

Immune Deficiency Foundation

Patient & Family Handbook

For Primary Immunodeficiency Diseases

.....

Chapter 40

Immune Deficiency Foundation

Patient & Family Handbook

For Primary Immunodeficiency Diseases

6th Edition

The development of this publication was
supported by Shire, now Takeda.



110 West Road, Suite 300
Towson, MD 21204
800.296.4433

www.primaryimmune.org
idf@primaryimmune.org

Chapter 40

Employment and Primary Immunodeficiency Disease

Brian Rath, JD, Immune Deficiency Foundation, Towson, Maryland, USA

For people with primary immunodeficiency diseases (PI), employment is about more than just making money and job satisfaction. You need a job that will allow you to perform at a high standard with your disorder and will offer good health insurance benefits. There are many people with PI who have amazing jobs, and you can be one of them.

Job Selection

Let's face the facts—depending upon your type of PI, there might be some jobs that will not be appropriate for you. However, as a rule, there is no limit to the types of employment a person with a PI can have. There are many ways to work in a field you are passionate about with some adjustments. For example, there are many people with PI who successfully work in the medical field while taking necessary precautions with respect to infectious diseases. Fortunately, the job market has innumerable opportunities that could be a great fit for you.

Whether or not you would be a good candidate for employment will be based on a few basic principles:

- You have skills that employers will know how to apply to a variety of workplace settings.
- You have a positive attitude despite having a chronic illness.
- You display initiative and self-motivation.
- You show that you are determined to have a successful career even though you have PI.

The best job plays to your strengths. Remember that you are not the only one with limitations—everyone has limitations in one way or another.

Disclosing Your Diagnosis

Legally, you do not have to disclose to your employer that you have PI unless it affects completing essential job functions, and you are seeking a reasonable accommodation to perform

the job. A reasonable accommodation is any modification or adjustment to a job, practice, policy, or the work environment that allows an individual with a disability to participate equally in an employment opportunity without creating an undue burden for the employer.

- **Potential Employer:** You have no legal obligation to disclose your PI to a potential employer when applying or interviewing for a job unless you have an immediate need for a reasonable accommodation.

A potential employer may not ask you if you have any disability during the application or interview period before offering you a job. An employer may only ask disability/medical-related questions if it makes a job offer to you that is conditioned upon meeting the reasonable and legitimate physical and medical requirements of the job. If the employer rescinds the job offer, the reason must relate to the job requirements only.

- **Current Employer:** Once on the job, you do not have to disclose your PI to your employer unless you have an immediate need for a reasonable accommodation.

Your employer may only ask about your disability if there is a reasonable basis for the employer to think that you are: unqualified to do the job; need a reasonable accommodation; or pose a direct threat to your own health or safety or the health or safety of others.

For more information about disclosure in the workplace from the U.S. Department of Labor Office of Disability Employment Policy, visit: www.dol.gov/odep/pubs/fact/ydw.htm.

Medical Coverage and Health Benefits

It is critical to consider the type of health insurance benefits offered by the employer. Insurance plans can differ greatly from one to the next even within the same company. Researching health insurance plans when you have a PI can be complicated, but choosing the right plan is critical. It can help you to save money and ensure the appropriate treatments are covered. (See Health Insurance Chapter.)

If you are applying or interviewing for a potential job, it is entirely appropriate to ask about health insurance benefits. Health benefits are considered compensation and should be investigated in the same way a salary is investigated. Note, the potential employer cannot ask about any disability or medical concerns in response to you asking for health benefit information.

Other Employee Benefits

In addition to health insurance benefits offered by the employer, you should also investigate the other benefits offered as well. Employers often provide short-term and long-term disability insurance coverage or wellness plans.

- **Short Term Disability.** Short-term disability (STD) insurance covers leave from work for a temporary disability, such as pregnancy, accidental injuries, and illnesses. STD insurance replaces a portion of your income, which is a huge benefit. The percentage of income paid depends on the insurance plan. The replacement income comes from the insurance company, not the employer. Some states with STD insurance: California, Hawaii, New Jersey, New York, and Rhode Island.

Note, many STD insurance plans do not cover preexisting conditions, such as PI, or do not cover such conditions until the expiration of a certain period such as 12 months. Also, some may cover preexisting conditions but have certain specific conditions which are excluded. Be sure to investigate these rules.

- **Long Term Disability.** Long-term disability (LTD) insurance picks up where STD insurance leaves off. Once the STD benefits expire (generally after three to six months), LTD insurance pays a percentage of your salary,

usually 50 to 60%, depending on the policy. The benefits last until you can go back to work or for the number of years stated in the policy.

It's important to note that like STD insurance many LTD insurance plans do not cover preexisting conditions, such as PI, or do not cover such conditions until the expiration of a certain period of time such as 12 months. Also, some may cover preexisting conditions but have certain specific conditions which are excluded. Be sure to investigate these rules.

- **Unpaid Medical Leave.** Even if you are excluded from STD insurance due to PI being a preexisting condition, you may be entitled to medical leave under the Family and Medical Leave Act (FMLA). This Federal law provides protections when you miss work because of PI or you need to care for a child/spouse with a PI. You may also be entitled to medical leave under the Americans with Disabilities Act (ADA). State workers' compensation laws and/or medical leave laws may have additional provisions that apply as well.
- **Cobra Insurance.** The Consolidated Omnibus Budget Reconciliation Act (COBRA) gives workers who lose their health benefits the right to choose to continue group health benefits provided by their plan under certain circumstances.

In the event that you lose your health coverage for a qualifying event, your employer will send you an election notice within 14 days after your last day on the health insurance plan. You will then have 60 days to decide whether to elect COBRA continuation coverage. You will then have 45 days after electing coverage to pay the initial premium. Expect to pay the total premium (both your employer's and your contribution to the premium) plus 2% for administration expenses. Also, another important note is that the premiums are not tax deductible, like they are when they are deducted from payroll.

COBRA defines certain qualifying events that would cause an individual to lose health coverage. The type of qualifying event will determine who the qualified beneficiaries are and the amount of time that a plan must offer the health coverage to them under COBRA. A plan, at its discretion, may provide longer periods of continuation coverage.

- **Qualifying Events for Employees (18 months coverage)**

- » Voluntary or involuntary termination of employment for reasons other than gross misconduct
- » Reduction in the number of hours of employment

- **Qualifying Events for Spouses**

- » Voluntary or involuntary termination of the covered employee's employment for any reason other than gross misconduct (18 months)
- » Reduction in the hours worked by the covered employee (18 months)
- » Covered employee's becoming entitled to Medicare (36 months)
- » Divorce or legal separation from the covered employee (36 months)
- » Death of the covered employee (36 months)

- **Qualifying Events for Dependent Children**

- » Loss of dependent child status under the plan rules (36 months)
- » Voluntary or involuntary termination of the covered employee's employment for any reason other than gross misconduct (18 months)
- » Reduction in the hours worked by the covered employee (18 months)
- » Covered employee's becoming entitled to Medicare (36 months)
- » Divorce or legal separation of the covered employee (36 months)
- » Death of the covered employee (36 months)

Additional information on COBRA benefits can be found at: www.dol.gov/general/topic/health-plans/cobra.

Legal Protections: Federal and State Governmental Policies

For those living with a PI, there are several Federal and State laws that provide protections.

Americans with Disabilities Act: The Americans with Disabilities Act (ADA) states that employers with more than 15 employees may not discriminate against a qualified individual on the basis of disability in regard to job (application hiring, promotion, firing, compensation, job training etc.). According to the ADA, a disability is:

- A physical or mental impairment that substantially limits one or more major life activities of an individual (PI qualifies under this definition).
- A record of such an impairment, or
- Being regarded as having such impairment

This means that you cannot be eliminated from consideration for employment or from your job because of your PI if you have the skills, experience, education, or other requirements for the job you already have or the job you want, and you can perform the essential functions of the position with or without reasonable accommodation.

The ADA requires employers to offer a reasonable accommodation to employees with a disability. As described earlier, a reasonable accommodation is any modification or adjustment to a job, practice, policy, or the 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; or many other accommodations.

As a result, you may be eligible for certain reasonable accommodations to permit you to perform your job despite some restrictions of your PI. For more general information about the ADA, visit www.ada.gov, and additional information about reasonable accommodations is available at www.eeoc.gov/policy/docs/accommodation.html.

Family and Medical Leave Act: The Family and Medical Leave Act (FMLA) allows qualified employees working for a company with more than 50 employees to take unpaid, job-protected leave for specified family and medical reasons, with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave. Qualifying reasons for FMLA leave include but are not limited to:


- A physical or mental impairment that substantially limits one or more major life activities of an individual (PI qualifies under this definition)
- A record of such an impairment
- Being regarded as having such impairment

Eligible employees may take up to 12 weeks of unpaid leave under FMLA. The leave does not have to be consecutive and can be taken intermittently.

Additional information about FMLA is available at www.dol.gov/whd/fmla/.

U.S. Equal Employment Opportunity

Commission: Another important government agency that is a valuable resource is the U.S. Equal Employment Opportunity Commission (EEOC). The EEOC is responsible for enforcing federal laws that make it illegal to discriminate against a job applicant or an employee because of the person's race, color, religion, sex (including pregnancy), national origin, age (40 or older), disability, or genetic information. It is also illegal to discriminate against a person because the person complained about discrimination, filed a charge of discrimination, or participated in an employment discrimination investigation or lawsuit. For more information, visit www.eeoc.gov/eeoc/index.cfm.



The development of this publication
was supported by Shire, now Takeda.



110 West Road, Suite 300
Towson, MD 21204

800.296.4433

www.primaryimmune.org
idf@primaryimmune.org