



for People with ITP

Health Insurance and Assistance Programs for ITP Patients

FREQUENTLY ASKED QUESTIONS



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Introduction

Whether you have been recently diagnosed with immune thrombocytopenic purpura (ITP) or another platelet disorder, or you are a chronic sufferer; it's bad enough to have the disease, and even worse to be additionally stressed by a bewildering maze of health insurance policies, procedures and regulations, as well as having to cope with the resulting health care costs. Layer onto this the current uncertainties surrounding health care in the United States because of the current legislative activities of the U.S. Congress and state governments, and you have an environment that can tax even the most patient soul.

The objective of this booklet is to offer some help, some guidance, and some hope. We don't have all the answers, and since things often change daily, new questions often arise. We have chosen a Web-based format so that we might be more agile. PDSA seeks to get you the information you need quickly. Please watch the PDSA Web site for updates: www.pdsa.org

Until recently there was a patchwork of insurance coverage available in the U.S. Some patients had good coverage, some had partial or incomplete coverage, and some had no coverage at all. Historically, costs for health care insurance have increased and this has left many patients without adequate coverage. Although the U.S. Congress has worked on legislation to improve the situation, it may still be years before many patients see much improvement. Thus, the need for a patient guide now.

This booklet would not be possible without the help of our ITP community. They provide regular constant feedback to PDSA on health insurance and financial approaches that have worked. We would also like to acknowledge Amgen, who has been kind enough to sponsor publication and updates of this patient guide.

When a patient is diagnosed with ITP or another platelet disorder, their first concern is to receive treatment to stop or prevent bleeding problems. Sometimes with little warning a patient can learn they have a very low platelet count and find themselves admitted to their local hospital for tests and treatment. Their ITP may go into remission or it may recur, necessitating further testing and treatment. This booklet provides guidance for ITP patients and their families as they face the many uncertainties of a chronic illness and health insurance. It provides answers to many questions pertaining to costs and insurance issues for patients with ITP.

Q In what ways do ITP patients face health care cost concerns?

A Patients with ITP may face months or years of ongoing medical care for the disorder. For those with chronic ITP, the ongoing care and various treatments can become costly for them and their families. For most patients these financial concerns add an additional level of stress to coping with a chronic disorder.

Q What are the key insurance problems faced by patients with ITP or other platelet disorders?

A The key areas where these patients may face problems as they cope with their platelet disorder include:

- No insurance coverage
- Not enough insurance
- Inability to afford co-pays for drugs or treatments
- Insurance coverage that is not allowed or is denied
- Long-term, chronic illness that requires ongoing treatment and costs
- Coverage uncertainties when traveling away from home and to other countries

Q What are the main costs that can occur when a patient has ITP or other platelet disorders?

A The most likely medical care costs for ITP patients include the following:

- Regular office visits to their local doctor and to hematologists (blood specialists).
- Diagnostic tests for ITP, including complete blood counts (CBCs), bone marrow tests, and sometimes additional blood tests. Blood counts are necessary to determine if the patient has a safe level of platelets.
- Hospitalization to bring serious bleeding under control and treatment to raise their platelet level. A patient's time in the hospital can vary from as little as a couple days to more than a week at a time.
- Treatment, which may be short term, long term, or recurring as needed (such as IVIg infusions or WinRho®) on an ongoing basis. With chronic ITP this is an ongoing financial concern. In some cases treatment may include surgery to remove the spleen (splenectomy).
- Pharmaceutical drugs/medications to help raise platelet counts, such as corticosteroids; immunoglobulin, such as IVIg; Anti-D, such as WinRho®; rituximab, such as Rituxan®; or new platelet growth factor drugs, like Nplate® or Promacta®.

Types of Insurance Coverage

Q What are the basic types of medical insurance coverage for patients?

A The term ‘health insurance’ refers to a wide number of insurance policies. These policies may cover the costs of seeing their regular doctors and hematologists, hospital visits, surgery, outpatient visits for treatment, payment for ongoing long-term care, and medications. There are four main types of coverage:

- Fee-for-service This is the typical health insurance coverage provided to an employee by their employer. Some refer to it as a major medical or comprehensive policy.
- Managed care There are three main types of managed care plans, including health maintenance organizations (HMOs), preferred provider organizations (PPOs), and point-of-service (POS) plans.
- Self-insured These are health insurance plans set up by private employers. They are generally very efficient and provide good health benefits to their employees.
- Medicare and Medicaid Medicare is the U.S. federal program of hospital and medical insurance designed specifically for patients aged 65 and older who are not covered by an employer’s plan.

Q How does fee-for-service work?

A With fee-for-service, the patient goes to the doctor(s) of their choice and either the patient or their doctor submits a claim to their insurance company for reimbursement. The patient receives reimbursement for what are called “covered” medical expenses, which are listed in the insurance benefits summary. The amount of the covered charge that will be reimbursed depends on the provisions of the insurance policy concerning coinsurance and deductibles.

In general, most fee-for-service plans cover 80 percent of the doctor or medical bills termed “reasonable and customary”. The patient pays the other 20 percent of the cost, which is their “coinsurance”. If the doctor or hospital’s charges are more than the “usual and customary” for that region, the patient will have to pay the difference. Many fee-for-service plans pay hospital expenses in full, while some reimburse at the 80/20 level explained above. (1) [See references on back page]

Q What about deductibles?

A Deductibles are the part of the covered expenses that the patient must pay yearly before the insurer begins to reimburse for medical costs. The average deductible ranges from

\$100 to \$300 per person per year, or sometimes \$500 or more per year for a family. In general, the higher the deductible paid by the patient, the lower their insurance premiums. We recommend that you check with your insurance company.

Q How does managed care work?

A Generally, managed care provides comprehensive health services to its members. It also provides financial incentives for patients to seek care from providers who are in the managed care plan. For example, when a patient joins a Health Maintenance Organization (HMO), they will pay a monthly or quarterly premium and it will be the same whether the member uses the HMO's services or not. Co-pays of \$10 - \$20 may be charged for certain services, such as an office visit.

Managed care plans often have a medical facility that employs doctors, nurses and other medical personnel who treat patients enrolled in the plan. HMO patients have a primary care physician, responsible for referring the patient to specialists if needed. HMOs have contracts with doctors, labs, and hospitals, with negotiated prices for services.

Q What about Preferred Provider Organizations (PPOs)?

A A PPO is a type of managed care health plan that combines some aspects of the fee-for-service plan with the savings of an HMO. With a PPO the patient is likely to receive some reimbursement if they receive care from a provider who is outside the PPO plan. PPOs have contracts with doctors, clinics, labs, and hospitals and have negotiated set fees with these providers. When patients get their care from these PPO providers, the providers may not request additional payment beyond the negotiated amount. However, many patients must pay a co-pay or a percentage when they receive care.

Q What does self-insured mean?

A Some large employers (usually those with thousands of employees) operate their own health insurance plan. They pay a third party, such as an insurance company, to administer the plan. The employer pays the costs (claims plus administration) directly from the company's own finances.

Certain federal laws apply to self-insured plans. These self-insured plans create rights and obligations under the Employee Retirement Income Security Act of 1974 (ERISA). Under ERISA, self-funded health plans are exempt from state insurance regulations. If a patient has difficulties with a plan that is not state-regulated, they should speak to an attorney specializing in health law. More details about ERISA are here: <http://webapps.dol.gov/dolfaq/go-dol-faq.asp?faqid=225>

Q What are Medicare and Medicaid?

A Medicare and Medicaid are federal and state programs that provide healthcare for the elderly, the disabled, and some children of parents with extremely low income levels.

Costs of premiums for Medicare Part B have increased in the past several years. In 2,000 a typical premium was \$46 per month, in 2005 it was \$78 per month, and in 2008 it was \$96 per month. In 2014 the premium was \$104.00. These increases have made it more difficult for patients on Medicare to pay their premiums. (2) Additional changes in Medicare and Medicaid coverage are expected to occur once the U.S. government health care plan is determined by the U.S. Congress. Watch the PDSA Web site www.pdsa.org for updates. Information about Medicare Part B premiums is available here: <http://www.medicare.gov/your-medicare-costs/costs-at-a-glance/costs-at-a-glance.html>

For general Medicare information, ordering Medicare booklets, and information about health plans, contact 1-800-MEDICARE (1-800-633-4227) 24 hours a day, 7 days a week for assistance. English and Spanish-speaking customer service representatives at this number can answer questions. Their Web site is <http://www.medicare.gov/>.

Medicaid is a state administered program. Each state sets its own guidelines regarding eligibility and services. This link shows benefits available to patients in each state in the U.S.: <http://www.benefits.gov/benefits/browse-by-state> For further information, contact your local state health department or go to www.benefits.gov, and in the Benefits Quick Search box, select “Medicaid/ Medicare”. This will give contact information and phone numbers for state and local health departments. Medicaid’s Web site is <http://www.cms.hhs.gov/MedicaidGenInfo/>.

Understanding Insurance Coverage Terms

Q What about a patient’s pre-existing conditions?

A Some health care plans previously have barred insurance coverage for “pre-existing conditions”. However, federal law now limits some of these exclusions or the length of time that a person can be denied coverage for a pre-existing medical condition. Under the new healthcare plans developed by Congress, additional limits for exclusions based on pre-existing conditions have become law the past year. Details of new laws about pre-existing conditions is here:

<https://www.healthcare.gov/health-care-law-protections/pre-existing-conditions/>

Q What can patients do if coverage is denied because of a pre-existing condition?

A Many patients would love to get “group insurance” under which a patient cannot be denied coverage because of a pre-existing condition, such as ITP. However, millions of people cannot get such coverage through a job for a variety of reasons. Some are self-employed or their employer doesn’t offer health insurance, and some patients are simply too sick to work. In a CNNhealth.com article, the Kaiser Family Foundation reported that over 20 percent of people who applied for health insurance on their own got turned down, were charged a higher premium, or were offered a plan that excluded coverage for their pre-existing condition(s). (3) [See reference at back]

In the same article, a state health care advocate in Connecticut suggested the following options for what to do when you have a pre-existing condition and have not found coverage:

- **Become a group of one.** In about 12 states you can become a group of one all by yourself for insurance purposes. In effect, you become like other companies, and insurers cannot deny you insurance or charge you higher premiums because of your pre-existing condition(s). To accomplish this, people open their own business such as landscaping or graphic design. To learn if your state will allow you to become a group of one, view this list from the Kaiser Family Foundation:
<http://kff.org/statedata/>

In some states where you can't become a group of one, you can become a group of two, by hiring your brother-in-law or niece to join your business. Note that under the group of one or group of two plans, you might still be unable to get coverage for a pre-existing condition but the exclusion is limited to the first six months of the coverage.

- **If you've been laid off from your job, be sure to sign up to get COBRA.** Although COBRA (Consolidated Omnibus Budget Reconciliation Act) insurance coverage is extremely expensive it is important to find the money to pay for the premiums. If you do not have a job, it can be difficult, if not impossible, to get health insurance any other way. COBRA offers the opportunity to extend your current insurance plan coverage for 18 to 36 months after your employment ends.

To qualify for coverage, individuals must experience a COBRA qualifying event that is the involuntary termination of a covered employee's employment. This event can include termination of the employee's employment for any reason (except gross misconduct) and reduction in hours of employment. . More details are available on the Department of Labor Web site:

<http://www.dol.gov/ebsa/faqs/faq-consumer-cobra.html>

If you lose your employer-related insurance, apply for new insurance within 60 days. In all states there is a designated "insurer of the last resort". It has to take all comers (using insurance lingo). You must apply for this coverage within 60 days of losing your group coverage. For a detailed explanation, visit the Families USA Web site: <http://familiesusa.org/>

- **Find out if your state offers an insurance high-risk pool.** These high-risk pools are designed specifically for patients with pre-existing conditions who have been unable to find affordable insurance. In 2014 30 states have high-risk pools. However, in mid 2014 some of those states are planning to cancel their high risk coverage plans as patients transition to health care through the Affordable Care Act (ACA). See details at this link:
<http://www.ncsl.org/research/health/high-risk-pools-for-health-coverage.aspx>

The American Diabetes Association lists those states on its Web site. Visit their Web page: <http://www.diabetes.org/living-with-diabetes/health-insurance/options-for-individuals-and-families.html>

- **Learn whether your professional organization offers health insurance.** Many professional groups, such as those that represent teachers, writers, real estate agents, and other professions, offer health insurance. Check to find out if your professional organizations offer such coverage.

Q What is not covered under most insurance plans?

A A number of medical items and services will generally not be covered under various insurance plans. These uncovered items and services may include: eyeglasses, contacts, and hearing aids (which are considered ‘budgetable expenses’), elective cosmetic surgery, and experimental procedures or treatments.

What is not covered will vary with each individual type of insurance coverage plan. In some cases drugs or treatments that are not FDA-approved for the treatment of ITP or other platelet disorders may be considered by some companies as “experimental”. In some plans, whether a treatment is covered by insurance may be determined by the way the medicine is administered, such as by an intravenous infusion versus a pill taken orally. It may vary by where the treatment is given, such as in a clinic or hospital versus given at home. It is important to read the details of your own plan to know what is covered.

Q If one of my medical bills was turned down by the insurance company (or health plan) is there anything I can do?

A Ask the company why the claim was rejected. If the answer is that the service isn’t covered under your policy, and you are sure that it is covered; then check to see that the correct diagnosis or procedure code was entered on the insurance claim form by the provider. Check that your deductible was correctly calculated. Also, **make** sure that you didn’t skip an essential step under your plan, such as pre-admission certification. If everything is in order, then ask the insurer to review the claim.

Q What about medical care and insurance coverage when a patient is travelling outside the country or far from home?

A Patients should familiarize themselves with the conditions at their destination, including type of medical facilities, doctors, and availability of pharmaceuticals. For travel outside the country, patients should keep in mind that medical treatment and hospital care can be expensive. U.S. medical insurance is generally not accepted outside the United States. In addition, Social Security Medicare and Medicaid programs do not provide coverage for hospital or medical costs outside the U.S.

Check with your insurance company to find out what is covered when you travel. If your insurance policy does not cover you while travelling outside the U.S., it is a good idea to purchase a short-term policy that does. There are health insurance policies that are designed for this type of travel outside the U.S. To learn the names of companies that offer such policies, visit the Bureau of Consular Affairs Web site at:

http://travel.state.gov/travel/tips/brochures/brochures_1215.html

ITP patients travelling abroad should carry a letter from their doctor, describing their medical condition and a list of all prescription medications or treatments, including generic names of prescribed drugs. All medication carried overseas on the trip should be clearly labeled and in their original container. Remember, it is a good idea to wear a “medical alert” bracelet and also have with you a list of medications and dosages, previous surgeries; and allergies and reactions to foods, insects, and medications.

For patients traveling from other countries to the U.S. there are options for short-term medical coverage, such as when students stay in the U.S. to attend college or take part in short research programs. A number of insurance programs offer coverage for these short-term visits.

<http://www.visitorscoverage.com/>

<http://www.immihelp.com/visitor-medical-insurance/>

<http://www.globalhealthinsurance.com/visitors-to-the-u-s>

Insurance Coverage for ITP Treatments

Q What are the treatments for ITP for which patients may need some type of insurance coverage?

A As part of their care, ITP patients may need various drugs or other treatments that are used to help raise their platelet counts to a safe level and to decrease bleeding symptoms. Some of these include:

- Corticosteroids, such as prednisone or dexamethasone (Decadron®)
- Immunoglobulin, called IVIg, IGG, or IGIV
- Anti-D, such as WinRho® or Rhophylac®
- Rituximab, such as Rituxan®
- Immunosuppressant drugs, such as azathioprine (Imuran®) or cyclosporine, such as Sandimmune®
- Platelet Growth Factors, such as:
 - Romiplostim (Nplate®) from Amgen, and
 - Eltrombopag (Promacta®) from GlaxoSmithKline

Q What about insurance coverage for lab tests, treatments, hospitalization and surgery for ITP patients?

A Most ITP patients will need to have regular lab tests for diagnosis, treatment, and ongoing follow up of their ITP: The most common tests include:

- Complete blood counts, bone marrow tests, and other blood tests.
- Other Treatments, such as intravenous immunoglobulin (IVIg), which may be given in an outpatient clinic, a doctor's office, or in the hospital.
- Hospitalization and/or surgery, which may be needed by a number of patients with ITP. Some patients who have very low platelets and are experiencing serious bleeding may be hospitalized. The most common surgical procedure for ITP is a splenectomy, removal of the spleen. In many cases this is now performed laparoscopically. In emergencies, some ITP patients receive platelet transfusions.

What Patients Without Adequate Insurance Coverage Can Do

This section provides patients with guidance to find help when a number of issues (already described) have prevented them from getting insurance coverage for their ITP treatments. There are a variety of organizations that provide assistance.

Q What types of organizations offer assistance with drug or treatment co-pays or cover treatment costs?

A There are several types of organizations that patients with ITP and other platelet disorders may turn to for help with their drug or other treatment costs, such as co-pays, including:

- State-run Programs
- County-run Programs
- Foundations
- Prescription Assistance Programs
- Non-profits for autoimmune diseases

Q What are state-run patient assistance programs?

A These are patient assistance programs run by the individual U.S. states. For instance, California offers a program through its Office of the Patient Advocate. On their Web site they provide information on various ways that patients can become their own advocate for medical care. <http://www.opa.ca.gov/Pages/Home.aspx> With the recent U.S. economic downturn, state budgets could be hit hard, which could limit their ability to expand these programs. Patients should regularly check the details of what assistance is available in their own state.

Some other examples of state health care assistance programs can be found at the following Web sites:

US states <http://www.healthinsuranceinfo.net/>
 Maryland <http://health.frederickcountymd.gov/>
 Alabama <http://www.healthinsurance.org/alabama/>
 Florida <http://floridakidcare.org/>

There are other organizations that provide assistance and guidance for adult or child patients. For example, the American Academy of Pediatrics advocates for children to have access to comprehensive, quality health care. On their Web site they offer a number of useful links for parents seeking additional assistance in their state with the costs of their child's health care.

<http://www.aap.org/en-us/advocacy-and-policy/Pages/Advocacy-and-Policy.aspx>

<http://www.insurekidsnow.gov/>

Q What patient insurance assistance is available with the Affordable Care Act (ACA) program that is going into effect throughout the U.S. beginning in October 2013?

A Under the ACA, each state in the U.S. will offer state exchanges that provide a number of insurance plans for the uninsured and underinsured to select from to meet their health care needs. The American Plasma Users Coalition (A-PLUS) (PDSA is a member of A-PLUS) created a Personal Health Insurance Toolkit as a component of its State Exchange Project. This recently updated toolkit reflects the current ACA regulations. The comprehensive guide to understanding and navigating the Affordable Care Act was especially designed for people with platelet and bleeding disorders.

Special thanks to the following A-PLUS member organizations who assisted with developing the insurance toolkit: National Hemophilia Foundation, Georgetown Health Policy Institute, Alpha-1 Association, Caring Voice Coalition, Immune Deficiency Foundation, and Patient Services, Inc.

The toolkit can be accessed at: <http://pdsa.org/component/k2/item/659.html?Itemid=134>
Then click on the title, "A-Plus Insurance Toolkit."

Q What is the InsureKidsNow program?

A The InsureKidsNow program is a White House initiative managed by the U.S. Department of Health and Human Services to insure that America's children receive medical care. It offers a national toll-free hotline phone number uniquely designed to connect patients directly to the Medicaid or Children's Health Insurance Program (CHIP) staff in their own state. State staff can help callers get information about the programs and can assist them in completing an application. The number is: 1-877-Kids-Now or 1-877-543-7669.

Q How does InsureKidsNow and CHIP help with insurance concerns?

A InsureKidsNow offers information and guidance for CHIP, which was created in 1997. CHIP is a state and federal partnership that provides low-cost health insurance for children in families who earn too much to qualify for Medicaid but cannot afford to purchase private health insurance coverage. States have considerable flexibility to establish the income eligibility rules for CHIP, but children who enroll in the program must be otherwise uninsured.

In February 2009, President Obama signed the Children’s Health Insurance Program Reauthorization Act (CHIPRA), which provided funding to renew and expand CHIP coverage. The new legislation offers health coverage for millions of children already relying on CHIP and expands coverage to millions more who are uninsured.

Additional information on CHIP can be found on the InsureKidsNow Web site:
<http://www.insurekidsnow.gov/chip/index.html>

Q What are county-run health insurance programs?

A Across the U.S. most counties offer financial assistance with medical costs for local families who have very low income and little or no insurance coverage. An example of county programs offered by Los Angeles County can be viewed at their Web site:
<http://dpss.lacounty.gov/dpss/health/default.cfm>

ITP patients or patients with other platelet disorders who need assistance to pay for their medical care should learn what programs are available at their own local county level. In addition, most counties offer some type of free or reduced cost health clinic for eligible low income patients.

Q Which foundations provide patient assistance with insurance?

A Many foundations offer guidance and assistance to patients who need help with costs of their medical care and insurance. The **Patient Advocate Foundation (PAF)** is an example of an organization that specializes in helping patients gain access to medical care. For more information, patients may call 1-800-532-5274, fax to 1-757-873-8999, email to: help@patientadvocate.org or visit their Web site: www.patientadvocate.org

For medical providers who wish to enroll in PAF’s Co-Pay Relief (CPR) Program on behalf of their patients, the PAF offers a dedicated, secure Web site for electronic enrollment. Providers should call the PAF toll free 1-866-512-3861 to obtain additional information. Details are here: <http://www.patientadvocate.org/help.php?p=905>

Patients should also contact the nonprofit **HealthWell Foundation** for detailed information of the patient insurance assistance they offer. Their customer service line (open 9 – 5 Monday through Friday) is 1-800-675-8416. Visit the foundation Web site at: <http://www.healthwellfoundation.org/faqs.html#services>

Q What are prescription assistance programs?

A Prescription assistance programs help qualifying patients who do not have prescription coverage get the medicines they need, through either a public or private program. Some eligible patients may be able to get the drugs they need for free or nearly free. There are a number of programs that might offer help, such as the Partnership for Prescription Assistance.

Q What is the Partnership for Prescription Assistance?

A The Partnership for Prescription Assistance (PPA) offers a single access point for more than 475 patient assistance programs that help Americans who are uninsured or struggling financially. It provides information about pharmaceutical companies that provide prescription assistance for the drug/treatment they make/provide.

Patients eligible for assistance from the PPA's participating patient assistance programs have access to more than 2,500 brand-name and generic prescription medicines. PPA also provides information on more than 10,000 free health care clinics in America. Patients seeking help from PPA can call their toll-free number (1-888-4-PPA-NOW) or (1-888-477-2669) to talk to a trained operator. They can also visit the PPA Web site (www.pparx.org). It takes only 10-15 minutes to learn if someone may qualify for free or discounted medications.

Q Does the PPA offer assistance with co-pays for drugs?

A PPA offers assistance with co-pays through its Patient Advocate Foundation (PAF) Co-Pay Relief Program (CPR), which provides direct financial support to insured patients, including those with Medicare Part D. This program offers personal service to patients through call counselors, who guide patients through the enrollment process. Patients will need to learn if they are financially and medically qualified and they must be undergoing treatment for a medical disorder, such as an autoimmune disorder like ITP. Patients may contact the Co-Pay Relief Program by calling 1-866-512-3861.

Q Does the Partnership for Prescription Assistance (PPA) provide other medication information?

A The PPA Web site offers a searchable list of medications, including those used for ITP patients, for which there may be assistance. Some of the ITP meds currently included on their list are:

Prednisone (prednisone) corticosteroid
Gammagard S/D® (immunoglobulin G) from Baxter
Rituxan® – (rituximab) from Genentech Inc.
Nplate® - (platelet growth factor) from Amgen

Patients may find more details on their Web site:

http://www.pparx.org/prescription_assistance_programs/list_of_participating_programs

Q What is the Rx Outreach Express-Scripts program?

A The Rx Outreach Express-Scripts program offers low cost prescription medications to people in need across the U.S. The prescriptions are mailed to the patient after Express-Scripts receives an Rx Outreach form, a prescription, and the payment. The program works with ITP patients toward paying their co-pays. Patients are required to meet

certain criteria but the organization is fairly flexible. The prescriptions are mailed to the patient after Express-Scripts receives an Rx Outreach form, a prescription, and a payment. For further information, visit their Web site at: <http://www.copays.org>

Q What about the NeedyMeds organization?

A NeedyMeds is a 501(c) (3) non-profit organization that offers another source of assistance for patients having trouble paying for their needed medications. Their mission is helping people who cannot afford medicine or health care. The information they offer is available anonymously and is free. They offer pricing for IVIg products, rituximab, Nplate, Promacta, WinRho, Dapsone, and Imuran. For further details visit their Web site: <http://www.needymeds.org/>

Q Is there assistance available from autoimmune disease non-profit organizations?

A Most non-profits for various autoimmune diseases offer some type of guidance or assistance for patients with a chronic autoimmune disease, such as ITP. Some useful Web sites to visit include Advocacy for Patients with Chronic Illness, Inc.; NORD; and the Lupus Foundation of America.

Q What is Advocacy for Patients with Chronic Illness, Inc.?

A This non-profit organization, started by the late Jennifer Jaff, offers prescription drug patient assistance programs. Their Web site lists links to many possibly helpful organizations: <http://www.thejenniferjaffcenter.org/>

Q What is NORD?

A NORD is the National Organization for Rare Disorders, which is a 501(c) (3) nonprofit organization. It is a federation of voluntary health organizations dedicated to helping people who have rare “orphan” diseases (which are defined as those affecting less than 200,000 people in the U.S.). NORD provides several programs to help people obtain certain medications. They offer the Medication Assistance Program to help needy, uninsured patients obtain certain medications they otherwise could not afford.

NORD also offers Medicare and insurance co-pay programs, early or expanded access to investigational products, travel and relocation assistance for clinical trial participants, and emergency or limited access to products in short supply. To learn more about the patient assistance programs being administered by NORD visit their Web site: <http://www.rarediseases.org/patients-and-families/patient-assistance>

Q What about the Lupus Foundation of America?

A The Lupus Foundation of America, Inc., is a national nonprofit dedicated to finding the causes of and cure for the autoimmune disease lupus. The organization provides support, services and hope to all people affected by lupus. It also offers a list of prescription assistance organizations on its Web site:
<http://www.lupus.org/resources/prescription-assistance>

Q Does the Kaiser Family Foundation offer patient assistance information?

A The Kaiser Family Foundation provides an extensive Web site with a great deal of helpful information about patient assistance with medical care and insurance. Visit the site at: <http://www.kff.org/>

Q What insurance assistance is available from the pharmaceutical companies that make the treatments or drugs that are needed for treatment of ITP?

A Most pharmaceutical companies that provide treatments for ITP offer some type of assistance program for patients who are unable to afford the medication or treatment their company makes. Most of the programs require income information and completion of an application form to determine eligibility.

Q What financial assistance is there from Amgen for patients receiving Nplate® a platelet growth factor treatment for chronic ITP?

A Amgen, the pharmaceutical maker of Nplate® (romiplostim), provides patient assistance for their FDA-approved treatment. Amgen supports three different reimbursement programs that may be of assistance to eligible patients. These programs are:

1. **SAFETY NET®**, which provides Nplate® for no cost to qualifying uninsured patients. This is based on the patient's household income and family size.
http://www.amgenassist.com/support_programs/safety_net_foundation.jsp
2. **Referrals to independently operated co-pay assistance foundations.** Amgen provides financial support to independent third-party foundations that assist qualifying patients with out-of-pocket costs for their treatments. This is a good option for Medicare Part B patients who do not have supplemental insurance.
3. The Nplate® FIRST STEP™ Program can help eligible, commercially insured patients with co-insurance or co-pay (out-of-pocket) requirements:
 - *No income eligibility requirement
 - *No out-of-pocket costs for initial injection
 - *Maximum out-of-pocket costs for subsequent injections is \$25*

For more information log on to www.AmgenFIRSTSTEP.com or call 1-888-657-8371 for complete list of eligibility requirements and program restrictions.

*Total program benefits may not exceed \$5,000 per patient per 6-month period defined by the program. The Nplate FIRST STEP™ Program is not valid in Massachusetts or where otherwise prohibited by law. Patients participating in Medicare, Medicaid, or any other federally funded healthcare program are not eligible for this program. Certain other restrictions and eligibility requirements apply.

For further information about any of these programs, contact My Nplate® Center at 1-855-MYCENTER (1-855-692-3683). Information is also found at Nplate.com or <http://www.nplate.com/patient/nplate-patient-support/my-nplate-center.html>

Q What patient assistance is provided by GlaxoSmithKline, the maker of a platelet growth factor drug, Promacta®, for chronic ITP?

A GlaxoSmithKline’s Commitment to ACCESS® program provides a single point of information, education and support for patients and healthcare professionals.

Commitment to ACCESS® also offers prescription drug reimbursement support for the uninsured and under-insured as part of GSK’s ongoing commitment to providing needed medicines to patients who may benefit from the assistance. Some patients may receive GSK Co-Pay Assistance. This program is for people who have prescription coverage but who need extra help paying for their oral medicine. Commitment to Access is a patient assistance program that provides free GSK medication to income-eligible patients. Knowledgeable counselors are available to speak with patients at the toll-free number: 1-8-ONCOLOGY (1-866-6491). Information is available on their Web site: <http://www.caresbygsk.com/patients-caregivers.html#Patient>

Q What other pharmaceutical companies offer ITP patient assistance with insurance or prescriptions?

A Another pharmaceutical company that offers patient assistance with insurance issues related to ITP treatments, such as intravenous immunoglobulin (IVIg), is the Baxter HealthCare Corporation. They offer *Live Phone Support* to health care professionals and their patients at 1-888-Baxter9. This toll-free access provides information about insurance coverage, reimbursement, and coding. Speak with a trained specialist whenever you have insurance challenges and questions. Their specialists can also assist your physician's office with benefits verification and coverage appeals.

For more details, visit Baxter’s Web site at: <http://www.rxassist.org/pap-info/company-detail?CmpId=150>

Insurance Assistance

If you lose your health insurance coverage, they can help provide access to Baxter IgG products at no cost (for those who qualify). This benefit, formerly known as the GAMMASSIST program, is now available to anyone on IgG therapy. These programs

offer a way for eligible users of Baxter's immune globulin intravenous (IVIg) (human) therapies to continue receiving their immune globulin at no charge if there is a lapse in their private insurance. Baxter offers a Reimbursement Hotline for assistance with IVIg insurance and billing issues at this Web site:

<http://www.gammagard.com/primary-immunodeficiency/hcp/resources/coverage/insurance.html>

Q What other assistance is available for ITP patients who receive IVIg treatments?

A The Immune Deficiency Foundation on their Web site lists several immunoglobulin manufacturers and their assistance programs. Information is available at:
<http://primaryimmune.org/patients-and-families/patient-assistance-resources>
<http://primaryimmune.org/treatment-information/manufacturers-and-assistance-programs/>

Q Is there pharmaceutical assistance for the treatment Rituxan® (rituximab), used for treatment of ITP?

A GENENTECH, INC, the pharmaceutical maker of Rituxan® has information about their patient assistance program called Access Solutions at this Web site:

<http://www.genentech-access.com/hcp>
<http://www.genentech-access.com/rituxan-ra/hcp/find-patient-assistance>

The GENENTECH, INC patient assistance program offers free medication to patients who otherwise could not afford it. Patients must meet financial and other program specific criteria to be eligible for assistance. To contact Genentech Access Solutions, call 1-866-681-3261.

Q Where can a patient seek assistance information about WinRho SDF® (an anti-D treatment for ITP) distributed by Emergent BioSolutions (drug made by Cangene bioPharma, Inc.)?

A For questions regarding ordering, reimbursement, or medical inquiries about WinRho®, please contact Emergent BioSolutions
<http://www.emergentbiosolutions.com/http://www.emergentbiosolutions.com/node/64>
<http://www.emergentbiosolutions.com/node/64?q=node/57>

Q What else can ITP patients do to cope with the financial costs and insurance issues related to ongoing treatment for ITP?

A There are several steps patients can take to be sure they are receiving all the coverage they are entitled to under their current health care plan.

1. Whatever your type of insurance policy, be aware you have federal and state protections that are determined by your type of insurance and state of residence.
2. Remember, if you develop an illness or medical condition, under the federal HIPAA law, your insurance company cannot use this as a reason to drop you from their insurance plan.
3. If you purchased your own insurance coverage on the individual market, you are protected by state law. Many states also have a patient's bill of rights.
4. If your insurance is through your employer, you are probably covered by the federal Employee Retirement Income Security Act (ERISA). This law sets the legal guidelines for private employee benefit plans. Under ERISA, your insurer must inform you about your plan's provisions, explain how to file a claim, tell you how to appeal a denied claim, and provide a process for reviewing appeals.
5. If you ever need to file an appeal for a denial of medical coverage, there are several tips that can increase your chances of winning. These include keeping detailed records of each step (including phone calls), following up phone calls with letters summarizing the conversation, and keeping all correspondence whether by email or letter. As part of your appeal you may want to ask your doctor to write a letter that explains why the treatment is necessary. Be sure to file your appeal and all required paperwork on time.

Q Where can I learn more information about coping with ITP?

A The Platelet Disorder Support Association (PDSA) has more information about ITP and its treatment. There are hundreds of pages on the PDSA Web site at www.pdsa.org. Our organization publishes a monthly e-news, a quarterly newsletter, and makes available many other publications and articles. PDSA holds an annual ITP conference, regional meetings, and has established more than 30 local support groups around the U.S. and Canada. Our members have access to the Name Exchange Program to communicate with other ITP patients. PDSA continues to expand its programs to offer more services and reach more people. Visit www.pdsa.org and join today to enjoy these benefits!

References:

1. A Buyers Guide for Health Insurance, http://www.quotit.net/resources/terms_health2.htm
2. 'We're Fighting for You.' AARP Bulletin, October 2009, p. 32.
3. 'Tips for getting insurance when you have a pre-existing condition.' CNNhealth.com. May 14, 2009. <http://www.cnn.com/2009/HEALTH/05/14/preexisting.condition.insurance/index.html>

Depending on your circumstances, one of our other guidebooks may also be helpful:

ITP in Adults – Frequently Asked Questions

ITP in Teens – Frequently Asked Questions

ITP in Children – Frequently Asked Questions

ITP and the Female Lifecyle – Bleeding Issues in the Stages of a Woman’s Life

La PTI y el ciclo de vida femenino: Problemas Hemorrágicos en las distintas etapas de la vida de una mujer

Coping with ITP – Frequently Asked Questions

Cómo Sobrellevar la PTI - Preguntas Frecuentes

Vivre avec le PTI – Questions Fréquemment Posées

PTI en la adultez – Preguntas frecuentes

PTI en adolescents -- Preguntas frecuentes

PTI infantil – Preguntas frecuentes

The Role and Function of Platelets in ITP – Frequently Asked Questions

Parents Resource Packet

When a Child Has ITP — A Resource Guide for Parents

Living with ITP – Answers to Common Questions

PTI chez l’enfant – Questions Fréquemment Posées

PTI chez l’adulte – Questions Fréquemment Posées

For more information about ITP, additional copies of this guide, or to become a member of PDSA, please contact us:

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The Platelet Disorder Support Association is dedicated to enhancing the lives of people with ITP and other platelet disorders through education, advocacy, and research.

Membership benefits include a quarterly newsletter, discounts to the ITP Annual Conference, optional participation in the Name Exchange Program, and the good feeling of helping others.

PDSA is a 501(c)(3) organization. All contributions are tax deductible.

PDSA would like to thank **Amgen** for their generous assistance in production of this patient information guide.

The information in this guide is for educational purposes only. For your unique medical condition, please consult a qualified medical doctor and/or health care provider.

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PDSA

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