

Immune Deficiency Foundation
Guide for Young Adults



About the Immune Deficiency Foundation

The Immune Deficiency Foundation (IDF) improves the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency through fostering a community empowered by advocacy, education, and research.

Primary immunodeficiencies (PI) are a group of more than 450 rare, chronic disorders in which part of the body's immune system is missing or functions improperly. PI is caused by genetic defects in immune response pathways and can affect anyone, regardless of age or gender.

PI results in high susceptibility to infections. Illnesses such as repeated bouts of pneumonia, persistent skin abscesses, and sepsis, or blood infections, are common and can lead to permanent organ damage. Antibiotics often have little effect on the infections longterm. The infections can become chronic and develop into life-threatening conditions requiring hospitalization. PI is also linked to autoimmune disorders and increased risk of certain forms of cancer.

According to the National Institutes of Health, there are approximately 500,000 individuals in the U.S. with a primary immunodeficiency. Every year, thousands go undiagnosed. Individuals affected by PI often find it difficult to receive proper diagnosis, treatment, and specialized healthcare. They experience difficulties financing healthcare, finding educational materials, and locating others who share their experiences.

As a nonprofit organization headquartered in Maryland, IDF provides accurate and timely information for individuals and families living with PI and offers valuable resources and support. IDF operations are carried out by staff, medical professionals, and volunteers. Through this network, IDF conducts research on various PIs, provides education seminars and support groups, coordinates nationwide fundraising activities, influences healthcare policy, develops PI specific programs, assists with navigating health insurance, provides general information about managing care, and offers annual conferences for the PI community.



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IMMUNE DEFICIENCY FOUNDATION GUIDE FOR YOUNG ADULTS

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Table of Contents

Introduction	4
Chapter 1 Making the Transition from Pediatric to Adult Healthcare	5
Chapter 2 Introduction to Health Insurance	10
Chapter 3 College, Career, and Dating	18
Chapter 4 Strengthening Ties with Family and Friends	22
Resources	24

Introduction

There are many adjustments and changes for any young adult on their 18th birthday. One of the largest, especially for those within the primary immunodeficiency (PI) community, is the transition from pediatric to adult healthcare. As an adult, you are now solely responsible for communicating with your provider and making healthcare decisions. While this may feel overwhelming, you are not alone. It's a process we all must undergo, and many tools can help you as you begin to transition the responsibility of your health from your parent/guardian over to you. You can sign a release of information form, which will allow your parent/guardian or anyone else you designate to also communicate with your providers, but the reality is that you are in charge.

The change to an adult approach to care comes at age 18, whether you can stay with your pediatric or family medicine providers or need to transition to a new adult provider. Also, since you are now the key person making decisions about your care, you are expected to manage your own appointments, medications, and healthcare payments/insurance. You will also want to be prepared with your own questions at your appointments. The transition to adult care should start well before you are 18 and occur in stages. This publication is meant to provide a guide to achieving this transition.

As you move from childhood to adulthood, it is a time filled with questions and anticipation. It's a time when a world of possibility is laid out before you, but it also can be an intense, stress-filled time for anyone. For people dealing with conditions like a PI, management of these stressors needs added attention.

You have a PI, but you're not defined by your condition. You will need to manage it your whole life, just as you have done until now. But rather than looking at your diagnosis as a limitation, try looking at it as something that builds inner strength and gives you an edge when facing life's challenges. Although you may have amassed a great deal of knowledge about a great many things, from the subjects you've excelled in at school, to the passions and talents you've developed, the process of defining and refining who you are and what you can become is just beginning.

In the coming years, your relationship with your parent/guardian, which until now has been that of cared-for and caregiver, will evolve. You'll enter new social circles and perhaps move to new places. You'll explore your interests, hone your talents, and find ones you didn't know you had. You'll lay the groundwork for your career, whether that means jumping right into the workforce, attending a 2- or 4-year college, or pursuing a graduate or postgraduate degree.

Whatever path you take—and there is no one right path—your PI will go with you. It doesn't take time off, so deciding to stop doing the things that have kept you healthy is not an option. You'll need to develop smart strategies for managing your PI while keeping it in its proper balance for the rest of your life. It is time to take charge of your medical condition and commit to making your health a priority.

This guide is intended to help you navigate the transition to adulthood and prepare for life in the decades that follow. Topics include optimizing your health, understanding health insurance, establishing new relationships and nurturing old ones, and planning your education, career, and family. There are worksheets and checklists at the end of this guide that you can use as tools to help you navigate the path to becoming an adult with a PI.

You are your own best advocate and caregiver, and with the right tools and mindset, you can achieve whatever you set out to do.



Chapter 1

Making the Transition from Pediatric to Adult Healthcare

No matter when you were diagnosed with a primary immunodeficiency (PI), whether it was as a young child or just a couple years ago, the chances are that you have become familiar with visiting healthcare providers and medical facilities. It's likely your parent/guardian has been at your side, fortunately, tending to the varying aspects of treating your PI—from making appointments to gathering information and filling prescriptions. As an adult, you will coordinate the many facets of your healthcare yourself and plan for emergencies that you hope will never happen.

Emergencies and Legal Realities

Most states consider you an adult when you turn 18. That is the point when, according to the Health Insurance Portability and Accountability Act (HIPAA), the law that governs healthcare privacy, your health records become confidential between you and your healthcare providers.

It is important to understand the significance of that 18th birthday. In the eyes of state governments and HIPAA, your legal status has changed radically, literally overnight.

It is vital for you to plan for potential emergencies by signing a few forms, including those which allow your healthcare providers to disclose information to your parent/guardian or whomever you designate. Without this planning, if you are injured and taken unconscious to a hospital, your parent/guardian or other family members would be unable to get information or make decisions on your behalf. Although HIPAA does allow healthcare providers some discretion in disclosing information to family members, providers usually err on the side of privacy because it is safer for them, legally. Note that HIPAA's privacy rules apply after age 18 even if you continue to live at home, are still on your parent/guardian's health insurance, and even if they pay for your care.

You can search for and download the necessary forms listed below from various websites. (If you're able, have an attorney prepare them—this is the best way to ensure the paperwork is complete and will comply with your wishes). If you're living in a different state than your parent/guardian, it's best to fill out the forms for both states just to cover all the bases.

In some states, the rights covered by these forms might be combined, but the basic authorizations that need your signature are:

- HIPAA authorization—by signing this, you legally grant permission for healthcare providers to disclose information to someone else (you designate whom). This authorization is not all-or-nothing, so you can specify (if you wish) that emergency information be disclosed but not your ordinary healthcare records.

Chapter 1 – Making the Transition from Pediatric to Adult Healthcare

- Medical power of attorney (POA)—this appoints a person of your choosing to make medical decisions on your behalf if you are unable to. In some states, the form may have different names, but does the same thing.
- Durable power of attorney—this is like a POA plus in that it designates a person to handle your private matters beyond just medical issues. These can include filing taxes, paying bills, and accessing bank accounts.
- Living will—this provides direction to healthcare providers on whether to administer interventions and prolong life in the worst emergencies, where permanent incapacitation is likely.

These forms should be stored in a place that is very easy for your parent/guardian (or whomever you've designated) to access. They could scan them into their phones or you could email them the forms. In stressful situations, the mind may forget answers to questions like "where is that form filed?" so if it is in their packet, that's the best case.



I AM
IMMUNOCOMPROMISED
CARD

It is also a good idea to fill out an "I Am Immunocompromised" card and keep it on your phone or even give it to your parent/guardian. If you have an emergency and cannot communicate, you can rely on this form to tell the medical team all they need to know about your condition. It may also be helpful to designate an emergency contact person on your phone. This can be done through the Apple Health App (under Medical ID) on an iPhone or under Emergency Information under "Users and Accounts" on Android.

Although emergencies and healthcare crises aren't pleasant to think about and hopefully will never actually come up, planning for them provides peace of mind for both you and your loved ones.

Taking Charge of Your Care

Your day-to-day, year-to-year healthcare will be far less dramatic than the emergencies described in the previous section.

Together with your parent/guardian, you can decide how involved they will be in your care and when their involvement can decrease.

You've probably already had a voice in decisions about your health and have acquired a basic understanding of the reasons for the medical treatments you receive. Still, as the age of 18 approaches, it's a good idea to practice taking the lead. If you're not used to handling your healthcare provider visits, observe how your parent/guardian does it. Listen to the kinds of questions that are asked; pay attention to the paperwork that crosses the reception desk. Do they show an insurance card? Make a payment? Set up the next appointment before leaving? As you feel ready, you can do these things.

You should never be afraid or embarrassed to ask healthcare providers questions about your health or treatments. Get to know the science behind your condition if you don't already. Many people have a tendency to go along with explanations they don't fully understand because they're embarrassed, but your healthcare providers are there to heal you, not judge you. They'll respect you for wanting to have a command of the facts.

You are not merely the recipient of your medical care—you are a collaborator in it. Think of your healthcare providers as your partners in wellness. Your current medical team might already include several specialists, like immunologists, who are experts in the treatment of PI.

Depending on your form of PI, you might see other specialists like pulmonologists and have a team of providers. Do everything you can to build a healthy, therapeutic relationship with all of them, as well as their staff and support personnel. The more you can establish a rapport with all these people, the better your medical experience will be and the more they can help you. If you do not feel that you are being heard or that you trust your medical team, it may be time to consider a different medical team.

Maintaining Care Over Time and Distance

Now that you are no longer a child, you will likely need to move from your pediatrician to internal medicine, a family medicine specialist, or a nurse practitioner. This happens to almost everyone about the time they turn 18. Given that you may be making this transition when you are joining the workforce or you're going to college, it is an important step to plan.

In addition to your primary healthcare provider, you still need to be seen by one or more specialists, one of which is an immunologist. Your current immunologist may continue to treat you. But in the case of a move out of your geographic area or if your current immunologist only sees pediatric patients, you'll need to find someone new.

Start by asking your current immunologist for recommendations.

They may personally know immunologists in the area where you are going or know of them through other colleagues. Your current provider can then help see that all your medical health records get transferred to the new healthcare provider and practice, and you should also request a personal copy of these files. Most importantly, given that they want to make sure you are in good hands, your existing healthcare provider can, with your permission, consult with the new provider over the phone about your health.

Chapter 1 – Making the Transition from Pediatric to Adult Healthcare

profile. The support staff might even help set up your first appointment for you. In this way, you won't feel as if you will be starting from scratch when you have your first appointment with your new healthcare provider.

If your current healthcare providers cannot recommend anyone, contact the Immune Deficiency Foundation (IDF) for recommendations of healthcare providers who have been vetted for PI expertise: www.primaryimmune.org/ask-IDF. Regardless of whether your current healthcare provider recommends an immunologist or you receive a list from IDF, you'll need to ensure the healthcare providers you choose are included in your insurance network (see Chapter 2).

Whatever you do, don't leave finding a new healthcare team to the last minute. Many healthcare providers have wait times of up to several months for new patients, and you'll need to have your appointments in place in order to avoid any lapses in treatment. If your previous healthcare team hasn't been in touch with your new team, you'll also need to allow time for you to request all your medical records so that your new providers receive them before your first appointment. You may also need time to request authorization for treatment from the insurance company.

Appointments and Prescriptions

Your condition requires ongoing treatment, so you'll soon master the routine of making appointments with the appropriate amount of lead time. It's important to keep your appointments because if you miss them, the office might have a hard time rescheduling you and your treatment might be delayed. If you absolutely must miss an appointment, let the office know at least 24 hours in advance and apologize for the unavoidable inconvenience.

This preserves goodwill and avoids unnecessary costs, as many medical offices will charge you a fee for canceling without adequate notice. When you reschedule, if it is for a time-sensitive treatment such as immunoglobulin replacement therapy, make sure the scheduler understands the urgency of your need.

Whenever you go to an appointment, it helps to do a little prep work in order to make the most of it. Healthcare providers typically work on tight schedules, so have all your questions ready, whether you write them in a notepad or journal or keep them on your smartphone. Take notes during your appointment or ask the healthcare provider if it's okay to record the conversation if that makes it easier for you. Make sure to tell the healthcare provider of any new developments that might be relevant to your health, such as medication side effects, or injuries, and other illnesses.

Visiting the Pharmacy

After an appointment, you might need to visit the pharmacy to fill a prescription. Usually, the healthcare provider will send your prescription to your preferred pharmacy. Before selecting a pharmacy, make sure it is in your insurance network, and before picking up a prescription, make sure the drug is covered (see Chapter 2). The healthcare provider might not know what's covered under your plan, but you can often look it up online with your phone so that the healthcare provider can suggest an alternative medication if needed.

The first time you pick up medication at your pharmacy, you'll have to provide your insurance information—typically, just show your card. The pharmacist will let you know if you owe a copay or coinsurance, and they will ask you if you have any questions about the drug or the instructions for taking it. Pharmacists are knowledgeable backups for any information you forgot to ask your healthcare provider or want to reaffirm, and they are happy to give you information. If you are taking multiple medications, the pharmacist can ensure that no drug interactions exist. Providing complete information regarding all medications, including birth control and herbal supplements, is essential for this to be accurate. Don't deviate from the instructions when taking your medication. The dosing instructions have been developed over years of rigorous testing. Minor changes that seem trivial, like skipping or delaying a dose, might have serious consequences.

If you have serious side effects from any drug, call your healthcare provider right away. The drug will come with a detailed information sheet listing common side effects. If your side effect is listed on the sheet and is not bothersome to you, just note it in your records.

Pharmacists can often put regularly used medications on auto refill for you, so you can pick them up hassle-free and on time. If a prescription is not on auto refill, you can still call in advance or order it online to have it waiting for you. Call a few days before you run out in case the pharmacy is out of stock and needs to order the medication. Prescriptions have a limited number of allowable refills before they need to be reauthorized by your healthcare provider, so stay on top of this when you visit your healthcare provider and remind them that you need a refill.

Specialty Pharmacies

You also might be working with a specialty pharmacy that provides your specialty drugs like immunoglobulin, interferon-gamma, or adenosine deaminase. It may not always be necessary to change specialty pharmacies if you are relocating or going away to

Chapter 1 – Making the Transition from Pediatric to Adult Healthcare

college, as many of these are nationally based. Check with your current specialty pharmacy several months before moving. Also, if you are attending college and living on campus, check with the specialty pharmacy and your college concerning any rules that might interfere with receiving and administering your medications in a college dorm. If you run into any confusing or conflicting information, your contact at your specialty pharmacy might assist you in clearing up the situation. If a change to a different specialty pharmacy is required, your current provider should participate in coordinating the care and transition to the new provider.

Managing the Stack of Information

Between your medical appointments, prescriptions, and specific therapy, there is a ton of information to keep track of. No one could keep it all straight without developing a recordkeeping system.

Keep all your insurance information together in one handy place. Whenever the insurance company sends you an Explanation of Benefits (EOB) or updates (see Chapter 2), read them and save them. Keep your insurance card with you but keep the rest of your insurance records on file. When you need to call the insurance company with a problem or issue, keep a log, noting when you called, what information you got, and to whom you spoke, and ask for a reference number for the call.

Minding Your Mental Health

There's no denying that having PI is a challenge. You didn't do anything to deserve it, and it's not fair that you have to deal with it. Those are facts. But dealing with a PI and knowing you'll probably have to for the rest of your life naturally might get you down sometimes.

"Going with the flow" is a good approach to some situations, but when it comes to feelings of depression, don't let those feelings sweep you into a downward spiral. If your thoughts are getting too dark, get some help. If you feel like talking with a professional, check to see what mental health benefits are covered by your insurance and who their providers are. Schools also offer counselors or therapists that you can see for free or at a low cost.

You know it's time to ask for help:

- If your depressed feelings prevent you from studying or performing your normal daily tasks,
- If you have lost your appetite or lost weight despite no change in diet,
- If you stop enjoying things you used to enjoy,
- If you stay in bed despite having somewhere to be,
- If you use drugs or alcohol to get through the day, or
- If you have thoughts of harming yourself.

These are all red flags you shouldn't ignore.

If you simply want to speak with someone who has PI, contact the Immune Deficiency Foundation and learn more about the Peer Support Program, which can network you with another young adult going through similar experiences as you.



PEER SUPPORT

Lifestyle Choices

Exercise and diet are shown to be powerful tools for improving your emotional outlook, so don't let those aspects of your life slide. Healthy eating is important for everyone, but especially for someone managing PI. It's all too easy to let your nutrition slide, but your body is counting on you to do right by it.

If you haven't been exercising, clear it with your healthcare provider first to help you get started and work up to your goal gradually. It's important not to push to the point of fatigue, as you want to avoid both injury and mental burnout. Having an exercise buddy is helpful in keeping up with workouts—if you know a friend is counting on you for a run in the park, you'll be more likely to follow through. There also can be wonderful benefits to solitary exercise; many people find exercising alone is a time to focus and find creative inspiration. Great music or interesting podcasts also go a long way toward making a workout fun.

Your primary healthcare provider is an excellent resource for direction and advice regarding a healthy diet. If your weight is above or below the optimal weight range, it should be addressed. If you struggle to change your weight in either direction, discuss it with your healthcare provider. Excessive dieting and weight loss are as serious as overeating and weight gain, and if you feel out of control with either, consider mental health support as discussed previously.

Chapter 1 – Making the Transition from Pediatric to Adult Healthcare

Getting an adequate amount of sleep is an essential requirement for good health, but getting enough sleep is hard for most people because our modern lives are so busy. Most scientists recommend a consistent number of hours of sleep per night and consistent bedtimes and waking times, as well.

Addressing stress and developing coping skills is essential. Identify activities that help with stress, whether it is exercise, yoga, painting, music, or meditation. Engaging in these activities regularly is beneficial.

Persist and Thrive

You are more than up to the task of managing your PI along with the rest of your life as an adult. Your PI is a constant companion that you can never ignore, but it isn't the boss of you. Treat it diligently, as you have learned to, and be mindful of the signals your body gives you. Watch for early signs of infection or illness and get prompt treatment. Be mindful of good hygiene. Partake in social activities, but not in unhealthful behaviors. When you're tired, rest; when you're hungry, choose healthy foods. Study seriously, work hard, and pursue your dreams.



Chapter 2

Introduction to Health Insurance

One of the trickier mazes you'll need to navigate in the world of adulthood is that of health insurance. Most people find it frustrating at times. Having a primary immunodeficiency (PI), however, makes it particularly crucial for you to ensure you have adequate health insurance and an ability to communicate effectively with your insurance provider. Not only will you need to understand what type of plan will best serve your needs, but you will also need to keep meticulous records of all your healthcare provider visits, treatments, and medications. You might sometimes need to deal directly with your insurance company to submit claims and dispute any expenses that are not paid.

Some people receive health insurance through their employers. If your employer does not provide health insurance and you are under 26 years old, your parent/guardian may include you in their plan. If you are over 26 or cannot get coverage through your parent/guardian's plan, then there are other ways to obtain health insurance. The best option is to go to [HealthCare.gov](https://www.healthcare.gov) to investigate purchasing a plan through a state or federal health exchange established under the Affordable Care Act (ACA). By utilizing this website, you can examine plan options and may qualify for subsidies to help pay your premium. You may also discover that you qualify for Medicaid. You also have the option of purchasing a plan on the private market without subsidies. In specific cases, you may also be eligible for disability-based Medicare.

It's important to recognize that healthcare is a constantly debated subject in American politics, and laws are subject to change. Even small adjustments to laws can have a big impact on someone who depends on regular medical treatment. It will be important to stay on top of these changes, as they may affect your own expenses and require you to change or modify your coverage.

You may carry different types of insurance throughout your life, and you will likely need to evaluate options to select the plan you can afford but that also meets your medical needs. In this chapter are some terms you'll need to know to make sense of any plan. These elements of insurance are collectively referred to as cost-sharing, which basically means the part of the cost you have to pay. The amount you must pay for each element varies from plan to plan.

Premium

Think of this as the base monthly price of the insurance. It is the amount the insurance company charges upfront in return for covering your healthcare. If you get your insurance through an employer, some of this monthly amount will be paid by your employer. Employers will typically deduct a set amount of money from your paychecks to put toward this cost. This is typically on a pre-tax basis, so it lowers your overall taxable income. If you don't get your insurance through an employer but purchase it yourself, you will pay the entire premium each month.

Unfortunately, premiums do not apply toward deductibles (defined at right) and are due every month, whether you receive healthcare that month or not. Premiums for individuals purchasing their own plans are usually higher than premiums in employer-provided plans because employers pay group rates that are lower than those on a per-person basis.

Copay

This is a fixed amount you will be expected to pay each time you get a certain service, such as a healthcare provider visit, treatment, or prescription. It is paid at the time of the service and will not be reimbursed by the insurance company. It may vary, depending on what it is used for. You might have a \$10 copay to see a primary care provider, \$25 to see a specialist, \$30 to fill a prescription and \$50 for an emergency room visit. Copays are fixed amounts, which means that they won't change during the year, and these copays are unrelated to the amount of the total bill.

Deductible

Many plans require you to pay a certain amount, called the deductible, toward your care before they will pay anything within any calendar year. If you have a \$1,000 deductible, you will be personally billed for the first \$1,000 in medical expenses starting January 1 or whenever your plan starts. Once your expenses go above \$1,000, your insurance will pay any costs for healthcare providers, procedures, or medications that the insurance plan defines as eligible. Note that your premium and copays don't count toward your deductible, and you must still continue to pay them even when you have met the deductible. Deductibles are fixed for any given plan during that plan year, so you can tell at a glance how much they will cost you each year.

Coinsurance

While some plans will kick in at 100% as soon as the deductible is met, many will expect you to continue to pay a percentage of each bill until the out-of-pocket maximum (defined below) is reached. A common split is 10/90, meaning after meeting your deductibles and in addition to copays, you will have to pay 10% of the bill. With many plans, the split is 20/80, and some are even 30/70. When evaluating a plan, you need to be sure you know what this percentage is. Unlike deductibles, coinsurance is not a fixed amount but rather a percentage of the bills, so you'll need to have an idea of what your bills are likely to be to estimate it. Plans with high coinsurance are generally intended for people with little medical need.

Out-of-Pocket Maximum

Luckily, there is usually a point at which you can stop sharing the cost of your medical care each year. Most insurance plans have a set dollar amount that, when reached, triggers the plan to kick in at 100%. Any more bills you incur after you've reached this point will be fully paid by the insurer, except for copays and premiums. It's important to understand this when choosing an insurance plan.

Do note that the above information applies to eligible costs. This means that you must be receiving a procedure or seeing a healthcare provider that your plan defines as covered, or else your insurance will not contribute money, and your money will not apply to your deductible. Not all plans cover the same things, so when choosing or enrolling, you'll need to review what is covered, especially pertaining to therapies needed to treat your particular PI. For more about evaluating coverage, see the section on page 15.

Group vs. Individual Insurance

Your insurance will either cover a whole group of people, such as the employees of an organization or enrollees in a government-run plan, or it will be a plan that you purchase individually.

Group plans are usually less expensive with better coverage than individual plans. This is because the risk for the insurance company is spread around. That is, if there are 100 people on the plan, maybe only ten will get sick and incur expenses for the insurance company; for the other 90, the insurance company is just receiving the premiums and making a profit.

Organizations with 50 or more employees must offer health insurance benefits to any employee who works at least 30 hours a week. Some employers offer one plan to everyone, while some offer a choice of plans. If there is a choice, you must carefully evaluate and compare each plan. Some employers offer health insurance for part-time employees working less than 30 hours a week, and others don't.

If you leave or lose your job, you can keep your insurance and its group rate for up to 18 months under a law called COBRA (Consolidated Omnibus Budget Reconciliation Act). Usually, you have to take over the full premium payments, but some employers might continue to pay the premiums as part of a severance package. The premiums might change slightly, but by law, they cannot go up by more than 2%, which is a service charge. You do not have to take this option if you prefer to seek insurance elsewhere. If you leave one job for another, it's important to understand if you'll need to elect COBRA for any coverage gap.

There are also group plans that are not employer-based. If you go to college, your school may have group plans you can enroll in, which may be a major consideration when deciding what school to attend. In the past, college plans tended to be fairly bare-bones but have improved in recent years. Contact your prospective college's admissions department to learn the details of what insurance they offer if you are not planning to stay on your parent/guardian's insurance plan(s).

Chapter 2 – Introduction to Health Insurance

Individual plans are those you purchase yourself and are usually more expensive than group plans. The enactment of the Patient Protection and Affordable Care Act (ACA or Obamacare) made individual plans more attainable by offering financial assistance on a sliding scale to Americans whose income falls below a certain threshold. If your income is above the threshold, you can still buy insurance, just without the subsidies offered by the ACA. Individual plans are largely used by people who are self-employed or work for small employers who don't offer insurance (according to ACA rules, employers with fewer than 50 full-time employees are not required to provide insurance). Note, though, that certain self-employed people (such as actors, writers, and artists) may be able to obtain group insurance at lower rates through unions or professional membership organizations.

Assistance Programs

If you don't have insurance through an employer, partner, or parent/guardian and cannot afford to buy coverage, government programs can help. Contact your local department of health and human services/social services.

Medicare is a federally run program that provides health coverage to Americans over age 65 and to people with certain disabilities. It is referred to as a single-payer program because there is only one entity (the government) that pays for the healthcare of its enrollees, as opposed to multiple payers (insurance companies). The program is funded by the tax dollars of workers before they reach age 65 and typically pays only a percentage, often 80%, of eligible costs. The rest must be paid out-of-pocket or by a supplemental insurance plan.

Medicaid is a program that covers Americans of all ages who have low incomes or certain disabilities. It is jointly run by the federal and state governments. Income levels and other eligibility criteria for Medicaid vary by state, and different states may use different names for their Medicaid plans. Typically, this plan has no cost sharing for needed services, but the income qualifications are strict.

Coverage through Parent/Guardian and Partners

The ACA contains provisions that allow you to remain on your parent/guardian's insurance plan, if you choose, until age 26. Even if you stay on your parent/guardian's plan, you will be making your own healthcare decisions—you may change healthcare providers, especially if you relocate for college, or you may try new treatment regimens as they become available—so it will be important to understand the details of your parent/guardian's plan. Discuss the plan carefully with them, and make sure you understand it. Depending on what you and your parent/guardian agree to, you may need to take over the out-of-pocket expenses associated with the health plan.

When you are nearing the point of "aging out" of your parent/guardian plan, have them check with their employer's human resources department to confirm the timing. Some employers will allow coverage to continue unchanged until the end of the calendar year.

Whether you leave your parent/guardian's plan at 26 or earlier, it is vital that you maintain your coverage without any gaps. It is a huge risk to be uninsured for even a short period. Continuous coverage is essential for someone with PI since your condition does not take a break. As soon as you are no longer covered by your parent/guardian's plan, you'll need to have insurance in place either through work, school, an aid program, or a private plan. Begin the process of securing coverage several months in advance.

If you marry and your spouse has coverage, you are likely to be eligible for coverage on that plan. However, some employer-based plans will not cover spouses who have access to health insurance through their own employers. Privately purchased plans also have spouse and family versions. Some employers also extend health benefits to qualified domestic partners.

When deciding whether to go on your spouse's or domestic partner's insurance plan or to put that person on your plan, you need to thoroughly compare the plan benefits to determine which is going to meet your needs and best cover your treatments. You may want to crunch the numbers as well. It may be financially advantageous for you and your partner to be on one plan, and there may even be a financial reward for doing so. Be sure to discuss the options with your human resources department, and take into account all of the factors.

Types of Insurance Plans

Most modern plans are what is known as managed care, meaning certain aspects of the plans are limited to keep the insurance company's costs down. The managed care plans you'll probably hear about most often are health maintenance organizations (HMOs) and preferred provider organizations (PPOs). The main aspects that are managed, or limited, are the range of services and procedures you can get and the pool of healthcare providers you can choose from. It is also important to note that, no matter what the type of plan is, some treatments will require pre-authorization, meaning that the insurance company needs to approve them before they happen. Your healthcare provider's staff will normally take care of this for you, as they will need to explain the reason for the treatment.

Health Maintenance Organization (HMO)

The premise behind the name is that if you maintain your good health—or maintain your chronic condition at its least severe state—you will cost the insurance company less by not requiring expensive treatments when you get sick. In an HMO, you are required to have a primary care provider, and in most cases, in order to see a specialist, you must initially be referred by your primary care provider. You are responsible for any referral that is needed, and it is helpful to send it to your specialist prior to the appointment. Once you are under a course of treatment with a specialist, such as your immunologist, you can continue to see that specialist.

Your primary care provider and any specialists must be members of the HMO's group of healthcare providers, known as its network, in order for the plan to pay for care. If you see a healthcare provider who is not a member of the network, you will be expected to pay for the entire bill. This is also true for laboratories and pharmacies. Some HMOs occupy their own facilities, so you go to the same building or campus for all or most of your care. Other HMOs are spread over various locations. The important thing is always to make sure all of your care comes from within the network of participating providers, known as in-network providers.

Exceptions to this rule occur when there is a dire emergency or when the network doesn't have a healthcare provider who can provide needed treatment. When that happens, you must go through an approval process with the HMO to go outside the network.

HMOs are often considered the most economical plans because they tend to have relatively low deductibles and coinsurances. Their premiums may be higher than plans that have high deductibles and coinsurances. HMOs are also relatively hassle-free in terms of payment. Usually, you show up, show your insurance card and referral, pay your copay if you have one, and the rest of the billing and payment happens behind the scenes.

Preferred Provider Organization (PPO)

'Preferred providers' refers to the plan's network, similar to an HMO's network, but usually more expansive. And, unlike an HMO, a PPO does not require a primary care provider to act as your central point of care and to make referrals. You can, in most cases, see a specialist whenever you choose. You can also choose to see a healthcare provider outside the network, and the plan will still contribute, but at a reduced rate. That is, your coinsurance for a PPO might be 10% for in-network healthcare providers and services but 50% if you go outside the network.

This is important if you already have healthcare providers who are true specialists and know how to treat PI. It can be advantageous to stay with healthcare providers who know your history. When choosing a PPO, find out if those healthcare providers are in the network; if they are not, then you have to decide whether staying with those particular providers justifies the higher cost.

Filing claims happens behind the scenes if you use network providers; if you go out of network, you'll need to handle the paperwork. Many treatments, in or out of network, require pre-authorization. If you're not sure whether they do, ask. Even treatments that are approved may not be covered and paid for if they have not been pre-authorized.

PPOs tend to have higher cost-sharing in the form of deductibles and coinsurance than HMOs, but if you choose very high deductibles and coinsurance, your premium could be relatively low.

Point-of-Service (POS)

This stands for point-of-service. It is sort of a hybrid of an HMO and a PPO. Like an HMO, it requires a primary care provider and referrals for specialists. But once those are established, any specific medical care event, or "point of service," can take place within or outside the network. As with a PPO, you will pay a higher percentage of the cost for out-of-network care, but you won't have to pay the entire cost of the visit, as you would in an HMO. You'll also have to handle the paperwork for out-of-network visits. Covered treatments don't usually require pre-authorization, but it's best to be safe and ask if in doubt.

Exclusive Provider Organization (EPO)

This stands for exclusive provider organization. This is almost just like an HMO, but it doesn't require you to have a primary care healthcare provider or to get referrals to see specialists. Cost sharing is relatively low, and billing is hassle-free. Be careful, though, that any healthcare provider you see, or procedure or prescription you get, is in the network, or you will be billed for all of it. Many procedures require pre-authorization.

Indemnity Plans

Indemnity plans, sometimes called fee-for-service plans, are becoming rare and do not fall under the rubric of managed care but rather are considered self-managed because they have no network restrictions. You can see any healthcare provider you choose,

Chapter 2 – Introduction to Health Insurance

but your out-of-pocket costs could be high. The plans are like others in that they do define what services they cover, and they have deductibles, after which they pay a set percentage, often 80%. Many have annual out-of-pocket maximums, after which they pay 100%.

However, these plans also limit their contribution by designating “usual, customary, and reasonable (UCR)” amounts for any medical services. So if a plan says the UCR amount for a certain procedure is \$1,000, but you get a \$2,000 bill, the insurance company will pay its percentage on the first \$1,000, and you’ll be completely responsible for the remaining \$1,000. Therefore, it is very important to pay attention to what your healthcare providers charge for procedures and what your plan deems to be UCR amounts.

A note about networks: Your college plans or your career may take you places where there are no healthcare providers that are part of the network used by your existing health plan. In this case, you will need to call your insurance company and request a network gap exception. You’ll need to be ready to tell them exactly what care you need, how often and how long you’ll need it, and the contact information of an out-of-network healthcare provider you believe can treat you, or if possible, the information for a few healthcare providers, including specialists for a rare disorder.

Saving for Your Shared Costs

Because people with PI can usually count on having to pay out of pocket for a substantial amount of medical care each year, savings accounts that help you maximize your healthcare dollars can be quite helpful.

The two main types of healthcare savings accounts are Flexible Spending Accounts (FSA) and Health Savings Accounts (HSA).

These accounts allow you to set aside money, tax-free, to use for out-of-pocket health expenses like copays, coinsurance, and prescriptions. If you get your savings plan through an employer, the amount you choose to put toward your savings is automatically deducted from your paycheck and placed in the account. Some employers even contribute money as well as an added workplace benefit.

You cannot simultaneously have an FSA and an HSA, so you have to decide which works better for you.

HSAs are available only with high-deductible insurance plans. If you know you’re stuck paying that deductible each year, an HSA can at least be an effective way to save for it. If you don’t use all the money you put into an HSA during the year, the amount will roll over to the next year, and you can also take your savings with you when you change employers or plans. Many employers offer HSAs if they offer high-deductible health plans, and they are also available to self-employed individuals through private insurers or banks.

With an FSA, you must use your funds within the plan period. Recently there has been a change that allows employers to amend their plan documents to allow participants to carry over up to \$500 to the following plan year. This amount may change on an annual basis.

Both accounts have a limit on how much you can put in them per year set by the Internal Revenue Service (IRS), but HSAs have higher limits. Be sure to keep records of all medical costs you use your savings for, and keep all your receipts in case you need to show that the expenses were eligible.

Healthcare Reforms

As you navigate the world of healthcare and insurance, you’ll frequently hear references to HIPAA. This is the Health Insurance Portability and Accountability Act, introduced in the 1990s to protect people from losing their coverage when they leave or lose their jobs. HIPAA helped people with chronic illness transfer from one group plan to another without letting the new plan reject them because of their condition. It also helped standardize codes that identify diagnoses, treatments, and providers. The ACA built upon these measures and is described in more detail below. HIPAA is also designed to protect patient privacy and requires patient permission to transmit certain kinds of information.

Patient Protection and Affordable Care Act (ACA)

The ACA expanded protections for patients with chronic conditions. It used to be that a person with a chronic condition like PI had to seek a job at a company with an excellent group plan or marry someone working for such a company. The passage of the ACA makes insurance more accessible to individuals by lowering costs for people who have less than a certain amount of income, and it defines a set of services that plans must cover. The most significant provision is that companies cannot charge higher rates or deny coverage for people with pre-existing conditions.

It also requires all plans to pay for certain preventive care without cost-sharing (i.e., with no copay or coinsurance and without the insured person having to meet their deductible) such as annual wellness checks that include weight, blood pressure, and cholesterol assessment, as well as screening for diabetes, sexually transmitted diseases, and certain other infectious diseases, testing for some kinds of cancer, screening for depression and substance abuse, and a number of other services that depend on age or gender. Be sure to take advantage of these since taking care of your overall health is crucial for managing your PI.

Also, as previously mentioned, the ACA allows young adults to stay on their parent/guardian's plans until age 26. Before the ACA went into effect, many plans canceled coverage for people when they turned 19. The ACA also prohibits insurance companies from placing a cap on the amount they will pay for your care in a year or in your lifetime. This means that companies cannot at any point say they won't pay for your needed care anymore because they think you are costing them too much.

For people not receiving insurance from large employers, schools, parent/guardian, or partners, the ACA streamlines the experience of shopping for a plan and may offer assistance in paying for it. The ACA Marketplace, also known as the ACA Exchanges, can be found at [healthcare.gov](https://www.healthcare.gov). Many states also have their own marketplaces.

The sites will lead you through a series of questions to determine if you qualify for assistance and if so, how much. You can then use comparison tools to assess plans, which come from various private insurance companies. In the ACA Marketplace, there are cost-sharing tiers referred to as bronze, silver, gold, and platinum. These levels all cover the same services. The difference is the out-of-pocket costs. A bronze plan will have lower premiums, and higher deductibles and coinsurances. A platinum plan will be the opposite, and silver and gold will fall in between.

Choosing a Health Insurance Plan

Some employers offer one plan, and some offer a few different options. On the private market, there are many, many options. However you are getting your plan, your criteria for evaluating and deciding will be roughly the same.

No matter which type of insurance you get, you'll need to check the details of the specific plan to be sure the treatments you need are covered. If you need to regularly see an immunologist or receive immunoglobulin (Ig) replacement therapy, confirm that those are among the treatments the plan covers. It may be difficult to ascertain online what various plans cover regarding Ig therapy, so you may need to call the company to find out. You're more likely to reach the appropriate department if you have diagnosis and procedure codes (for example, ICD10, CPT, J codes, and HCPCS) at hand. Ask your current healthcare provider's office for these codes before calling insurance companies.

Also, check whether receiving your treatments comes with conditions, such as the site of care or route of administration. You should also check the prescription coverage section of the plan to find out whether all medications you use are listed, and if they are not, let your healthcare provider know so possible substitutions can be made. You should confirm the coverage amount of any specialist, treatment, or drug you anticipate needing regularly. If you receive care or get a prescription that is not listed as eligible, you may end up being billed for its full cost, so, it would be better to keep looking for a different plan if these items are not included. If you receive immunoglobulin therapy, you should know that it is not covered under the prescription plan for many insurances but rather the major medical benefit. Sometimes people mistakenly think Ig therapy is not covered if they only ask about it in the context of the insurance's prescription plan.

If your insurance comes from your employer, you can ask your human resources department these questions, but if you have not told your employer about your condition, you might want to contact the insurance company yourself. If you do, have your plan info—group number and plan number—ready. Normally these are on your insurance card and are easy to find. It will help to have the diagnosis and procedure codes in front of you as well.

Crunching Numbers

Some plans will have very high premiums and low deductibles, coinsurance, and out-of-pocket maximums. With other plans, the premium is low, but the other costs are high.

In general, plans with low premiums and high other costs are suitable for people without known health conditions since the odds of needing substantial medical care are relatively low. People who choose these plans figuratively roll the dice and bet that they will not become seriously ill or injured. In the event something happens to them, they still owe only their out-of-pocket maximum in a given year. That may be \$10,000 or so, but it beats the hundreds of thousands of dollars of debt that could be incurred if something serious happened and they had no insurance. In this scenario, health coverage is really just a safeguard against financial catastrophe in case of an accident or serious or chronic illness diagnosis.

For people who already have health conditions—such as PI—the story is different. You can expect to incur many medical expenses every year. That means you might come out ahead in the long run if you pay a higher premium each month but have a low out-of-pocket maximum that you meet early in the year and afterward enjoy the insurance company's full coverage.

It's all a matter of doing the math. But often, the math can play out in many different ways. Maybe your January treatments will knock out the whole out-of-pocket for a plan and cause your insurance to kick in fully. In that case, if you can manage that up-front January cost, it makes sense to carry a plan with low premiums, which will cost you less for the rest of the year.

Contact IDF if you have questions about insurance: www.primaryimmune.org/ask-idf or 410-321-6647.

Chapter 2 – Introduction to Health Insurance

Manage Your Costs

Just because you have PI doesn't mean you won't be as successful and fulfilled as anyone else. But your medical costs, which will be ongoing and likely significant, present a bigger financial challenge than many people face. Through smart management of your health plans and savings, though, you can minimize the financial impact of your condition.

It is very important to keep your care in-network if at all possible. This includes your healthcare providers, treatment facilities, laboratories, and pharmacies. It may be the case that you've built a relationship with a certain provider, and when you change plans, your provider is no longer in-network. You have to decide if staying with that healthcare provider is worth the increase in your cost. Talk with your current healthcare providers about your situation and see if they have any recommendations for network healthcare providers with similar practices and philosophies. Alternatively, speak to your medical team regarding the cost of healthcare if you are out of network.

It's also important to:

- Be sure you know if procedures require pre-authorization, and if they do, take steps to get it or make sure your healthcare provider does.
- Know whether seeing a specialist requires a referral from a primary healthcare provider, and if it does, get it.
- If your plan requires a primary healthcare provider, make sure your insurance company has that healthcare provider's information on file. If you see a primary healthcare provider but your plan thinks you're supposed to go to a different healthcare provider, it can cause problems.
- Keep scrupulous records of all your interactions with insurance and medical providers.

Whenever you receive medical treatment, you will receive an Explanation of Benefits (EOB), from your insurance company. You'll need to learn how to read these documents and determine whether the insurance has paid or denied bills. Always check the EOB against the receipt from your healthcare provider's office to make sure there are no errors or inconsistencies. Sometimes a denied claim is simply a mistake.

If a claim is denied, call your insurance company, and have all your records, including diagnosis and procedure codes, ready. Each time you call, get the agent's name and keep a record of the call. If necessary, ask your healthcare provider's office to contact the insurance company. Sometimes the healthcare provider will need to explain to the insurance company exactly why a procedure is medically necessary and not optional.

Remember that your healthcare providers and their staff are your allies. They are in the business of healing people, and the last thing they want is to see someone's lack of funds result in a lack or a delay of treatment. Plus, they are the real experts on conditions such as PI and knowledgeable on the most effective, medically necessary treatments for you. Having your healthcare providers explain these things to your insurance company and assure insurers that the treatments are necessary can go a long way toward getting claims paid.

Your healthcare provider's office may be able to help in other ways. Sometimes scheduling appointments strategically can help you manage expenses. If you have treatment due in January of the next year, but you have already met your out-of-pocket maximum for the current year, the healthcare provider's office might be able to shift your appointment slightly, so it falls in December. This gets it in under the wire for full coverage. As long as your healthcare provider says it's okay, any costs you can squeeze into the end of the year will buy you a little more time before you have to start paying in the next year.

Your healthcare providers might also be willing to work with you to pay your portion of out-of-pocket costs in installments if it is difficult for you to pay the full sum at once.

Also, work with your healthcare provider if certain drugs are not covered. There may be a very similar one that is more affordable. With some plans, generic versions of drugs are less expensive than branded drugs, and if so, you can ask your healthcare provider if generic drugs are acceptable alternatives.

If you have infusions, you might also be able to save money by adhering to your insurance company's guidelines on site and route of care: home vs. hospital, IV vs. subcutaneous, or facilitated subcutaneous. If you and your healthcare provider are flexible, you could save substantially. But remember that your insurer is not your healthcare provider. If your healthcare provider recommends a particular drug or treatment that is not preferred by your insurance company, there are avenues for appeal. Your healthcare provider can do a peer-to-peer consultation with the medical directors or pharmacists at the insurance company to get your therapy approved. You also have the right to appeal any adverse decision. Every state also has an insurance commission to help with insurance problems. The staff in this office can help you file an official grievance against an insurance company and can be a valuable ally in helping you to get a resolution.

Insurance plans are fluid and frequently change their coverages and conditions. By law, they must let you know when this happens, either by mail or by email, if you have opted into electronic communication. Such letters might not be the most fascinating items in your mailbox but always read them. They may be telling you about changes that require action or planning on your part.

Your insurance company will probably have a website where you can create a profile. There you can view Explanations of Benefits, track your spending, and use calculators to estimate the costs of planned treatments. You can also check what brands of drugs are covered and find the names of alternatives to drugs you need that aren't covered.

Some drug manufacturers offer loyalty programs in which they'll provide discounts on their products, help pay pharmacy copays, or even offer free products for a limited time if you qualify. Check the manufacturer's website.

If your career plans lean toward self-employment, research professional membership organizations in your field to see if any offer group rates for insurance.

If you are married or living with a domestic partner, remember that your finances are a team effort, and do the research to figure out whose insurance will serve you best. If you have children, find out whose plan better covers them.

And finally, sometimes you find help where you least expect it. The IRS allows some tax relief for medical expenses if they are high enough. If the amount you spend on medical care exceeds 10% of your adjusted gross income for a year, you can deduct those medical expenses on your tax return. As a long-term patient, you may well qualify for this deduction, so be sure to investigate it when filing your taxes.



Chapter 3

College, Career, and Dating

As you approach adulthood, possibly the most important question you'll ask is: What am I going to contribute to the world? If you're one of those people who has known the answer to this question for some time, congratulations—your work is half done! But don't worry if you don't know the answer yet. Some extremely interesting and successful people in their 40s or 50s are still searching for what they want to be when they grow up. You just have to do your best to find whatever path seems to lead toward a combination of financial support and satisfaction.

College Life

If your life plan includes a college degree, you might already be making a list of potential schools to attend. This huge and difficult decision is based on many factors, and people who have PI have some additional considerations.

Considerations for everyone:

- What schools offer the course of study I want (if I know what that is)?
- Do I want to live near or far from my parent/guardian?
- Are the schools I like public or private?
- What schools among these are located in the state where I currently reside?
- Are there scholarships I might qualify for that would help cover costs at particular schools?
- Do I have the required grades and coursework to meet the school's admissions requirements?

Additional considerations for students with PI:

- Do I want to stay close enough to home to keep seeing my same healthcare providers and places for treatment?
- What health insurance will I be on, and does it cover healthcare providers and infusion sites (if needed) in the location I am considering?
- Can my current healthcare providers recommend healthcare providers in the place I'm considering?
- Are the people in the Student Services office of the schools I am considering accommodating and knowledgeable about my rights and needs as a student with a chronic illness?

**It is important to note that not all immunologists have the same level of expertise and experience. They may not have patients with your particular condition, so their knowledge can vary dramatically. You'll need to make sure any new healthcare team is up to speed on your specific condition. If the location you're considering doesn't have any top-notch experts, it may be grounds for reconsidering that location. Some world-class immunologists are affiliated with universities; their presence might cause you to consider going to or, at least, consider that university if it also meets your academic needs.*

Under the Americans with Disabilities Act (ADA), it is illegal for an educational institution to discriminate against people with disabilities. This means they must be equally accessible to those with disabilities. As a person with PI, you can request that your school provide what is called an academic adjustment—modifications to their normal procedures that will allow you to pursue your degree despite your condition. It is your legal right to request the modifications if you feel you need them, and it is the school's legal responsibility to provide them within reasonable limits. Please note, however, that they do not have to let you receive infusions in your dorm room; they can make other arrangements if there is a perceived liability issue.

You can contact the ADA coordinator or the office that handles such requests at any school you are considering. If you think you need particular accommodations, the staff can guide you through the process of putting in place accommodations that will level the playing field between you and your fellow students. You may have to provide proof of your condition, such as documentation from your healthcare providers.

Depending on the school, it might also be helpful if your healthcare provider and immunology care providers can furnish some general information about your PI—what it is, why it needs treatment, how it affects people—in case the staff at your school are unfamiliar with PI. Think of yourself as educating your educator. Your work might pave the way for future students.

To help keep track of all the tasks associated with making your entry into college life, look at the “Countdown to College” checklist in the Resources section.

College Housing

You'll also need to discuss with the school your options for housing and any rules they have about receiving treatments, such as infusions, within on-campus housing.

There are other housing factors to weigh besides any treatments. Dorms can be a more economical option than renting a place to live. They also offer the benefit of convenience—walking or biking to class—and the excitement of being at the center of the action. Living in a dorm throws you right into the thick of things socially and can be a way of finding your bearings and developing fast and, possibly, lasting friendships. In addition, you can buy semester meal plans covering the dorm cafeterias, and having ready-made meals can be both a time-saver and a reliable supply of nutritious food.

On the flip side, you'll lack privacy in a dorm, especially if you have a roommate. If you'd rather keep your PI private, this could be a problem. If you do infusions around dorm mates, you will likely need to explain your condition to them.

Another consideration is whether you're likely to be able to get enough rest. If you're on a rowdier floor, it might be a challenge. Plus, you'll have to share a bathroom, possibly with a whole floor full of people, and that might not be ideal given your health needs. You will want to discuss all of this with your healthcare providers ahead of time.

Some middle-of-the-road options to explore include private dorm rooms, dorm rooms on designated quiet floors, or an on-campus apartment with one or two roommates with whom you're already friendly. Private dorm rooms are usually much more expensive than shared rooms, but housing accommodations are covered under the ADA, and the staff at the school can tell you if they can allow you a private dorm room based on your medical needs without charging you the extra cost. In some cases, private or semi-private bathrooms might even be available. It doesn't hurt to ask and explore all the options.

Medications in School

If you have a PI that requires you to administer any medication, like immunoglobulin, interferon-gamma, or adenosine deaminase, you need to find out if there are any limitations on injections or infusions in on-campus housing. Medication and supply storage also need to be considered. If you are using a particular specialty pharmacy or infusion care provider, you need to see if that provider can service you in your new location. It may be that you will need to find a new provider. You may need to contact your insurance company to find out who their preferred providers are. Changing providers sometimes requires you to have a new pre-authorization. All of these arrangements need to be made well in advance of your move. See Chapter 2 for more details on insurance. Don't commit to living in or out of a dorm until you know for sure how your choice will affect your treatments.

Also, be sure there are some people around you whom you've briefed on what to do if you have a medical emergency. These may be your roommates, neighbors, or the dorm's residence assistants. It's also a good idea to fill out and keep with you an “I Am Immunocompromised” card.

The Balancing Act

College is a busy time when you balance studies with social life and work. As a person with PI, you need to approach all of these aspects of college with caution. If you find yourself struggling with your schedule, staff in the Student Services or Office of Disability should be able to assist in finding resources to help you.

If you do need to work during school, try to find a job you enjoy and one with coworkers you like. If the job provides experience pertaining to your future career, all the better. The main thing is to avoid piling on physical and emotional stresses that wear you down and weaken your body's defenses.

Chapter 3 – College, Career, and Dating

Your PI needn't determine the trajectory of your education, whether it's a vocational program, a Ph.D. track, or something in between. The real success factors in school will not be your health condition but your commitment and passion for achieving your goals. In the end, it all comes back to choosing the course of study that's right for you. With proper planning for treatments and healthcare, you'll achieve as much in school as you hope to.

The Working Life

Whether you start your career right after high school or after postsecondary education, you can thrive if you keep a few things in mind. Remember, it is a personal decision to disclose your diagnosis to your employer. You are not required to do so. If you choose to, you do have particular rights under the ADA and other employment laws.

Work Rights and Responsibilities

Employers with 15 or more employees must comply with the rules of the ADA. This mandate gives you several protections if you choose to avail yourself of them. Again, it is up to you whether you choose to disclose your PI to your employer or not. In any event, you need to be able to meet the essential requirements of your job.

If you decide to disclose your PI, tell the human resources department, and be ready to explain what the condition is and provide documentation from your healthcare team. Also, have a discussion with your direct supervisor. Don't present your condition as an obstacle, but instead emphasize that you've always managed your illness, and it has taught you a great deal about perseverance and resourcefulness. Emphasize your commitment to the work you are doing. By law, an employer cannot fire you or otherwise let your disclosure affect your position, but it is still a good idea to reinforce confidence in your performance ability.

Federal employers are required to proactively seek workers with disabilities, who will have a checkmark for disabilities on their applications. In this case, you would disclose your condition before the interview process begins, and it could actually be to your benefit. With most employers, however, you probably wouldn't want to mention a health condition prior to being hired, and they are not allowed to ask. They can ask only if you are able to perform the essential duties of the job. You need to be able to answer that question honestly for yourself as well as for them, and if the answer is yes, it's usually best to leave it at that. Even though employers cannot legally reject your application based on your health condition, the only way they can be held accountable for that is for you to sue them and show evidence that your condition was the reason they did not hire you.

The ADA requires employers to offer a reasonable accommodation to employees with a disability. A reasonable accommodation is any modification or adjustment to a job, practice, policy, or work environment that allows an individual with a disability to participate equally in an employment opportunity without creating an undue burden for the employer. Reasonable accommodations may include:

- Modifying a work schedule.
- Acquiring or modifying equipment.
- Time off for medical appointments
- Telecommuting arrangements.

Don't worry that you're withholding information or keeping secrets. It is your life and your business. If you choose not to tell your employer about your condition even after being hired, they cannot accuse you of doing anything wrong. There are many aspects of your personal life you don't share, and PI can be one of those if you wish.

If you do ever feel you have experienced discrimination based on your condition, visit these websites for information on recourse options: ada.gov, www.askkjan.org, and www.wearecapable.org.

Relationships

People you date need a chance to get to know you before they get to know your condition. When you decide to tell them about your PI is a very personal decision. If you tell them too early, it may negatively affect the relationship, perhaps even ending it before you really get to know each other. On the other hand, if you wait too long, they may wonder why you weren't more open. Trust your intuition to guide you in this decision. If a relationship is becoming serious, you'll be able to figure out when the time is right.

When you do discuss your condition, your partner will have questions, so be ready with answers. The questions might be about your long-term health outlook, whether it's safe for you to have children, and if you could pass your PI on to those children. When you ask your immunologist these same questions, how are the answers phrased? You can use similar phrasing to answer your partner.

It will help your partner accept your condition if you demonstrate that you accept it yourself. It won't help to convey your PI as a burden but rather as just a part of your life.

You can assure your partner that your PI is not contagious and doesn't require special precautions. However, it is especially important for you to engage in safe sexual practices such as using a condom, since an STD could pose more serious problems for your compromised immune system.

If you and your partner want children, the two of you should discuss with your immunologist the likelihood of passing your illness on to your children. If you and your partner both want children, together you will decide whether to have your own, or to opt for an alternative such as adoption or fostering.



Chapter 4

Strengthening Ties with Family and Friends

Your Evolving Relationship with Your Parent/Guardian

In the process of becoming independent from your parent/guardian, clear communication is key. Maintain dialogue and let them know what you are thinking regarding college, career, and other plans. There will be many issues to consider in making sure your health receives the continuous attention it needs, especially if you move out on your own. Your parent/guardian can help you—not as decision-makers and caregivers as they were before, but as supporters and consultants.

When you turn 18, by law, your parent/guardian will need your written permission to view your medical information or speak with your healthcare providers about your treatments. In taking care of your health and in other situations, they can, and hopefully will help you, but they can't direct you.

Your shift to independence might be difficult for them. Letting go is always hard, and being in charge of your well-being has probably provided a sense of security for them as much as it has for you. They might feel sad or wistful that your childhood is drawing to a close. Even if they don't show you these feelings, they probably have them. You need to be aware of this. Being sensitive to their perspective will help avoid conflict and assure them that you are ready for your new role.

Speaking with them and educating yourself about different aspects of adult life, especially your medical care, will not only reassure your parent/guardian, but it will also give you confidence that you are ready to take over steering your own course.

Strengthening Your Circle of Friends

Whether you leave home or stay close by for college or work, your social circle will probably expand as your interests shift. When that happens, you'll need to determine when and with whom to talk about your primary immunodeficiency (PI).

You don't have to tell most people about it at all unless you want to, but it might come up with roommates, good friends, people you date, and possibly with college professors and employers. Explaining your illness is likely not new to you—you already know what questions people have and what assumptions they tend to make. But this might be a good time to brush up on your PI "elevator speech." It's probably easiest to just keep things simple and assure people that you're basically okay. You can tell them that your immune system doesn't function the same way as individuals without a PI, so you're always at higher risk of getting sick. Explain that even with this risk, you still live a normal or near-normal life. An example of a script you can follow can be found in the Resources section.

Having a PI is only a part of you—it doesn't define you. You should never feel embarrassed about it. Don't let having a PI dissuade you from exploring all the social avenues you want to.

Chapter 4 – Strengthening Ties with Family and Friends

Your true friends will encourage you to make healthy decisions. If you're out late with friends, they shouldn't mind if you say you need to get home to get needed rest. If they encourage you to engage in unhealthy behaviors like cigarette smoking or using harmful drugs, your "friends" are not really thinking of your best interest. They also should understand that you should not be exposed to anyone who is sick. If they're impatient because you cancel plans due to illness, they are not being mindful of your reality. They probably don't mean any ill will, but they lack understanding of your situation and may not be the best people for your circle of true friends.

On the other hand, there will be people who understand and support you, and they will be your vital allies. They will help you through difficult times. It is always a good idea to invest in these relationships. Show these friends the same support they show you, and make sure to express your gratitude for who they are and what they do for you and mean to you.

You'll develop a sense of which friends can help and in what ways. Some friends will be emotional lifesavers, making you laugh when you most need to, and some will be able to help you in practical ways, like picking up prescriptions, looking in on you when you're sick, or driving you to your healthcare provider. Some may be people who know your family and can act as a bridge to them in an emergency. Make sure there are at least a few people near you who know what to do and whom to contact if you ever have a medical emergency.

Don't be afraid to ask for support when you need it. You can't be a good friend if you're struggling, so don't feel bad if you're down and need a little assistance in getting on your feet again. Getting help will put you in a position to offer help to others when they need it.

The web is a great world-shrinking support network too. We're fortunate to live in a time when we can find our own communities all over the globe. You might want to use forums and social media groups to connect with other people and share your PI experiences. IDF Friends, the online social network just for the PI community, is a great place to connect with others, www.idffriends.org. Check out other IDF resources in the Resources section.

But keep in mind that while the web is a wonderful resource, like everything, it does have some limitations. Don't believe everything you read and hear from others online. Be sure to consult your healthcare provider and make decisions that are best for you and your health.

Resources

Table of Contents

Personal Health Record Checklist	24
Transition Skills Checklist, Ages 12–14	25
Transition Checklist, Ages 15-17	26
Transition Checklist, Ages 18 And Up	27
College Checklist, 18 Months Out	28
College Checklist, 6 Months Out	29
College Checklist, 1 Month Out	29

Explaining Your PI

Since primary immunodeficiency diseases (PI) are rare, most people won't know what they are. You'll need to be able to explain your condition simply and politely to people, without going over their heads with too much detail. People are usually well-meaning but will inevitably wonder out loud why you don't look sick, whether your condition is a big deal, why you can't just fix it with better health habits, and whether they can catch it. Here are some scripts you can use or adapt to explain your PI to people.

In Casual Situations

"When I was [xx] years old, I was diagnosed with [your type of PI], which means part of my immune system is not working and I get sick really easily if I don't get [your type of treatment] treatments. Luckily, my treatments allow me to live a healthy and normal life."

OR

"I have a primary immunodeficiency called [your type of PI], which means I was born with [all or part] of my immune system missing. I get treatments called [name your treatment], which help me live a normal life. My PI is a genetic condition and not contagious."

In Emergencies

In emergency situations, you just need to convey your condition to the healthcare professionals who are helping you. You can share your "I Am Immunocompromised" card.

Checklists

Personal Health Record Checklist

Recommended information to record and keep readily available. Check off items as you add them to your personal health record.

	Brief history leading to your diagnosis, written by you or your healthcare provider.
	Copies of laboratory evaluations confirming your diagnosis.
	Current list of healthcare providers caring for you with accurate addresses and phone numbers.
	Letters of medical necessity written by your healthcare providers.
	Chronology of important events including: types of treatment, changes in treatment and subsequent response, infections, surgeries, hospitalizations.
	List of your current medications.
	Allergies, especially to medications.
	Infusion log, if you receive immunoglobulin replacement therapy.
	Immunization record, noting any lack of immunizations.
	Current insurance information.
	Explanation of benefits records; these can be kept in the journal or separately but should be reviewed for accuracy.

Transition Skills Checklist, Ages 12–14

GENERAL INFORMATION	YES	NO	ALMOST
I can tell someone the name of my primary immunodeficiency.			
I can describe the effect of my primary immunodeficiency on my body.			
I can share my medical history with a healthcare provider.			
I can list any allergies.			
I tell my parent/guardian about changes in my health.			
My parent/guardian keeps a personal health record for me.			
My parent/guardian and I carry a medical summary, such as the “I Am Immunocompromised” card.			

MEDICATIONS AND TREATMENT	YES	NO	ALMOST
I can list the names of my medications and the dosages and times at which to take them.			
I can explain why each medication is necessary, the result of not taking it as prescribed, and its side effects.			
I take all medications as prescribed and notify a parent/guardian when the supply is low.			
I use and take care of medical equipment/supplies and notify a parent/guardian if there is a problem or supplies are low.			
I can list medical tests that need to be completed regularly.			

MEDICAL APPOINTMENTS	YES	NO	ALMOST
I tell my healthcare provider how I am feeling.			
I answer at least one question per medical appointment.			
I ask at least one question per medical appointment.			
I spend some time alone with the healthcare provider during a medical appointment.			
I talk with my parent/guardian and healthcare providers about the medications and treatments I need.			
I tell the healthcare provider whether I understand and agree with the medication or treatment being prescribed.			

UNDERSTANDING THE HEALTHCARE SYSTEM	YES	NO	ALMOST
I know the date and reason for my next medical appointment.			
I know the names of my healthcare providers and how to contact them.			
I know the name of my health insurance and the importance of being insured.			

HEALTHCARE TRANSITIONS	YES	NO	ALMOST
I am taking more responsibility for my healthcare.			
I have talked with my parent/guardian and healthcare providers about whether I will need to see new providers when I’m an adult.			
I have talked with others about their healthcare transition experience.			

Transition Skills Checklist, Ages 15–17

GENERAL INFORMATION	YES	NO	ALMOST
My parent/guardian and I keep a personal health record.			
I carry a medical summary, such as the “I Am Immunocompromised” card.			

MEDICATIONS AND TREATMENT	YES	NO	ALMOST
I can explain why each medication is necessary, the result of not taking it as prescribed, its side effects, and the management of its side effects.			
I can select medication for a minor illness, such as a headache.			
I can refill a prescription.			
I can list medical tests that need to be completed regularly and make sure they are scheduled.			

MEDICAL APPOINTMENTS	YES	NO	ALMOST
I answer many questions during a medical appointment.			
I ask many questions during a medical appointment.			
I spend most of the time alone with the healthcare provider during a medical appointment.			
I decide with my parent/guardian and healthcare providers about medications and treatments I need.			
I can contact the appropriate healthcare providers to tell them about changes in my health.			

UNDERSTANDING THE HEALTHCARE SYSTEM	YES	NO	ALMOST
I can explain the difference between a specialist and primary care provider.			
I can explain legal rights and responsibilities available to me when I turn 18.			
I can explain how my health insurance works (network, deductible, copays).			

HEALTHCARE TRANSITIONS	YES	NO	ALMOST
I know whether any of my healthcare providers have transition policies.			
I have talked with my parent/guardian and healthcare providers about things I should think about if I need to see new providers when I’m an adult.			
I have identified some healthcare providers who will care for me when I’m an adult.			
I have talked with other teens and young adults about their healthcare transition experience.			

Transition Skills Checklist, Ages 18 and Up

GENERAL INFORMATION	YES	NO	ALMOST
I keep a personal health record.			
I carry a medical summary, such as the "I Am Immunocompromised" card.			

MEDICATIONS AND TREATMENT	YES	NO	ALMOST
I understand and arrange payment for my medications, equipment, and treatments.			

MEDICAL APPOINTMENTS	YES	NO	ALMOST
I can check myself in early or on-time at appointments and provide my insurance card.			
I can answer all questions during a medical appointment.			
I ask questions during a medical appointment.			
I am alone or choose who attends a medical appointment with me.			
I decide with the healthcare provider about medications and treatments I need.			
I can locate and share healthcare information with my providers and take part in making decisions about my care.			
I can sign medical consent forms.			

UNDERSTANDING THE HEALTHCARE SYSTEM	YES	NO	ALMOST
I can explain the difference between a specialist and a primary care provider.			
I can explain legal rights and responsibilities available to me since I turned 18.			
I can explain how my health insurance works (network, deductible, copays).			

HEALTHCARE TRANSITIONS	YES	NO	ALMOST
I have decided which things to consider when selecting a new healthcare provider.			
If necessary, I have transitioned to a new healthcare provider.			
If necessary, I have shared medical information with a new provider.			

Countdown to College for Students with PI

Use the checklists below to evaluate the suitability of schools in terms of your unique healthcare needs. Start with the first list about midway through your junior year of high school and fill it out for each school you're considering. Finish up with the third list about a month before launching into freshman year of college.

For each school you're considering, check off each item as completed and fill in any needed information. If you find it helpful, in the right-hand column, assign a grade for each item according to how it makes you feel: A for items that make you favor the school, F for items that could be deal-breakers. Use the grades as part of your process of narrowing the options to a short list.

By six months before leaving, you'll probably know not only which schools you like, but also which have accepted your application. In the next few months, you'll make the big decision.

You can use the third list to help wrap up final details of ensuring your PI care will be continuous and consistent as you begin your studies.

18 Months to Blastoff: Researching and/or Visiting Colleges

NAME OF SCHOOL	DONE	GRADE
Distance from home: _____		
Time it takes you to drive home to visit family/friends, or see old healthcare provider: _____		
Name of the contact person in the Office of Disability Services, or the ADA coordinator: _____		
I have met with the contact person virtually or in person.		
I understand what disability accommodations are offered.		
I understand policies for administering medications in dorms.		
I understand policies for administering medications in non-dorm housing on campus.		
Can I get a private dorm room?		
Does it cost more to get a private dorm room?		
Can I get a private bathroom in the dorm?		
How many bathrooms are there per floor?		
I have looked at the dorm rooms and floors.		
Are quiet floors available in dorm buildings?		
How far is it from potential housing to the farthest likely classroom?		
I have walked the campus to get a feel for distances.		
I have researched and/or tried public transportation in the area.		
I understand what parking permits are needed for various areas of campus.		
I have visited or learned about the campus healthcare center.		
I have spoken to admissions personnel about available health insurance.		
I have a summary of available insurance options and a plan for how I will be insured.		

6 Months to Blastoff: Honing in on Details

NAME OF SCHOOL	DONE	GRADE
There are high-quality healthcare providers in the area who are in my insurance network and who are qualified to treat my PI.		
I have met with my potential healthcare providers, in person or virtually.		
There is an infusion center nearby where I can receive my infusions, if I'm not receiving them at my residence.		
I know how to get to my medical appointments (drive, walk, public transport).		
I have requested pre-authorization for my treatments from my insurance plan, if needed.		

1 Month to Blastoff: Final Countdown, All Systems Go

SCHOOL I AM ATTENDING: _____ DATE OF ARRIVAL: _____ DATE CLASSES BEGIN: _____	DONE
I have completed my HIPAA authorization form, medical power of attorney (POA) form, and durable power of attorney forms, both for my home state, and the state where I'm attending college.	
I have an "I Am Immunocompromised" card stored where it will stay with me.	
My new healthcare providers have received my records from my previous team.	
My existing prescriptions have been transferred to my new pharmacy, including my specialty pharmacy.	
I have appointments in place for medical treatments or visits needed within the first few months of school.	

Additional Resources

Immune Deficiency Foundation

Ask IDF: Contact IDF for free, individualized assistance on questions about living with primary immunodeficiency (PI) through the IDF website: <https://primaryimmune.org/ask-idf>.



Get Connected Groups: Designed to connect individuals diagnosed with PI and family members in their local communities: <https://primaryimmune.org/idf-get-connected-groups>.



Publications: All IDF publications can be downloaded at <https://primaryimmune.org/resource-center>. You can also order free hard copies if they are available. Specific publications that are helpful include:



- This publication (*Immune Deficiency Foundation Guide for Young Adults*©).
 - The chapter from the *Immune Deficiency Foundation Patient & Family Handbook for Primary Immunodeficiency Diseases – 6th Edition*© that describes your child's specific type of PI.
 - "I Am Immunocompromised" card.
-

Education Resources

Go Transition | <https://gottransition.org/>

Got Transition is the federally funded national resource center on healthcare transition (HCT). Its aim is to improve the transition from pediatric to adult healthcare through the use of evidence-driven strategies for clinicians and other healthcare professionals; public health programs; payers and plans; youth and young adults; and parents and caregivers.

HEATH Resource Center at the National Youth Transitions Center | <https://www.heath.gwu.edu/>

The HEATH Resource Center is the national clearinghouse on postsecondary education for individuals with disabilities. It provides information about educational support services, policies, procedures, adaptations, and opportunities at college campuses, vocational-technical schools, and other postsecondary training sites.

U.S. Department of Education, Office of Civil Rights | <https://www2.ed.gov/about/offices/list/ocr/index.html>

OCR's mission is to ensure equal access to education and to promote educational excellence through vigorous enforcement of civil rights in our nation's schools.

U.S. Department of Education, Office of Special Education and Rehabilitative Services

<https://www2.ed.gov/about/offices/list/osers/index.html>

OSERS' mission is to improve early childhood, educational, and employment outcomes and raise expectations for all people with disabilities, their families, their communities, and the nation.

U.S. Department of Education, Student Privacy Policy Office

<https://www2.ed.gov/about/offices/list/oeped/sppo/index.html>

SPPO is responsible for the administration and enforcement of federal laws relating to the privacy of students' education records, and for the provision of technical assistance on student privacy issues for the broader education community.

Organizations Focused on Primary Immunodeficiency

International Patient Organization for Primary Immunodeficiencies | <https://ipopi.org/>

International Patient Organization for Primary Immunodeficiencies (IPOPI) is an international organization whose members are national patient organizations for primary immunodeficiency diseases. The website provides general information on primary immunodeficiency diseases and resource contacts for patients and professionals worldwide.

The Jeffrey Modell Foundation | <http://www.info4pi.org/>

The Jeffrey Modell Foundation is dedicated to early and precise diagnosis, meaningful treatments, and, ultimately, cures for primary immunodeficiency.

Primary Immune Deficiency Treatment Consortium | <https://www.rarediseasesnetwork.org/spotlight/v9i1/PIDTC>

The Primary Immune Deficiency Treatment Consortium (PIDTC) is a part of the Rare Diseases Clinical Research Network (RDCRN) funded by the National Institute of Allergy and Infectious Diseases (NIAID) and the National Center for Advancing Clinical and Translational Sciences (NCATS).

Diagnosis-Specific Patient Groups and Organization

A-T Children's Project | <https://www.atcp.org/>

The A-T Children's Project is a nonprofit organization that raises funds to support and coordinate biomedical research projects, scientific conferences, and a clinical center aimed at finding a cure for Ataxia-Telangiectasia (A-T), a lethal genetic disease that attacks children, causing progressive loss of muscle control, cancer, and immune system problems.

APS Type 1 Foundation | <https://apstype1.org/>

The APS Type 1 Foundation was started by a group of dedicated parents who were determined to ensure that their children received the best care possible and that no one should have to wait for a diagnosis or treatment for Autoimmune Polyglandular Syndrome Type 1. The foundation supports education, awareness, and fundraising for critical research in APS Type 1.

CGD Association of America | <https://cgdaa.org/>

The CGD Association of America is an independent, nonprofit organization that is committed to advocating for patients and carriers with chronic granulomatous disease.

Chronic Granulomatous Disease Association | <http://www.cgdassociation.org/>

The Chronic Granulomatous Disease Association (CGDA), founded in 1982, is a non-profit international support group for persons with chronic granulomatous disease (CGD), their families, and physicians. The organization networks patients with similar CGD-related illnesses or infecting organisms. It provides research grants aimed at finding a cure for CGD.

Hereditary Angioedema Association, Inc. | <https://www.haea.org/>

Founded and staffed by HAE patients and HAE patient caregivers, U.S. Hereditary Angioedema Association, Inc. (US HAEA) is a nonprofit patient advocacy organization dedicated to serving persons with angioedema. The association provides HAE patients and their families with a support network and a wide range of services including physician referrals, and individualized patient support.

Hyper IgM Foundation | <https://hyperigm.org/>

The Hyper IgM Foundation's mission is to improve the treatment, quality of life and long-term outlook for children and adults living with Hyper IgM.

International 22q11.2 Foundation | <https://22q.org/>

The International 22q11.2 Foundation is a nonprofit organization dedicated to supporting the needs of families and individuals affected by chromosome 22q11.2 differences by promoting awareness, state-of-the-art clinical care, cutting edge research endeavors, and solidarity with related associations around the globe.

liam's lighthouse foundation | <https://www.liamslighthousefoundation.org/>

liam's lighthouse foundation (LLF), a non-profit, tax-exempt organization, was established to create and provide educational material and awareness about Hemophagocytic Lymphohistiocytosis (HLH) including Histiocytic Disorders, and to distribute unbiased, factual information to physicians, hospitals, and the community regarding this disease.

SCID Angels for Life | <http://www.scidangelsforlife.com/>

SCID Angels for Life is a nonprofit organization that increases awareness, benefits research, and provides parent and family education for those affected by Severe Combined Immune Deficiency (SCID).

Wiskott-Aldrich Foundation | <http://www.wiskott.org/>

This site provides information about Wiskott-Aldrich Syndrome (WAS). The links on this site include information for patients and families, the latest research related to WAS, and financial support.

XLA Life | <https://www.xla.life/>

XLA Life's mission is to improve the quality of life for those affected by X-Linked Agammaglobulinemia (XLA).

XLP Research Trust | www.xlpresearchtrust.org

This organization promotes and funds research into the cause, management, symptoms, and cure for X-linked Lymphoproliferative (XLP) disease; raises awareness of the disease; and is a point of contact and support for families affected by XLP.

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