups, or local chambers of commerce. You may qualify for individual or group benefits. Document each time you contact your insurer. Get the full name and title of each person you talk with. This information will be important if you experience difficulties with your coverage and need to document your situation in writing. If your problem becomes more complicated, don't panic.

You may appeal to the medical director of the insurance company and may need to work with the provider to submit additional justification of your claim. Often, in the case of primary immune deficiencies, insurers need to be educated as to what the condition is and what the approved forms of treatment are. Most of the manufacturers of intravenous immune globulin (IVIG) offer reimbursement support services for their products and should be an excellent source of information.

The IDF can refer you to these sources. There may come a time when an insurance

company terminates your policy. If it does for any other reason than bankruptcy, they are required by state and federal law to find you new coverage. Enforcing this law is up to the State Insurance Commissioner. You should contact them especially if you feel your cancellation is due to a pre-existing condition. Arbitrary cancellation is illegal.

CONCLUSION

You could spend a major portion of every waking day working on coverage and reimbursement issues for yourself or your family. Some of you are fortunate enough to never experience problems. Others of you are in an endless search for coverage or adequate reimbursement. While we do not assume to have provided all the answers to your questions in this section, we hope you have picked up a few, bits of information. Never hesitate to seek assistance from resources. There is no such thing as a stupid question when it comes to you or your family's well being.

GLOSSARY OF INSURANCE TERMS

ASSIGNMENT OF BENEFITS: A written authorization by the patient/insured to make payment to the provider of services (hospital, physician, home care company, etc.) directly.

BALANCE BILLING: If a provider chooses not to accept assignment, he or she can "balance bill" the patient for the portion of the charge not recognized by Medicare.

BASIC BENEFITS: Refers to the portion of the insurance policy which generally provides coverage for inpatient services: room and board, surgery, drug therapy, physician services, etc.

BENEFICIARY: A person entitled to insurance benefits under the insurance plan; a patient.

“CAP”: The maximum length of time or dollar amount that a plan will continue to pay benefits; also referred to as “contract maximum.”

CARRIER: A private insurer that contracts on a regional basis with the Medicare program to process and pay claims. Also a term generally to describe an insurer.

CHARGE-BASED: Reimbursement based upon billed fees for physician’s services.

CLAIM FORM: Requests for payment are submitted to insurers on claim forms. Claim forms include spaces for showing the patient’s name and address, diagnosis, documentation of medical necessity and kinds of services received.

CODING: Several coding systems are used to describe patients and the services they receive in the health care system. These are used on medical records and billing forms.

CO-PAYMENT: A percentage of medical costs which the patient is required to pay, usually up to a certain limit.

COST-BASED: Reimbursement methodology typically used to pay institutions on the basis of accounting cost audits. The books of the provider are examined in an effort to avoid paying profits and unallowed items.

COVERAGE: The products and services your health plan is willing to pay for.

DEDUCTIBLE: A flat amount that the patient is automatically responsible for paying before the insurance plan begins to pay benefits.

EFFECTIVE DATE: The date that coverage begins for the insured.

ELIGIBILITY: The screening method used by an insurance company or government program to determine whether the patient qualifies for benefits.

EXCLUSIONS: Illnesses, injuries, devices, procedures, or conditions for which the policy will not pay.

EXPLANATION OF MEDICAL BENEFITS:

This form is sent to patients to report on the status of their insurance claim. It outlines the services for which a bill was received, describes whether the service is covered and delineates the reimbursement that will be made for the service or product.

FEE-FOR-SERVICE: A predetermined charge for a given medical service.

FEE SCREEN: Many insurers established a price cap, also called a fee screen, on the total they will pay for a service or product.

GROUP HEALTH INSURANCE: An arrangement for insuring a number of people under a single, master insurance policy.

HEALTH CARE FINANCING ADMINISTRATION: A branch of the federal government’s Department of Health and Human Services that administers the Medicare program.

HEALTH MAINTENANCE ORGANIZATION (HMO): A prepaid health plan that provides comprehensive benefits using certain health care professionals, at times in specified locations, generally within certain geographic areas.

HEALTH INSURANCE AND PORTABILITY ACT OF 1996 (HIPAA): Guarantees availability of individual health insurance coverage without pre-existing limitations to certain individuals who have lost group coverage.

INDIVIDUAL INSURANCE: Policies that provide protection to the policy holder and/or his or her family. Sometimes called personal insurance as distinct from group insurance.

INSURED/POLICYHOLDER: The person for whom the insurance policy is registered under.

LIFETIME MAXIMUM: The maximum amount that the insurance company will pay for medical expenses. This amount may be listed as the maximum amount for

each illness or condition. Or it may be listed as total costs paid from a portion of a policy; e.g. inpatient expenses vs. outpatient.

MAJOR MEDICAL: Refers to the portion of the insurance policy which usually provides coverage for outpatient services: doctor's office visit, outpatient pharmacy services, factor concentrate home therapy, etc

MEDICAID: A federally and state funded program for low-income people. Eligibility criteria will vary by state but are usually tied to income and assets.

MEDICAL NECESSITY: In order to be financed by an insurer, a service must be medically necessary.

MEDICARE: A federally funded medical insurance program for people age 65 and over, individuals with end stage renal disease, or those who qualify for Social Security disability.

OPEN ENROLLMENT: A time period when a person can obtain insurance coverage or change insurance carriers without penalty for a pre-existing condition. This opportunity may be available from some employers on an annual basis.

OUT-OF-POCKET EXPENSES: Those medical expenses that an insured must pay that are not covered under the group contract.

PRE-EXISTING CONDITION CLAUSE: Any medical, obstetrical or psychiatric condition that the patient had at the time the plan became effective. If your plan contains this clause there is usually a defined waiting period beyond the effective date of the plan before the plan will make payment for treatment of the preexisting medical condition.

PREFERRED PROVIDER ORGANIZATION (PPO): A group of health care providers (physicians, hospitals, and other providers) located within a specific geographical area that have contracted with an entity (a physicians' group or hospital, for example) to provide health care services.

PREMIUM: The payment a subscriber must pay in order to maintain medical benefits.

PRIMARY CARE PHYSICIAN (PCP): The network physician designated by an employee (and each of his or her dependents) to serve as that employee's entry into the health care system. The PCP often is reimbursed through a different mechanism (such as capitation) than are other network providers. This physician sometimes is referred to as the "gatekeeper."

PRIMARY COVERAGE: The insurance plan that is required to pay benefits first based on state and federal insurance regulations.

PROVIDER: Refers to any party that delivers health care services. For example, can be used to describe doctors, hospitals, or suppliers.

REIMBURSEMENT: The amount the plan pays for a particular product or service. Your plan may reimburse the full amount charged by your doctor, pharmacy, or hospital; or it may reimburse a percentage or set amount.

SECONDARY COVERAGE: An insurance plan that is required to pay benefits after the primary plan has paid or denied payment for medical expenses.

STOPLOSS/OUT-OF-POCKET EXPENSE: The maximum amount of money an insured individual is required to pay (as a deductible or co-pay) before the plan will pay benefits at 100 percent.

UTILIZATION REVIEW: The process of evaluating the appropriateness, necessity and quality of medical care for purposes of insurance coverage.

REFERENCES: *Guide to Health Insurance. The Health Insurance Association of America, Washington D.C., 1997.*

Choosing and Using a Health Plan. U.S. Department Health and Human Services and the Health Insurance Association of America. AHCPR Publication No. 97-0011, March 1997.